# Core Report: A Systematic Literature Review of Indigenous Wise Practices for Community Assessments

**Overview of Results** 

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## Acknowledgments

The Core Report - which inspired the creation of the Project Guide - was completed by a team of research partners. This includes members from Function Four Ltd. and Myera Group, as well as a team of students, staff and faculty from the University of Winnipeg (UW) and the University of Manitoba (UM). This research began with Bruce Hardy (F4), Wayne Kelly (F4 and UW) and Ryan Bullock (UW) who conceptualized this systematic review as a piece of the larger Myera Project. Through securing financial funds, they were able to make this project a reality. Bruce, Wayne and Ryan also provided guidance throughout the entire systematic review process.

Under the supervision of Ryan and Wayne, Alex Ireland (UW) completed the essential first steps of creating the search strategy and conducting the article search in the Spring of 2022. Alex and Amaanat Gill (UM) completed the first analysis phase, and Bryanne Lamoureux (UW) joined them in June to guide and assist with the second round of analysis. Olivia Kehler (UW) joined the team in September of 2022. Under Bryanne's guidance, Olivia completed the scoping review and analysis of grey literature. The writing of this report was completed by Olivia and Bryanne, with Olivia creating a majority of the visual representations included in the results section. Nicole Breedon (Brandon University) conducted the reviewing of this report, turning it into the version as it exists today.

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Environment and Society Collaborative Lab



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## **Section 1 – Introduction**

Community assessments are "a comprehensive process to identify the strengths, resources, assets and needs of a defined community that will lead to action to address an issue" (Richardson et al., 2018). They involve collecting data on community resources, needs, problems and assets to identify what must be addressed to meet a certain community goal (Sharpe et al., 2000). Community assessments have largely been conducted in relation to health challenges and opportunities experienced by communities (e.g., Paronen and Oja, 1998; Pikangikum First Nation and Beringia Community Planning Inc, 2013; Yitalo et al., 2016). However, community assessments are also being conducted for the purpose of community planning (e.g., Indigenous Services Canada, 2018), assessing climate risks and adaptive capacity (e.g., Centre for Indigenous Environmental Resources, 2009), identifying processes related to environmental impact (e.g., Gibson, 2017), and examine food sovereignty (e.g., First Nations Development Institute, 2014). Community assessments that seek to meaningfully engage community members in culturally appropriate ways have proven to be helpful and can be used to exemplify the current realities of community life (Clark et al., 2003; Frances et al., 2016).

The Myera Group project a multi-year research undertaking, aiming to establish a circular food production system that is culturally tailored to Indigenous communities across Canada and countries around the world, such as Australia. Initiated by the owner of Function Four, an Indigenous owned tech company, this undertaking aims to create a food system that creates capacity and provides economic sovereignty to Indigenous communities in Canada, Australia, and beyond.

This systematic literature review was initiated as part of a process to update Function Four's E-Index - a digital assessment tool developed in the early 2000s. The idea is to evolve the E-Index into a community assessment tool that will be used throughout the Myera project. This community assessment tool will serve to assess community capacities in infrastructure, energy, transportation, food sovereignty, health, and sovereign wealth creation before circular farm systems are adopted to ensure communities have what they need for a successful food system.

The purpose of this systematic review was to identify existing Wise Practices for conducting community assessments with Indigenous communities. Wise Practices are defined as "locally-appropriate actions, tools, principles or decisions that contribute significantly to the development of sustainable and equitable conditions" (Calliou and Westley-Esquimaux, 2010, p. 19). Where best practices assume assessments can be replicated, Wise Practices ensure assessments adapt to the local context.

We prioritized identifying Wise Practices in research and assessment practices conducted by, with, and for Indigenous communities. These practices move away from methodologies in which research practices have historically (and problematically) been done "on" Indigenous communities. To prevent the inclusion of problematic practices, articles included in this systematic review had to demonstrate i) research with communities, whereby a partnership exists between the researcher(s) and the community and the research serves the community; ii) research for communities, whereby a community has approached researcher(s) to conduct research and the research serves the community (Koster, 2012); and iii) articles where research was undertaken by community members.

The practices identified in this systematic review provide a preliminary structure and guide for how to assess infrastructure, energy, transportation, food sovereignty, health, and sovereign wealth creation in a culturally appropriate manner. While applying the Wise Practices identified in this review is impactful, we emphasize that simply applying certain methodologies and methods does not ensure meaningful engagement. Researchers and practitioners who undertake assessments have the responsibility to ensure their work is truly participatory, culturally safe, and beneficial for the communities involved.

## **1.1 Research Strategy and Methods**

To identify Wise Practices for conducting community assessments with Indigenous communities, we undertook a systematic review of peer-reviewed literature and a scoping review of grey literature.

## 1.1.1 Systematic Review: Peer-Reviewed Literature

## Data Collection

Our systematic literature review of the academic literature sought to answer the question:

What Indigenous community-based assessment tools exist within peer reviewed academic literature since the 2007 adoption of the United Nations Declaration on the Rights of Indigenous Peoples by the General Assembly?

Based on this research question, we input the search string into Web of Science and EBSCOHost (see Figure 1). We excluded articles we were unable to access. In addition to the 2007 timeline, selected articles had to meet the following criteria:

- 1. The study focused on Canada and/or Australia.
- 2. The way in which research was conducted aligned with research by, with and for Indigenous communities as defined by Koster (2012).

This systematic review contributes to the development of a community index tool that will be applied in Canada and Australia. As a result, we chose to limit our scope to these two countries. To ensure all articles met these criteria, Alexandra Ireland scanned the abstracts, methods, author(s) acknowledgements and removed any ineligible articles. Selected articles also had to demonstrate research by, with and for communities, whereby i) a partnership exists between the researcher(s) and the community and which serves the community; ii) a community has approached researcher(s) to conduct research and the research serves the community (Koster, 2012); and/or iii) the research is being conducted by community members. The initial search produced 270 papers. Our final corpus consisted of 143 peer-reviewed articles.

(indigenous or aboriginal or first nations or metis or inuit.) AND ( "community assessment" OR "community evaluation" OR "community-based" OR "community-led" OR "by with and for" ) AND ( best OR wise OR common OR recommend\* OR lesson ) AND ( practice OR process OR approach OR engag\* OR adaptat\* ) AND ( method\* OR framework\* OR tool\* OR principle\* ) AND ( <u>Canad</u>\* OR Australia\* )

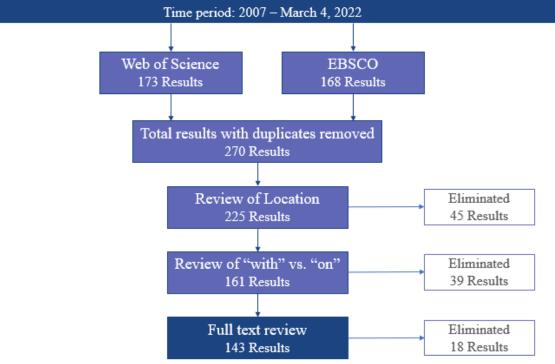


Figure 1.1: Systematic literature review search and process of elimination

#### Data Analysis

We conducted two separate phases of data analysis. The first phase of analysis focused on bibliometric data and key components of OCAP<sup>TM</sup>. These categories were determined ahead of time by the research team and the analysis took place in a deductive format. This phase was conducted by two team members over a two-month period. Articles were divided amongst the two members, and coding was completed in a Google Sheet to facilitate collaboration. Components of this analysis are seen in the table below.

Country of Focus	Is the study location(s) in Canada, Australia, or both?
Field of Study	What is the most represented field of study of the authors?
Community(ies) of focus	Which Indigenous community(ies) were involved in the research and where are they located?
Indigenous Authorship	See results
Indigenous Involvement	Do partners, collaborators, and/or funders self-disclose Indigenous identity?
Indigenous Led	Is the research led by Nation members from within the region that research was conducted?
Data Ownership	Is there information on how the relationship of Indigenous peoples to their cultural knowledge, data, and information and collective community ownership was honoured in the study?
Data Control	Is there information on how the rights of Indigenous peoples, their communities, and representative bodies in having control over all aspects of research and information management processes that impact them were upheld?
Data Access	Is there information on how Indigenous peoples' access to information and data about themselves and their communities and the right of communities and organizations to manage and make decisions regarding access to their collective information, were upheld?
Data Possession	Is there any information on how possession - the physical control of data and mechanism by which ownership is asserted and protected - to the physical control of data - was honoured?

 Table 1: Overview of the Deductive Analysis Categories

The second phase was a mostly inductive-dominant analysis (Armat et al., 2018) conducted by three team members - including those who conducted the first analysis - to identify practices for conducting assessments with Indigenous communities. This process began with one team member doing a preliminary analysis of ten randomly selected articles (Biesbroek et al., 2018). This created a preliminary coding framework that guided the remainder of this analysis. The remainder of the team reviewed this preliminary analysis and provided feedback before moving forward with the preliminary coding framework. The remaining 133 articles were divided equally amongst the rest of the team in a way that ensured members who coded the first round of analyses did not re-analyze the same articles in this second round. To facilitate a collaborative and iterative process, coding took place in Google Sheets, with new columns representing new codes. When one member identified a new code, the code was clearly defined in another tab to

ensure consistency and each member was notified. The three team members met on a weekly basis to review new codes and modify and adjust them as needed. The team also communicated over Slack in-between meetings. Previously analyzed articles were reviewed regularly to identify any additional information matching emergent codes.

Throughout our analysis, it became evident that a majority of our articles were not specific to community assessments, but about research with Indigenous communities in general. The majority of articles did not identify "Wise Practices" explicitly. As a result, our inductive coding captured a mix of common practices, best practices, recommended practices, and culturally relevant practices. Our final coding structure had the major themes of:

- 1. Research approaches and lenses
- 2. Important concepts and theories
- 3. Methodologies
- 4. Data collection and knowledge documentation methods
- 5. Community engagement and leadership in research
- 6. Indigenous ways of knowing and their translation into research and assessments
- 7. Considerations for research and assessment design

When coding, we prioritized capturing information on approaches, concepts and theories, methodologies that indicated a cultural relevance or adaptability to cultural contexts. This prioritization determined which information was captured under each major theme.

Alongside this inductive-dominant analysis, we also identified any frameworks, protocols, practices, Wise Practices, tools, principles, criteria, evaluations, and strengths and limitations specific to community assessments. This coding was done to contribute to an inventory of existing tools and protocols that we plan to create as a result of this research work. Once coding was completed, all three members met to review each code one by one until all were satisfied with the codes present. One team member also reviewed the information under each code to ensure consistency of information in each code before moving to data synthesis.

## 1.1.2 Scoping Review: Grey Literature

### Data Collection

Grey literature, which can include reports, policy literature, working papers, newsletters, government documents, speeches, and so on, is "information produced outside of traditional publishing and distribution channels" (Simon Fraser University, 2022). Organizations such as government, inter-governmental, non-governmental organizations and industry can produce grey literature for their own use or for wider distribution. Since grey literature does not have the same delays and restrictions of other forms of publishing, it can be more current; however, its quality may also vary greatly, as it does not generally go through a peer-review process (Simon Fraser University, 2022).

We developed a grey literature scoping search protocol based on the same initial search question as for peer-reviewed literature. Online resources and a university librarian were consulted when selecting databases for the review. Due to differences in grey literature databases, search terms varied, from "community assessment" to using the full search string as in the peer-reviewed search. Some databases were instead filtered to show reports and publications and manually searched.

Most databases and websites consulted are listed below, with search categories based off of the work from Godin (2015):

## Grey literature databases:

The following databases were consulted: Alternative Press Index, Canadian Public Policy, CBCA, iPortal, BASE, CORE, ETHOS, NDLTD, and OAlster. Searches were made with search strings as short as "community assessment", or as long as the full list of terms as in the peer-reviewed search depending on the quantity of results yielded. Canadian Public Policy and iPortal were the only two databases that yielded sources of relevance.

## Customized Google search engines:

Both Google and IGO search, a customized Google search engine, yielded relevant sources. NGO search was also consulted, with no relevant results found.

## Targeted websites:

Several websites were encountered throughout the search (e.g., through Google searches); however, the First Nations Information Governance Centre Online Library, which was recommended by a UWinnipeg librarian consulted when creating the search protocol, was the only one which yielded relevant results.

### Contact experts:

Some sources from grey literature were recommended by practitioners in related fields.

Other grey literature sources were identified through a snowball method by looking through links and citations within selected peer-reviewed publications and grey literature documents.

While grey literature was assessed, inclusion criteria similar to the peer-reviewed literature search were used. This included the fact that material had to be (i) published after 2007; (ii) from Canada or Australia; and (iii) identified to be by, with, and for Indigenous communities. Some exceptions were made to incorporate sources which were relevant and applicable to the review. Two of the grey literature sources are from the United States but still hold relevance to Canada, and one source from 2005 was kept as it was only resource found that was specific to assessments with Métis communities. A total of 56 publications were identified and read more closely to evaluate relevance, and only 34 of these were analyzed for the purpose of this report.

## Data analysis

Data analysis took place using the coding structure created as a result of the peer-reviewed literature. First, key bibliographic information was identified. Second, a larger coding process took place to identify frameworks, protocols, practices, Wise Practices, tools, principles, criteria, evaluations, and strengths and limitations specific to community assessments. Finally, using the coding structure created from the inductive-dominant analysis of the peer-reviewed literature, grey literature documents were coded to identify (i) research approaches and lenses; (ii) important concepts and theories; (iii) methodologies; (iv) data collection and knowledge documentation methods; (v) community engagement and leadership practices; (vi) practices for

integrating Indigenous ways of knowing into research and assessments; and (vii) any additional considerations for research and assessment design deemed relevant.

## 1.1.3 Data Synthesis

Data synthesis of the peer-reviewed literature took place with two team members - one who participated in the peer-reviewed literature analysis, and the other who completed the grey literature review. Considering the studies included in the review come from different fields of study and employ a large variety of methods, we chose a narrative synthesis approach to summarize and present the data (Snilstveit et al., 2012). To do so, each team member chose some of the major themes and created thematic summaries based on the information present within the child codes of each theme. Bibliographic information collected in the first phase of data analysis such as authorship, date published, and country of focus were summarized in quantitative format with visuals where appropriate.

Once the peer-reviewed results were completely summarized, we integrated the grey literature findings into this report with the purpose of enhancing and complementing the peer-reviewed findings. Findings from 18 of the 36 analyzed sources were integrated into this report; information from others will be documented in other reports forthcoming from the review.

These syntheses were reviewed by other team members who participated in other parts of the process (e.g., data collection and analysis) to confirm accuracy and representation of the data. All team members were given the opportunity to review and provide feedback on the report before it was finalized.

## Section 2 – Results

## 2.1 Bibliometrics: Peer-Reviewed Literature

A total of 143 articles were identified in the systematic literature review. Most of the reviewed articles are not about assessments specifically, but rather about research in general. As a result, the terms "research" or "research processes" are used generally throughout this summary. In addition, most articles also did not specify "Wise" Practices; however, many recommended best practices and lessons learned when conducting research by, with and for Indigenous communities. These results are synthesized in the remainder of this report.

## 2.1.1 Years Published

As shown in Figure 2, studies that fit the systematic search criteria start after 2007. This is because this was the year that the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the General Assembly. In both Canada and Australia, there started to be more studies which fit all criteria in 2012, with a steady upward trend since then. 2020 was the year with the largest number of relevant studies published. The search for the systematic review took place in the spring of 2022, explaining the smaller number of relevant studies from that year.

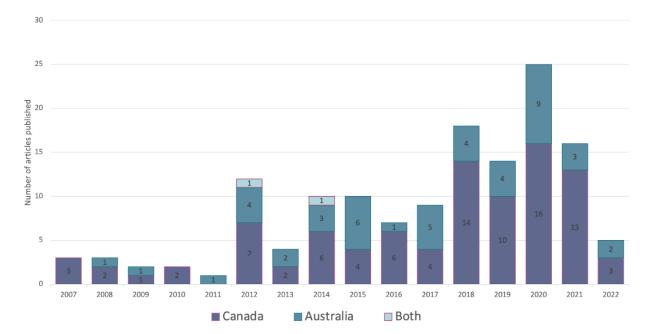


Figure 2: Publishing year of selected peer-reviewed studies

## 2.1.2 Country, Regions and Communities of Focus

Of the 143 articles, 95 are focused on Canada, 46 on Australia, and two on both countries. While many studies included a region or location of focus, some studies did not. These studies were literature reviews unbound to a specific location, community-based studies where communities were not named, or studies with regions not specific enough to be plotted. With this, there are 14 studies from Canada and eight studies from Australia not accounted for in the maps below.

All other studies are represented in the maps below according to two geographical factors:

- 1. The province, state, or territory where each study took place is represented by a specific colour. The use of colonial boundaries for these maps were found to be the most consistent geographical boundary for determining patterns between studies. When there were multiple communities of focus in a single study, this counted as +1 in the province or territory where these communities were located.
- 2. The specific locations or communities named in the studies are indicated by a pin.

Together, these factors illustrate both the density and locations of focus of the studies.

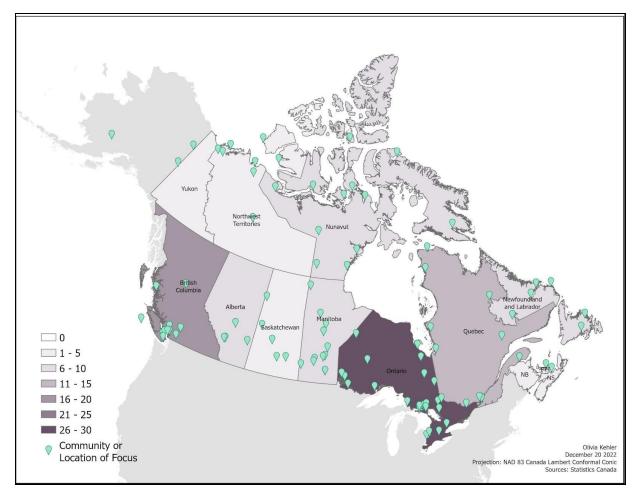


Figure 3: Regions and communities of study focus in Canada by province or territory

Politically, Canada is divided into ten provinces (Alberta, British Columbia, Manitoba, New Brunswick, Newfoundland and Labrador, Nova Scotia, Ontario, Prince Edward Island, Québec, and Saskatchewan) and three territories (Northwest Territories, Nunavut, and Yukon). As illustrated in Figure 2, the majority of the study sites in Canada were located in Ontario (28), followed by British Columbia (16) and Quebec (11). Ontario is Canada's most populous province (followed by Quebec, then British Columbia). Ontario is home to 22% of Indigenous peoples in Canada – or rather, 3% of Ontario's total population (Ontario Population, 2022; Statistics Canada, 2022). British Columbia has the second highest Indigenous population (16% of Indigenous Peoples in Canada), and Alberta (7 studies) has the third highest (15% of Indigenous population (86% of the total population), while Manitoba (10 studies) is the province with the highest proportional Indigenous population (18% of total) (Indigenous Services Canada, 2020).

Certain communities were the focus of multiple studies, including Rigolet, Quebec (5 studies) and Wiikwemoong, Ontario (6 studies). The provinces and territories of New Brunswick, Northwest Territories, Prince Edward Island, and Yukon were each only involved in one study from the systematic review. Wendt and colleagues (2019) had multiple study locations, including a study location in Alaska, USA.

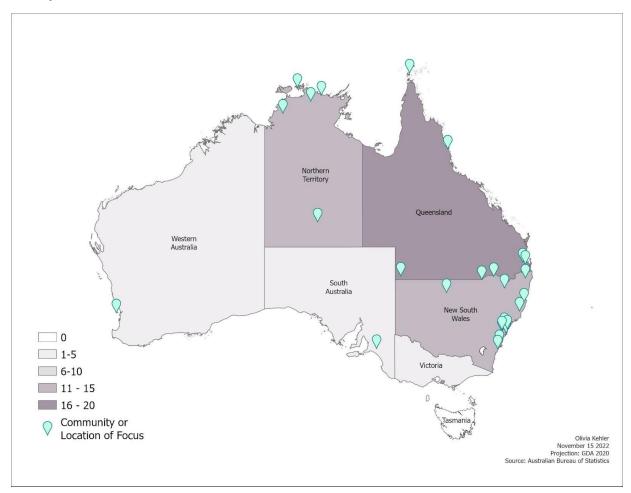


Figure 4: Regions and communities of focus in Australia by state or territory

Australia's political boundaries consist of six states (New South Wales, Queensland, South Australia, Tasmania, Victoria, and Western Australia) and two territories (Australian Capital Territory and Northern Territory). As illustrated in Figure 3, a majority of studies were focused on Queensland (16), followed by Northern Territory (14) and New South Wales (12). The three most populous states or territories of Australia are New South Wales, Victoria, then Queensland (Australian Bureau of Statistics, 2021). The states or territories with the highest Aboriginal and Torres Strait Islander population are New South Wales, Queensland, then Western Australia, accounting for almost three-quarters of the total Aboriginal and Torres Strait Islander population in Australia (Australian Bureau of Statistics, 2021). There are no studies from Tasmania or Australian Capital Territory.

## 2.1.3 Field of Study

The majority of studies in the systematic review were related to the field of Health with 104 articles or 73% falling into this category. This encompassed articles with many different understandings of health, including health sciences, public health, community health, and holistic well-being. Fifteen articles (10%) were in the fields of Environmental Studies and Natural Resource Management. Five articles or 4% were from Geography; Education and Food Studies each had 4 articles (3%), while Anthropology, Indigenous Studies, Psychology and Social Work each represented three articles (2% each). Fields of study were determined by the field of study of the lead authors; however, several studies could also be categorized as interdisciplinary.

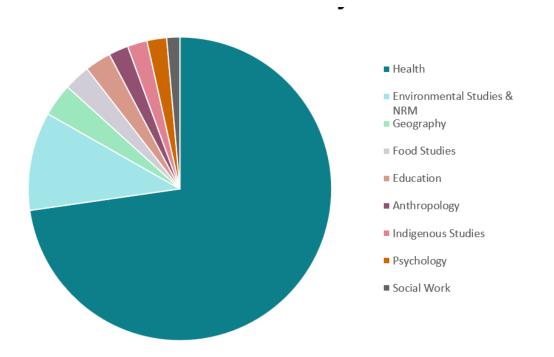


Figure 5: Field of study of included articles

## 2.1.4 Indigenous Authorship

Due to our commitment to identifying literature where research took place by, with, and for Indigenous peoples and communities (Koster, 2012), part of our analysis included identifying Indigenous authorship where possible. Indigenous authorship was determined by either i) identification within the article and/or ii) identification on authors' professional pages or reports (i.e., faculty biographies, organization biographies, interviews, etc.).

Based on this approach, of the 143 peer-reviewed articles, 76 articles had demonstrated Indigenous authorship through the community of focus. 14 articles have Indigenous authorship without confirmation of whether they were from the community of focus. 1 article identified that all authors were non-Indigenous. We also have 52 articles that remain unknown, meaning we were unable to identify whether they included Indigenous authorship.

## 2.2 Bibliometrics: Grey Literature

Grey literature was located iteratively with a scoping review approach rather than systematically. Peer-reviewed findings shaped the core structure of this report, and grey literature findings were synthesized and added where it provides new, different, or expanded information in relation to the peer-reviewed findings. Content sourced from grey literature is written in purple font.

Several formats of grey literature documents were consulted:

- 1. Assessments: Some documents affiliated with assessments included manuals for needs assessments, food sovereignty assessments, community readiness assessments, and impact assessment. Some documents provide guidance for external practitioners, whereas others are manuals for community members looking to assess and create conditions for positive change within their own communities.
- 2. Documents by the First Nations Information Governance Centre (FNIGC): The FNIGC is a non-profit First Nations organization "committed to producing data that can contribute to the health and well-being of First Nations people" across Canada (FNIGC, 2018 p. 2). There are several publications by this organization that are referenced in this review.
- 3. Community planning: Several sources from grey literature are guides and manuals for community planning, including comprehensive community planning (CCP). The CCP are community-led approaches to planning (BC Aboriginal Child Care Society, 2019) which looks at all aspects of a community including the environment, economy, land, people, programs, and housing (NADF, 2017). The CCP is an action-focused, inclusive, and holistic process that involves an entire community in planning for a better future (NADF, 2017). While this process has crossover with assessment processes, it also goes beyond as a community-driven process for long-term change. While a CCP process may be initiated by external contractors, community members are responsible for implementing the plan. This process requires buy-in from a community from all levels, and may span multiple years. CCP processes relevant to assessments have been integrated into this report.
- 4. Other guides and manuals: Guides and manuals for community engagement and relationship-building were referenced throughout this report.

## 2.2.1 Year Published

Of the eighteen sources, sixteen were published between 2007 and 2022 (see Figure 6). One source has no specified year of publication; however, based on its bibliography, it is expected that this document was published in 2011 or later (The Canadian Aboriginal Aids Network, n.d.). Through these assessments, a document on Métis Needs Assessments (Hughes and Shmon, 2005), which predates the timeline inclusion criteria for the systematic review, was included in the results section on data management principles as it provided helpful information not present in other sources.

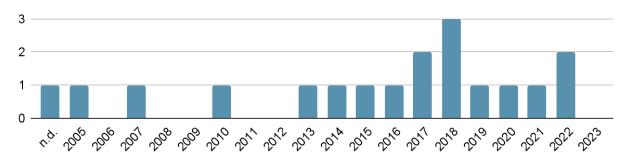


Figure 6: Publishing year of selected grey literature documents

## 2.2.2 Country of Focus

Sixteen of eighteen (88.8%) of the reviewed sources were from Canada, one (5.5%) source was from Australia, and one (5.5%) was from the United States.

Multiple sources from Australia were collected; however, upon analysis, the majority of these did not appear to meet the "by, with, and for" parameter of the review. A shortage of grey literature sourced from Australia is noted as a limitation of this review.

Despite going beyond our systematic review inclusion criteria, we chose to include one source from the United States (see Plested et al., 2016) because it was created specifically for use by Indigenous communities. It was designed to be adaptable to a specific community and its needs, and there are examples of it being adapted for use by Indigenous communities in Canada (e.g., Canadian Aboriginal Aids Network, which is included in this review).

## 2.2.3 Indigenous Authorship

Grey literature sources were generally published by organizations. In this case, individual members who contributed were not always named. The highlighted organizations who published, or collaborated in publishing, literature were Indigenous-led (e.g., Firelight Research Group); or engaging with Indigenous individuals and/or communities as a part of their mandate (e.g., Indigenous Services Canada). Where Indigenous involvement in authorship was unknown or absent, there was collaboration from Indigenous Nations or organizations.

## **2.3 Principles for Research and Assessment Processes**

We begin our summary of these articles by focusing on principles for research and assessment processes. Principles are defined as "accepted truths' – things that everyone believes are true and add value to what we do" (Indigenous Services Canada, 2018, p. 21). Principles appear in various forms throughout this report. Here, we begin to explore and outline principle frameworks employed by authors in the reviewed articles. Throughout this section – and the report in its totality – we review the ways in which these principles are enacted in practice, and the tools that facilitate their application in research and assessment processes.

## 2.3.1 Research By, With and For Indigenous Communities

Certain peer-reviewed articles outlined clear principle frameworks that were guiding and informing their research (see Table 2). These frameworks provide an overview of common principles seen in this research by, with and for Indigenous communities.

Principles highlighted in blue were applied in Canada, while those in orange were applied in Australia. As seen in the Table, the principles of reciprocity, respect, and responsibility span the two countries. It is important to note that this is not an exhaustive list of principles, and that the most appropriate principles are those chosen by and with the community that is part of the research process. Examples of community-specific principles are reviewed later in this section.

Seven Guiding	Three R's of	Four R's of	National Health and
Principles for	Indigenous	Indigenous	Medical Research
Indigenous and	research	research	Council (NHRMC)
Western Knowledge	Wilson (2008) as	Kovach (2009)	principles
and Intersectionality	cited in Bennett et	as cited in	As cited in Haynes et
Levac et al. (2018) as	al., 2019	Nagy et al.,	al., 2019; Smith et
cited in Hanson, 2018		2020	al., 2020
Reciprocity	Reciprocity	Reciprocity	Reciprocity
Relationality	Relationality		
Reflexivity			
Respect	Respect	Respect	Respect
Reverence			
Responsivity			
Responsibility		Responsibility	Responsibility
		Relevance	
			Equity
			Survival and
			Protection
			Spirit and Integrity

 Table 2: Principles for Research By, With and For Indigenous Communities from Peer-Reviewed Articles

## 2.3.2 Community Engagement and Partnerships

## Principles for Culturally Safe Ethical Engagement

The principles outlined throughout Table 3 (see below) were applied by Dieter and colleagues (2018) in the context of dementia research. By applying these principles and engaging the community in the research process as researchers themselves, the relevance and value of the research was enhanced, and community members were better positioned for self-determination.

**Table 3**: Principles for Culturally Safe Ethical Engagement – Table created based on recommendations from Dieter et al., 2018.

Principle	Application	
Ensuring cultural safety	<ul> <li>Implementation of a culturally safe care model through:</li> <li>Researchers reflecting on their own biases and evaluating their own cultural background before the start of the research</li> <li>Having ongoing project reflections and discussions</li> <li>Redistributing power during data collection and analysis processes</li> <li>Grounding the research in local Indigenous protocols</li> <li>Creating trusting and respectful relationships with co-researchers</li> </ul>	
Creating community-based participatory partnerships	<ul> <li>Creating these partnerships looked like:</li> <li>Beginning with exploratory discussions</li> <li>The hiring of a community research assistant</li> <li>The creation of a community research advisory committee</li> <li>Ensuring knowledge keepers and invested community members had designated roles and responsibilities, and equal opportunity to design and direct the project</li> <li>Building trusting and authentic relationships</li> </ul>	
Ownership, Control, Access and Possession	A research agreement was collaboratively created between the parties involved which outlined how OCAP <sup>™</sup> principles were followed.	
Knowledge Brokers: Community members as researchers	Community researchers were considered knowledge brokers - people who have the ability to transform knowledge from the research project in ways that benefit their community - throughout the research process. This was supported through reciprocal relationships, and through proper cultural protocols to recognize the essential roles played by community members.	
Knowledge translation and reciprocal learning	<ul> <li>Knowledge translation took the form of:</li> <li>The research team offered educational sessions on topics and at a time/place defined by the community.</li> <li>Attending local events to share information</li> <li>Hosting a lunch and learn to share information and food</li> <li>In this case, these activities took place before data collection occurred and assisted with building trust, recruiting potential participants, and led to additional educational sessions as requested by communities.</li> </ul>	

## 2.4 Community-Based Participatory Research with Indigenous Communities

Throughout their research with Wikwemikong Unceded Indian Reserve in Ontario, Jacklin and Kinoshameg (2008) identified eight key principles for the development of a culturally and community appropriate research project (see Figure 7). These principles included: partnership, empowerment, community control, mutual benefit, wholism, action, communication and respect. Their table (featured below) provides specific examples for applying these principles into practice throughout the duration of a research project.

Principles	Research Philosophy	Specifics
PARTNERSHIP	Local involvement and participation in planning and implementation	The project should be conceived by the community. The methodology should include mechanisms for community representatives to participate in the research design, process and outcomes. Communication should be continuous through the process.
EMPOWERMENT	Research as a process that enhances community empowerment and moves towards self-determination	The project incorporates and values local knowledge and experience The project meets the political/policy needs of the community. Community participation guides the research process. Capacity is developed in the community.
COMMUNITY CONTROL	Community maintains ownerships and control of research process and outcomes	The tools developed, the results, and the planning belong to the community, not the researcher. There is a process for the community to review, comment on, and approve the tools, methods, findings, reports, publications, etc.
MUTUAL BENEFIT	Working in partnership with and for the community for a mutually beneficial outcome	There are tangible benefits for the community. Process allows for skills and knowledge transfer. Academic outcomes (dissertations, publications, presentations) reflect community needs.
WHOLISM	Use and production of wholistic knowledge	Value is placed on all forms of knowing: spiritual, cultural, local, and academic. Knowledge transfer is two-way. Local knowledge is respected.
ACTION	Knowledge produced is used for action	Wholistic knowledge to be used for action is the result. Cycle of knowledge to action is continuous.
COMMUNICATION	Commitment to communication, dissemination and knowledge translation of research and results	Local colleagues, participants, and community members are aware of the study, its progress, and the results. Data is readily available and accessible to community members. Knowledge produced is communicated to participants, community members, policy developers, government officials and academics.
RESPECT	Respect for local research philosophy and culture	A research philosophy that respects and is compatible with local teachings and culture is maintained. Local ethical standards are respected and adhered to.

**Figure 7**: "Eight Principles of Appropriate Community-Based Participatory Research" (see Jacklin and Kinoshameg, 2008): Key principles for the development of a cultural and community appropriate research project.

Ritchie and colleagues (2013) also provide a list of adapted principles of community-based participatory research with Aboriginal communities, which includes:

- 1. Acknowledging historical experience with research and health issues and work to overcome the negative image of research
- 2. Recognize traditional sovereignty

- 3. Differentiate between band and community leadership
- 4. Understand community diversity and its implications
- 5. Plan for extended timelines
- 6. Recognize key gatekeepers
- 7. Prepare for leadership turnover
- 8. Interpret data within the cultural context
- 9. Utilize Indigenous ways of knowing

These authors emphasized the importance of recognizing community sovereignty by ensuring the choices made throughout the research process are grounded in community contexts. They suggest the slogan "this is how we do research in our community" instead of "this project followed the principles of [Community Based Participatory Research (CBPR)]" (Ritchie et al., 2013, p. 188). While not covered here, they also offer insight into how conducting CBPR fluctuates based on geographic proximity and access.

### Principles to Guide Partnership Work

Gomes and colleagues (2014) established principles to guide partnership work in research that is decolonized and works towards reconciliation in the healthcare system. These principles include ceremony, sovereignty, protocol, culture, Indigenous pedagogy, centring Aboriginal health leadership, and reciprocal sharing. The application of each principle is described below (see Table 4)

Principle	Application	
Ceremony	Work always begins in Ceremony guided by local Elders	
Aboriginal Sovereignty	Uphold and promote self-determined sovereignty and inherent rights	
Protocol	Ensure protocols are put into practice	
Culture	Ensure cultural values are "woven through the work every day" (p. 569)	
Indigenous pedagogy	Remain as true as possible to Indigenous ways of knowing, doing, and teaching	
Centring Aboriginal (Health) Leadership	Seek ongoing consultation with Indigenous communities and how values and beliefs can inform work	
Reciprocal Sharing	Provide educational and learning opportunities for both Indigenous and non-Indigenous communities through forums, networking, etc.	

#### Table 4: Principles of Engagement - Summarized from Gomes et al., 2014

### Determining the Best Principles

While the lists provided above each differ slightly in their purpose, there are various overlapping principles related to community control and sovereignty, reciprocity and mutual benefit, as well

as recognizing and integrating Indigenous ways of knowing and doing. These lists provide a potential starting point for determining principles for specific research assessment processes. However, it is important that principles are decided upon by and with the community involved so that the work itself may reflect unique local protocols and practices. Examples of community-specific principles can be seen in Gwynn and colleagues (2015) for research with Aboriginal and Torres Strait Islander people; Tran and colleagues (2020) with principles based on Kitasoo/Xai'xais law; Borish and colleagues (2021) where principles of the National Inuit Strategy on Research informed the research process; and Beveridge et al. (2021) with principles specific to Nuxalk people. Chung-Tiam-Fook (2022) also provides a regionally specific set of Inuit Qaujimajatuqangit (IQ)/ Inuit Ways of Knowing principles and values used across Nunangat that can inform research and assessment processes.

Indigenous Services Canada (2018) recommends developing statements that reflect a community's own vision and principles for their community in the future. As featured below, the authors provide a guide to develop visioning principles – this activity could contribute to determining community-specific principles to guide research and assessment processes.

## Feature: Developing Community-Specific Visioning Principles

Indigenous Services Canada (2018, p. 33) recommend in their comprehensive community planning handbook that visioning principles should:

- Be specific but general (not so abstract that it doesn't have any effect, nor so rigid that it creates limitations).
- Reflect a course that can be acted upon (but does not apply to only one specific situation).
- Be inclusive and proactive in reaching out to everyone.
- Be accountable have an open and transparent visioning process.
- Use traditions as a resource draw on history and tradition to determine how to face the future.

**Example 1:** "We will be a community with a strong and distinct culture, where our language, traditions, and the teachings of our ancestors live on throughout the generations. We will continue to be caretakers of our sacred and important places. We will gather often to celebrate and support each other" – Excerpt from Gwa'sala-'Nakwaxda'xw First Nations vision statement (Indigenous Services Canada, 2018, p. 33).

These vision statements can be developed by bringing people together for a community meeting or focus group, and tools such as conversation, drawing, painting, acting, and community mapping can facilitate creating these statements.

With these principles in mind, several practices (outlined below) should be considered before data collection for research and assessment processes take place.

## 2.5 Approaches and Guiding Concepts to Research and Assessments

Throughout the articles, common approaches and guiding concepts influenced researcher and community decisions on how to conduct research. Decolonizing, strengths-based, and trauma-informed approaches and the concepts of Two-Eyed seeing, ethical space, and cultural safety guided research decisions and shaped research interactions.

## 2.5.1 Decolonizing Approach

The act of decolonizing research is referred to by authors as a verb, a practice that informs decision-making, and a process (Beveridge et al., 2021; Farrant et al., 2019; Hanson, 2018; Hudson and Vodden, 2020). Nagy and colleagues (2020) describe decolonizing approaches as ones that "not only recognize the harms of settler colonialism, but systematically work toward repair and redressing such harms" (p. 94). The practices and processes in applying a decolonizing approach in research should align with this idea. As well, a decolonizing approach must ultimately be context specific (Hudson and Vodden, 2020).

Research partnerships, collaborations, community leadership and self-determination were noted as crucial to decolonizing approaches (Angelbeck and Grier, 2014; Borish et al., 2021; Elliott et al., 2015; Flicker et al., 2014; Hudson and Vodden, 2020; Lopresti et al., 2022). In practice, this meant prioritizing community voices (Lopresti et al., 2022), creating partnerships that focused on social transformation, mutual engagement, and activities (Elliot et al., 2015), prioritizing Indigenous leadership, and bringing attention to and/or actively supporting and advancing Indigenous self-determination (Borish et al., 2021; Hudson and Vodden, 2020).

An important part of ensuring these practices occur is making space for Indigenous worldviews. With Western understandings of knowledge often dominant in research, creating meaningful space for and embracing Indigenous ways of knowing (e.g., knowledge systems) and doing (e.g., tradition and Ceremony) can contribute to a decolonizing approach (Hudson and Vodden, 2020; Kandasama et al., 2017; Lopresti et al., 2022). Ensuring community voice is prioritized can facilitate prioritizing Indigenous ways of knowing and doing (Lopresti et al., 2022), and ultimately support shifts in power relations and self-determination in the research process. To create space for this, Elliot and colleagues (2015) practiced regular internal self-evaluations where they asked themselves and reflected critically on how they had done at previous tasks to ensure all knowledges were being considered of equal importance.

Another key component to decolonizing approaches is relationships. Due to the historically inequitable power imbalances between researchers and Indigenous communities, resisting unjust and inequitable relationships and shifting power inequities by, for example, building capacity among community partners are important practices (Beveridge et al., 2021; Elliot et al., 2015). Building authentic partnerships and friendships between academic researchers and community members is also important for these relationships to be built. Lopresti and colleagues (2022) suggest it is important for researchers to be aware of and acknowledge colonial history and continued colonial policies and practices before and when engaging in building these relationships. They also note the importance of doing things in a 'good way,' meaning with good intention (Lopresti et al., 2022).

These processes and practices can be facilitated by certain approaches, theories, methodologies, and methods. For theories, this includes Indigenous standpoint theory, decolonizing theory, and historical trauma theory (Fitts et al., 2019; Haynes et al., 2019; Rizkalla et al., 2020). Methodologies that can facilitate decolonization practices include community-based and Indigenous methodologies (Beveridge et al., 2021). As part of their decolonization approach, Flicker and colleagues (2014) applied arts-based methods within a decolonization research framework for the development of HIV prevention and Indigenous youth leadership. Decolonization can also be applied directly to the data analysis process. Firestone and colleagues (2019) applied a critical decolonizing lens to their data analysis process which "examines ongoing power structures and social systems driving inequities and marginalization of Indigenous peoples" (p. 407). While certain tools can facilitate a decolonizing approach, the tools themselves are not enough. Decolonizing practices and processes have to be integrated meaningfully throughout the research.

## Author's Summary: Practices and Processes for Decolonizing Research Approaches

As suggested and exemplified by scholars in the selected articles, the following practices and processes may contribute to decolonizing research approaches:

- Strengths-based approach (Hudson and Vodden, 2020; Hayward et al., 2021).
- Rooted in historical context: This includes the practices of positionality (Hayward et al., 2021) and critical reflection (Elliott et al., 2015).
- Rooted in local context, including local worldviews and ways of knowing, being and doing, and values (Hudson and Vodden, 2020; Morton Ninomiya et al., 2020; Smith et al., 2020).
- Ensuring community ownership this includes Indigenous Data Sovereignty (Smith et al., 2020; Hayward et al., 2021).
- Community-based/driven approach (Hudson and Vodden, 2020; Hayward et al., 2021).
- Resisting and/or critiquing power structures including in personal relationships (Morton et al., 2020).
- Integrating Indigenous worldviews, ontologies, epistemologies (Morton Ninomiya et al., 2020; Smith et al., 2020).

### 2.5.2 Strengths-Based Approach

A strengths-based approach to research was applied in articles across different fields (see Cooper and Driedger, 2018; Hatala et al., 2019; Hudson and Vodden, 2020; Kyoon-Achan et al., 2018a; McElhaney et al., 2021; Murray et al., 2014; Nadin et al., 2018; Vaughan et al., 2018; Young et al., 2018). This approach moves away from narratives of identifying "deficits" or needing to "fix" (Harper et al., 2012; Hatala et al., 2019), and instead focus on the strengths that communities already have, and identifying how existing resources can be leveraged for change (Kyoon-Achan et al., 2018a). As a suggested approach for decolonizing research (Hayward et al., 2021), a strengths-based lens moves past identifying and understanding existing challenges, and plans strengths-based actions.

In Hudson and Vodden's (2020) work, their framework of strength-based decision making and planning meant situating Inuit participants and knowledge holders as "experts on matters that impact them and on their lands" (p. 6). Cooper and Driedger (2018) integrated a strengths-based approach into knowledge dissemination by ensuring that the message present in knowledge dissemination products was strength-based and hopeful. Hatala and colleagues (2019) conducted a strength-based analysis by focusing specifically on how young Indigenous people build positive human-nature relationships in urban areas. Strength-based approaches in general focused on identifying and understanding existing strengths and positive outcomes across research topics (e.g., Murray et al., 2014; Nadin et al., 2018).

The First Nations Information Governance Centre (FNIGC) provides a description of strengthsbased approaches for the development of well-being indicators for Indigenous communities (FNIGC, 2020). They indicate the importance of focusing on ethical, epistemological, and methodological issues when taking a strengths-based approach - meaning "respectful ways of engaging with multiple forms of knowledge, culturally safe and appropriate research methods, and Indigenous values and worldviews related to living a good life" (FNIGC, 2020, p. 20). For indicators to be strengths-based, they need to be culturally valid and reflective of community values and aspirations (FNIGC, 2020). While the establishment of indicators can begin from ones used in previous studies, the development of and final decision on which indicators to use in assessment processes requires the involvement of the community. This can be done through open-ended qualitative exploration and cognitive inquiry methods (see FNIGC, 2020, p. 21 for additional details).

## 2.5.3 Trauma and Violence-Informed Approach

A trauma or violence-informed approach was applied in a small number of articles from the health and social work literature (Henderson et al., 2018; Morton Ninomiya et al., 2020; Oster et al., 2016). A trauma-informed approach is considered a value of Indigenous health research frameworks (Morton Ninomiya et al., 2020). In addition to informing a research process, this approach informs health programs, resources, and interventions to better understand how to take care of those experiencing trauma (see Nagy et al., 2020; Lavalley, 2021; Ogenchuk et al., 2022). Henderson and colleagues (2018) define a trauma-informed approach as one that "orients teams (in this case researchers) to awareness of trauma, its impacts on mental health, substance use, and coping strategies, as well as the importance of collaboration, consent, trust, and safety" (p. 95). This approach can also be applied as an analytical lens (Henderson et al., 2018). Oster and colleagues (2016) consider awareness of the continued impacts of colonization – including trauma – as part of the cultural understanding required to do research respectfully.

## 2.5.4 Ethical Space

The concept of ethical space conceptualizes the "in-between space" amidst the sphere of Western knowledge/culture and the sphere of Indigenous knowledge/culture (Ermine et al., 2004). The authors define the creation of ethical space as a process, whereby i) the ethical space itself has to

be affirmed; ii) dialogue about intentions, values, and assumptions towards the research process occur; and iii) an agreement to interact across the two cultural divides is created (Ermine et al., 2004). Hampton and colleagues (2007) define ethical space as the creation of environments in gatherings throughout their research process that "demonstrate respect and commitment that moves people to share their hearts" (p. 32). Through the work of Lopresti and colleagues (2022), creating ethical space in a community of practice allowed for the successful implementation of an Indigenous Youth Mentorship Program across communities because members were able to share locally appropriate best practices for implementation. It has been emphasized that researchers should be trained in how to create ethical space for dialogue (see Maar at al., 2019).

### 2.5.5 Two-Eyed Seeing (Etuaptmumk)

A decolonizing approach discussed the importance of making space for Indigenous worldviews (see Section 2.5.1). Two-Eyed Seeing is one tool to help create this space. Coined by Mi'kmaq Elder Albert Marshall, Two-Eyed Seeing/*Etuaptmumk* is described as "learning to see from one eye with the *strengths* of Indigenous knowledges and ways of knowing, and from the other eye with the *strengths* of Western knowledges and ways of knowing, and to using both these eyes together" (as cited in Bartlett et al., 2012, p. 335). *Etuaptmumk* was described further in Chung-Tiam-Fook (2022) as "the ability of Indigenous and non-Indigenous partners to engage in a process of mutual respect for one another's values and practices, while building a shared platform for learning and knowledge translation, and balanced understanding" (p. 62).

Two-Eyed Seeing was applied in a small number of the reviewed articles in several forms (Hatala et al., 2019; Kelley et al., 2018; Nagy et al., 2020; Prince et al., 2019; Young et al., 2019). It informed the weaving together of Indigenous and non-Indigenous methodologies (Nagy et al., 2020); the local cultural adaptation of a Randomized Controlled Trial (Young et al., 2018); policy development processes (Kelley et al., 2018); and public health approaches and service implementation (Prince et al., 2019). Hatala and colleagues (2019) applied a Two-Eyed Seeing frameworks to their qualitative data analysis process by blending both Western and Indigenous interpretations of emerging stories. Understanding an issue from both Western and Indigenous perspectives creates opportunity for reciprocal learning and provides greater potential to address various issues and challenges (Dieter et al., 2018).

Ethical space can be applied alongside two-eyed seeing to facilitate respectful interactions between different worldviews. Both of these guiding concepts contribute to trust building, participatory dialogue and participatory co-design in intercultural engagements (Chung-Tiam-Fook, 2022).

## 2.5.6 Cultural Safety

Creating a culturally safe research process was a priority in several studies (see Flicker et al., 2007; Dieter et al., 2018; Bennett et al., 2019; West et al., 2020). The concept was originally developed by Indigenous Māori nurses in New Zealand to address institutional discrimination, colonization, and relationships with colonizers in the healthcare system. This was done by requiring healthcare practitioners the examine personal biases, authority, privilege, and territorial history to improve relationships between healthcare providers and Indigenous peoples (see

Dieter et al., 2018). Siyám and Raphael (2022) define cultural safety as "the recognition that one needs to be aware of and challenge unequal power relations at the level of individual, family, community, and society. In a culturally safe environment, each person feels that their unique cultural background is respected, and they are free to be themselves without being judged, put on the spot, or asked to speak for all members of their group" (p. 45). Cultural safety in the research process reduces perpetuation of colonialism and contributes to decolonization through empowering participants (Flicker et al., 2007; Dieter et al., 2018; Brooks-Cleator et al., 2019). Ensuring cultural safety in the healthcare system decreases negative health outcomes (Health Council of Canada, 2012 as cited in Dieter et al., 2018) and increases the success of health interventions (Dieter et al., 2018). Ensuring cultural safety can also contribute to positive impacts resulting from research processes. Cultural safety can be evaluated based on whether or not participants feel safe in research processes and objectives (Bennett et al., 2019).

The terms *cultural relevance* and *cultural competence* are also mentioned in relation to cultural safety. Cultural relevance is defined as the inclusion of cultural practices that promote safe spaces of acceptance and comfort (Coppola and McHugh, 2018). Cultural competence refers to a "person's ability to understand, appreciate, and interact respectfully with Indigenous peoples and their cultural teachings and traditions" (EOLFN, 2015, as cited in Prince et al., 2019, p. 11). Though cultural competence can help lead to cultural safety, it is also criticized as equipping employees (or researchers for that matter) with cultural knowledge does not necessarily lead to safety for participants involved (Jackson et al., 2015). As a result, it is crucial that cultural safety is determined by community members, not external researchers.

Cultural safety includes safety for Indigenous worldviews, values, and identity. In practice, this can look like Knowledge Keepers being involved in research processes and decisions (see Dieter et al., 2018); incorporating Indigenous cultural practices (e.g., ceremony and traditional healing methods) (see Lavalley et al., 2020; Maina et al., 2020; Rizkalla et al., 2020); and hiring Indigenous Peoples (Kildea et al., 2012; Rix et al., 2014; Firestone et al., 2019). Location of research and project activities also plays an important role regarding cultural safety. Busija and colleagues (2020) conducted data collection and structuring activities in a community space where participants felt safe and comfortable. Additionally, Murray and colleagues (2014) found that providing a safe place for Indigenous people to socialize and practice culture contributed to success and sense of Indigenous and community ownership of the research. For Firestone and colleagues (2019), hosting events where Indigenous and non-Indigenous people could both attend cultivated understanding in the larger community.

Certain methodologies and methods can facilitate cultural safety, including interpretive phenomenology (Nasir et al., 2021) and talking circles (Kurtz et al., 2014). In some cases, cultural safety can mean being open to the transformation of methods to make them more culturally safe (Bennett et al., 2019). The type of data being collected can impact decisions regarding culturally safe and relevant practices. For example, Prince and colleagues (2019) chose to limit their collection of demographic data with the purpose of decreasing burden and increasing the cultural safety of the research process.

Overall, these aspects of cultural safety should be determined by the participants engaged in the research as it may vary across individuals and communities (Rizkalla et al., 2020). Taking a twoeyed seeing approach can assist in creating a space for dialogue to work towards cultural safety (e.g., Hatala et al., 2019), and collaborative engagement in general can promote cultural safe work (Kyoon-Achan et al., 2021a). Researchers have a responsibility to ensure cultural safety through their own actions. This can include but is not limited to reflecting on power dynamics and relationships in academic research (Bennett et al., 2019); reflecting on the research processes; acknowledging one's own cultural background, perspectives, and personal biases (particularly when it differs from participants' (Dieter et al., 2018)), and researcher training for appropriate research protocols and methodologies for cultural safety (Fitts et al., 2019).

#### Establishing guides for cultural safety

Establishing a guide at the beginning of a project provides a structure to support the integration of cultural safety throughout research and assessment activities. In Benoit and colleagues (2020), an advisory committee established principles for creating culturally safe spaces. Dieter and colleagues (2018)'s culturally safe model for dementia research followed the tenets of: "(a) relationships between researchers and community members are essential; (b) the environment within which the research project takes place is important; (c) Knowledge Keepers play a vital role in dementia health research in First Nations communities; and (d) the reflection of the research team must be continuous" (p. 11). Bennett and colleagues (2019) review key components to transforming a data collection method in a culturally safe way (reviewed in Section 2.9). Maar et al. (2019) found that ensuring cultural safety helped with the success of their research – their guidelines are reviewed in the box below.

#### Feature: Creating a Culturally Safe Randomized Control Trials and eHealth Research

Maar and colleagues (2019) found that successful eHealth research required a focus on cultural safety, which includes the following points:

- 1. Building a respectful relationship
- 2. Maintaining a respectful relationship
- 3. Good communication and support for the local team
- 4. Commitment to co-designing the innovation
- 5. Supporting task shifting with the local team
- 6. Reflecting on mistakes and lessons learned or areas for improvement that support learning and cultural safety (p. 5-6)

### 2.5.7 Concluding Remarks on Approaches and Guiding Concepts

While the approaches and guiding concepts covered in this section are presented separately, they are not mutually exclusive – they often intersect and support one another. It is possible to consider a project where they would all be included. This should be considered when deciding which (if not all) concepts will guide the research or assessment process.

## 2.6 Relationships, Meaningful Engagement and Trust

"When working with many unique communities, researchers recognized that there is no standardized way of doing things across multiple communities, but by putting relationships first, the intentions of the partnership are kept true."

(Lopresti et al., 2022, p. 6).

## 2.6.1 Relationality

Relationship building in community-engaged research intertwines with relationality, a concept central to Indigenous ways of being. This traditional understanding of relationships is one that is holistic, seeing all living beings as interconnected (Haag et al., 2019). Contrary to dominant academic practices of "fragmenting, simplifying and decontextualizing knowledge," research with Indigenous Peoples must capture relationships between the environment, the past and the future, and the spirit world (Henderson et al., 2018, p. 99). This holistic understanding is all-encompassing, reaching beyond the limits of Western research methods (Hayward et al., 2021). This relational worldview is evident in First Nations and Inuit expressions of health and healing (Haag et al., 2019), and is a foundation upon which all findings must be understood. It is important for research approaches to have the capacity to consider and facilitate relationality.

## 2.6.2 Building Trusting Relationships

The principle of relationality translates to the importance of relationships in research and assessment processes. The importance of building trust and meaningful relationships amongst researchers and community members is a common theme across several articles (Anthony et al., 2018; Bennett et al., 2019; Benoit et al., 2020; Carter, 2008; Carter et al., 2019; Henderson et al., 2018; Jacklin and Kinoshameg, 2008; Jackson et al., 2015; Kyoon-Achan et al., 2018a and 2021c; Mayo and Tsey, 2009; McElhaney et al., 2021; Morton Ninomiya et al., 2020; Murphy et al., 2021; Murray et al., 2014; Ogenchuk et al., 2022; Woodward and Marrfurra McTaggart, 2016; Ziabakhsh et al., 2016). It is central to ethical research practices in many Indigenous communities (see Morton Ninomiya et al., 2020). As well, as showcased in Table 1, it is a common principle in research by, with and for Indigenous communities. Taniguchi and colleagues (2012) recommend that "trust" also be recognized as a principle within Indigenous research guidelines. This section highlights themes and practices across articles described as contributing to trusting relationship-building in research processes.

*Knowledge of local culture and context:* It is important for researchers to familiarize themselves with the context of a community (Ogenchuk et al., 2022). When researchers are willing to work to understand communities and community needs, this helps build trust and respect (McElhaney et al., 2021). Familiarity can be particularly helpful for establishing a good first impression, as well as important preparation for defending a project from criticisms (Jacklin and Kinoshameg, 2008). This can be done by becoming aware of local culture, history, politics, and historical relationship to one's own culture (Jacklin and Kinoshameg, 2008). Young and colleagues (2018) found that meeting on traditional territory was a beneficial learning experience for academics who were not familiar with First Nations ways of life.

*Establishing contact and familiarity:* Jacklin and Kinoshameg (2008) recommend establishing contact with communities through formal introductions to community leadership, followed by a presentation of ideas and a participatory discussion. Before beginning their research, Kyoon-Achan and colleagues (2018a) visited each community relevant to their study focus, informing them of the study and inviting them to participate. They found that this process of initiating the study allowed for respectful engagement. Other approaches for initiating respectful research relationships include personal invitations for starting relationships (recommended by Nagy et al., 2020), face-to-face meetings (Shea et al., 2013; Young et al., 2017), community visits prior to initiating research (Murphy et al., 2021), multiple visits to a community (Patel et al., 2022); and group planning and collaborative activities (Shea et al., 2013).

*Communication:* Communication is central to relationships (Kyoon-Achan et al., 2021c). Communication styles and interactions with community members should be patient (Kyoon-Achan et al., 2021c), respectful of diverse perspectives (Benoit et al., 2020), accepting and nonjudgemental (Nagy et al., 2020), considerate of people's time, non-obtrusive, and allow for flexibility (Woodward and Marrfurra McTaggart, 2016). Researchers should be willing to sit with people and answer their questions (Henderson et al., 2018). Researchers' disclosure of personal information can assist in establishing a reciprocal relationship between researchers and community members (Morton Ninomiya et al., 2020). Inconsistent engagements with community members can have ill effects such as negative perceptions of researchers (Anthony et al., 2018); researchers have a responsibility to ensure they themselves have the capacity to engage consistently with communities.

Time: Lopresti and colleagues (2022) advise that researchers and institutions value the time dedicated to building connections and encourage researchers to go slowly, be personable, and allow people ample time for reflection before making decisions. Allocating adequate time for building trust may be essential for community members to overcome hurdles relating to the legacy of Indigenous and non-Indigenous relations and negative perceptions of white academics that may be based on previous research experiences (Mayo and Tsey, 2009). Both researchers and community members have wider obligations to their social and institutional contexts, which means that building relationships in the context of research engagements can be a slow process, particularly for hired researchers from the community (Woodward and Marrfurra McTaggart, 2016). There may be changes in participant attitude as trust develops (Woodward and Marrfurra TcTaggart, 2016). For example, in Mayo and Tsey (2009), initial hesitation to participate developed into trust as community members realized these academics were "normal" and even knowledgeable, kind, and helpful. Relationships were found to improve over time (Mayo and Tsey, 2009). Several articles describe how long standing partnerships contribute to trust, collaboration, and relationship building, and enabled researchers to engage more deeply, sometimes leading to collaborative research projects (Jackson et al., 2015; Lucier et al., 2020; Maina et al., 2020; Murphy et al., 2021; Wray et al., 2020).

*In-person presence:* Informal, in-person presence can contribute to relationship and trustbuilding. Wray and colleagues (2020) found that spending time with people and on the land was critically important. This can look like:

• *Participating in a community's daily life:* Attending social events, ceremonies, on-theland activities like fishing or woodcutting, grocery shopping, volunteering locally, eating at local businesses, sharing meals and tea helped build connections and friendships between researchers and community members (Bennett et al., 2019; Carter et al., 2019; Wray et al., 2020, etc.). Community members may invite researchers into these activities as trust is built (as in Woodward and Marrfurra McTaggart, 2016).

- *Informal moments*: Discussing research over a meal instead of a formal presentation may more effectively engage community members (Irving et al., 2017). Other researchers undertook opportunities to participate in powwows, community feasts and other gatherings. Some researchers initiated events, such as a homework club for children which contributed to trust and rapport (as described in Murphy et al., 2021).
- *'Taking up residence'* (Jacklin and Kinoshameg, 2008 p. 58): Relationships can be built by spending significant lengths of time in a community before, during, and beyond data collection. In Bennett and colleagues (2019), the lead author was housed with a local family. Jacklin and Kinoshameg (2008) had local office space, with this opportunity for frequent engagement and communication with community members allowing for both a more flexible research approach and for the development of trusting relationships.

Gaining insight through community immersion can reveal potential disconnects between academic research processes and cultural norms (Bennett et al., 2020; Beveridge et al., 2021).

*Partnership*: Approaching community members from a stance of partnership within research, rather than hierarchy, may contribute to trust. In a study on Indigenous women's heart health, researchers engaged with women participants as women/sisters and fellow participants, not as medical staff (Ziabakhsh et al., 2016). This equal stance contributed to power-sharing and a sense from Indigenous partners that researchers were becoming more like them as they learned from participants. Kyoon-Achan and colleagues (2018a) found that basing participation on the need for information rather than on hierarchies contributed to a flexible and collaborative partnership. Nagy and colleagues (2020) found that a respectful, non-judgemental relationship that honoured participant self-determination and agency and viewed service providers and participants as allies in achieving change was essential for their work to have meaningful impact. Building shared understandings of motivation and intention also contributed to trust (Jardine and Frugal, 2010, as cited in Murphy et al., 2021).

## 2.6.3 Research Relationships in Practice

A participatory research process itself can foster trust as researchers, community research associates and participants engage in joint activities and work towards common goals (Lopresti et al., 2022; Murray et al., 2014). Mayo and Tsey (2009) developed good working relationships by ensuring i) ideas were not imposed on communities, rather based on community discussion; ii) initial ideas were released to community members for feedback; and iii) program implementation and evaluation were discussed. Maar and colleagues (2019) outlined three stages of research relationships: i) engaging in the community research relationship pre-trial; ii) maintaining community research relationship during the trial; and iii) maintaining the relationship post trial, demonstrating that continuity is key. They include the above diagram (Figure 8) which captures the importance of collaboration, communication, and reflection in maintaining research relationships.

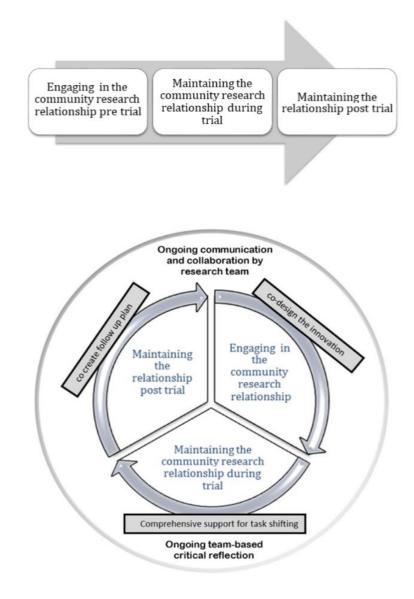


Figure 8: Maintaining Research Relationships (Maar et al., 2019)

### 2.6.4 Concluding Remarks on Relationships, Meaningful Engagement and Trust

The process of building and maintaining trusting relationships may provide research-specific benefits including project momentum (Beveridge et al., 2021), community trust of the researchers' intentions, a more pleasant atmosphere with less research-related anxiety (Kyoon-Achan et al., 2021c), limited conflict, deepened researcher understandings (Bennett et al., 2020), local collaboration (Carter et al., 2019), expanded project reach (Carter, 2008); and can contribute to a decolonizing approach (Shea et al., 2013). Beyond research (and just as importantly), fostering meaningful connections can also enrich people's lives (Carter et al., 2019).

However, building trusting relationships can be challenging, particularly for larger research projects (Murray et al., 2014; Wendt et al., 2019). Even when studies describe processes to build trust and promote accountability, this does not guarantee that the research was accountable or reciprocal, or that the community perceived the research as successful (Oberndorfer et al., 2017 as cited in Murphy et al., 2021). The remainder of this document provides additional details for how these standards can be met. Overall, researchers need to recognize the importance of building relationships as a "foundation to all research endeavours" (Murphy et al. 2021, p. 10) and as a relational process that proceeds and goes beyond data collection.

## Author Summary: Practices Contributing to a Positive Relationship Within the Research Process

The following actions were described as contributing to a positive relationship within the research process itself:

- *Hiring local people* for local communication and organization (e.g., Irving et al., 2017 who hired a local community liaison). Hiring local research associates can also enhance the reach of research activities, as "people trust those they know" (Khayyat Kholghi et al., 2018 p. 86).
- *Offering compensation* for community members' contributions to a project (e.g., cash or other culturally appropriate compensation) can also build trust as it indicates respect for people's time and knowledge (Woodward & Marrfurra McTaggart, 2016).
- *Speaking local languages*: Carter (2008) found that speaking the local language helped foster relationships and expand project reach, and indicated regret that project facilitators had not had training in local languages prior to data collection.
- Having a *formalized process*, such as a community advisory body to direct research (Murphy et al., 2021). Other formalized processes, including governance structures and research agreements, are discussed in the following section.
- *Incorporating cultural teachings* into research is described as beneficial for relationship and trust building (Ogenchuk et al., 2022).

## Further Readings

Additional references for building trusting relationships include the Government of Canada's *Tri-Council Policy Statement* and the report from the *Truth and Reconciliation Commission* (Ogenchuk et al., 2022; Simms et al., 2016).

Siyám and Raphael (2022), in their document on economic reconciliation, provide historical context on Indigenous-settler relationships alongside resources for reflection and learning.

Chung-Tiam-Fook (2022), a document intended to enhance Indigenous-settler partnerships, includes a section on "teachings, tools, and approaches for community engagement" and details case studies of partnership in action.

## 2.7 Protocols for Ethical Research and Assessment Processes

Researchers have a responsibility to ensure work by, with and for Indigenous communities is conducted ethically. There are several examples of projects opposed by Indigenous groups who felt they were being seen merely as sources of information (Taniguchi et al., 2012). In these projects, researchers did not recognize the legal, ethical, and socio-cultural implications of their research. Taniguchi and colleagues note that due to these observed patterns "Indigenous peoples are becoming more cautious about data interpretation, data ownership, and involvement in research design" (2012, p. 2).

Individual researchers are responsible for acting in ethical and trustworthy ways in their engagements with community partners. The roles of institutional bodies are generally limited to minimizing risk through ethics approval procedures, which is not sufficient to ensure the building of meaningful relationships. In its most basic form, ethical research should include sharing jointly documented information (Woodward et al, 2020), but research based in Indigenous ethics is "collective and collaborative, creating a space where reciprocal learning happens" (Dieter et al., 2018 p. 9). Relationship building is central to ethical research practices in many Indigenous communities (Morton Ninomiya et al., 2020). This type of research creates lasting positive impact by engaging and empowering community members.

# Feature: Indicators to be reported in peer-reviewed articles representing Indigenous individuals or interests

Jones and colleagues (2018, as cited in Murphy et al., 2021) offer a list of indicators that should be reported in peer-reviewed articles to convey to the reader the author's knowledge of conducting ethical research with Indigenous communities and how these communities were engaged:

- Recognize the Indigenous government or organization as an author.
- Identify whether community permission to conduct the research was granted.
- Describe the relationship of the Indigenous government or organization to the research project (i.e., initiator, principal investigator, collaborator).
- Acknowledge the contributions of the advisory board.
- Identify and describe the role of the community in the article and abstract, and not solely in the acknowledgments section.

They note that "these indicators are not provided as a prescriptive or final check-list; rather, they serve to inspire a broader discourse on the issues of conducting health research with Indigenous populations" (Jones et al., 2018, as cited in Murphy et al., 2021, p. 17).

The following sections review key protocols and processes that contribute to creating clear research expectations, roles, and guidelines for key considerations, such as ownership of data.

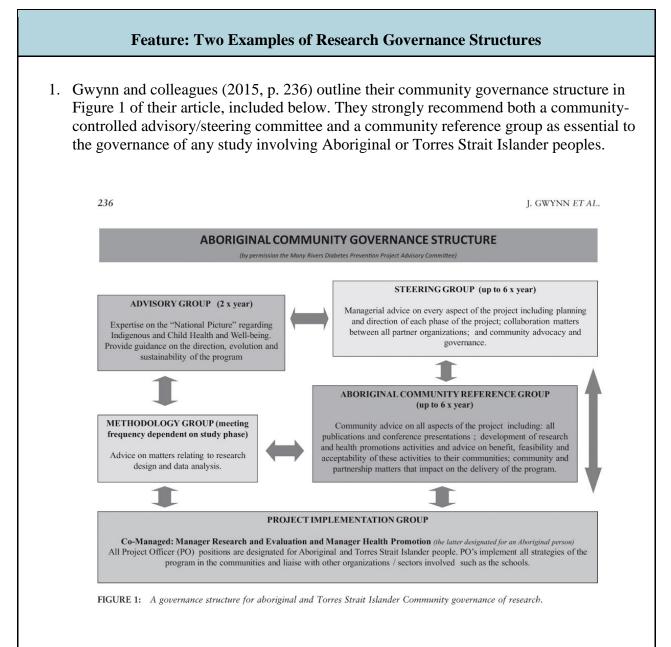
## 2.7.1 Governance Structures

Governance Structures are defined as "the way a community organizes itself to best meet the needs of its citizens" (Indigenous Services Canada, 2018 p. 118). These structures may include political bodies (e.g., Chief and Council, Boards of Directors), administration (e.g., staff), arms-length entities (e.g., Health or Treaty Societies), and community groups. A feature of Indigenous-led impact assessments is to embed the assessment's governance process into a community's existing governance and decision-making processes to aid in decision-making relating to land and resources (Gibson et al., 2018). Research and assessment processes may be designed to be complementary to, rather than in conflict with, these existing structures and processes.

The establishment of a governance structure for a research or assessment projects is a recommended protocol in several reviewed articles. Gwynn and colleagues (2015) describe 'governance' as consisting of: "processes (p) – how things get done; relationships (r) – the interaction and connection between people; institutions (i) – how processes are 'embedded' so they become operational; and structures(s) – which can be concepts or activities" (p. 240). They recommend developing and agreeing on a governance structure early in the research process to govern research decisions and community engagement. Wendt and colleagues (2019) noted that collaborations with high levels of community engagement enhanced communities' own research capacity, governance and management over time. Expanded on in the Feature box below, Gwynn and colleagues (2015) and McCalman and colleagues (2020) outlined specific governance structures for their studies, which informed community engagement in decision making throughout the research.

### Co-Governance

Co-governance is a concept attracting attention in the natural resources sector; its application is also possible in governing research and assessment processes. Co-governance can help ensure Indigenous knowledge and conceptualizations of governance are part of a research structure. Co-governance can have beneficial outcomes including increased Indigenous participation, addressing issues of power sharing, reinforcing trust, reducing conflict between parties, and enhancing the sustainability of resource management by incorporating Indigenous worldviews (Simms et al., 2016). Simms and colleagues (2016) advise that co-creation of governance structures must be mindful of existing power imbalances to avoid recreating colonial governance which exclude Indigenous knowledge and conceptualizations of governance (Simms et al., 2016).



2. McCalman and colleagues (2020) had an operational research management team that consisted of three overlapping levels of governance: community health partners, a Community Youth Advisory Group, and the project investigators. Each of these levels of governance reported to an Indigenous-led project management team, which comprised research and community representatives and was responsible for operational decisions.

#### 2.7.2 Research Agreements

Developing a research agreement is an increasingly common practice as a means of promoting ethical research practices (Wray et al., 2020). Research Agreements, protocol agreements, or memorandums of understanding were collectively developed between researchers and partner communities or organizations prior to the start of several studies and projects (Hayward et al., 2020; Gwynn et al., 2015; McElhaney et al., 2021; Oster et al., 2017; Parlee et al., 2021; Ritchie et al, 2015; Tran et al., 2020; Woodward and Marrfurra McTaggart, 2016; Young et al., 2017). Such an agreement is a helpful means of discussing research processes and goals with a community to ensure that research is conducted in a 'good' way (Coppola and McHugh, 2018). While such an agreement is not necessarily binding, they should explicitly outline the needs of partners and the goals of the project, and establish a common understanding between partners as they work together to meet their goals. Involving community members as co-partners, particularly in discussion of data management strategies, can be a helpful means of levelling power imbalances from the early stages of research (Dieter et al., 2018). Coppola and McHugh found that discussing their research agreement worked best as an iterative process, with frequent meetings with a community Elder providing opportunity to discuss their respective roles "honestly, openly and equally" (2018, p. 13).

#### Memorandums of Understanding

The Australian Government (2010) recommends creating a document such as a memorandum of understanding (MOU) when a project involves complex forms of community involvement. An MOU is "a short document in plain English that identifies what each party is expected to do or provide in their involvement," and is signed by all parties involved. This agreement can be useful for "laying the ground rules for communication and decision making" (p. 37). This can prevent conflict and establish clear roles and expectations in projects.

#### Benefit Sharing Agreements

Taniguchi and colleagues (2012) note that a common complaint from Indigenous peoples who have participated in research is that benefits of research are unlikely to go to those who were studied, described as patterns of harm. To change this pattern, "benefit sharing agreements should be in place prior to the decision of whether or not to participate in a study" (Taniguchi et al., 2012, p. 10). While research can have long-term beneficial outcomes, these agreements can focus on how research will immediately benefit communities (e.g., employment for community members).

#### 2.7.3 Indigenous Data Sovereignty

#### Indigenous Intellectual Properties

Four peer-reviewed articles discussed Indigenous intellectual property rights (IIP) and processes for protecting these rights. The term Indigenous intellectual property frequently refers to Indigenous knowledge and the affirmation of the rights of Indigenous peoples to have ownership over this knowledge (Marinova and Raven, 2006). However, IIP goes beyond knowledge and includes "the right to maintain, control, protect, and develop intellectual property over cultural heritage, traditional knowledge, and traditional cultural expressions" (Gomes et al., 2014, p. 566). Taniguchi and colleagues (2012) discussed IIP and how to protect them in their study involving genetics research. Woodward and Marrfurra McTaggart (2016) followed this guide in their research: "...all Indigenous knowledge (IK) remains the intellectual property of the Indigenous owner at all times, that owners of that knowledge can negotiate the use of that information by researchers, that use of this knowledge must be fully acknowledged, and that negotiation surrounding the use of IK is an ongoing process that involves the researchers and the IK holders" (p. 134). Parlee and colleagues (2021) ensured their partnership's governance agreement included principles for the respect of intellectual property rights of individuals and Indigenous government partners. Salerno and colleagues (2021) recommend developing a knowledge protocol based either on OCAP<sup>TM</sup> or a Nation-specific set of protocols and principles to guide how intellectual property is managed.

#### **ОСАР**<sup>тм</sup>

Ownership, Control, Access and Possession (OCAP<sup>TM</sup>) are guiding principles for how First Nations' data and information should be collected, protected, used, and/or shared (The First Nations Information Governance Centre, 2023). OCAP<sup>TM</sup> has been described as a "de facto standard" of Indigenous data sovereignty (Chung-Tam-Fook, 2022 p. 119). Following OCAP<sup>TM</sup> principles can allow knowledge, stories, and information to be treated as sensitive and sacred, protecting informants and the information they provide (Salerno et al., 2021). Rather than external researchers owning knowledge collected from research, a process designed in line with OCAP<sup>TM</sup> allows assessment processes to be specific to and owned by the community.

For several of the studies, OCAP<sup>TM</sup> guided data-related decision making (Brussoni et al., 2012; Dawson et al., 2020; Dieter et al., 2018; Flicker et al., 2007; Gwynn et al., 2015; Kandasamy et al., 2017; Kelley et al., 2018; Kyoon-Achan et al., 2021b; Kyoon-Achan et al., 2021c; Lopresti et al., 2022; Neufeld et al., 2020). Implementing OCAPTM principles meant detailing clear protocols and procedures for how data would be collected and analyzed (and by whom), how participants would be protected, how (and who) would store the data, and how data would be shared. These protocols and procedures were generally documented in formal agreements (e.g., Dieter et al., 2018; Gwynn et al., 2015). For example, for Kyoon-Achan and colleagues (2021b), part of implementing OCAP<sup>TM</sup> principles meant participating communities decided how data would be collected and by whom, how it would be stored and managed by the partner organization, how data would be disseminated, and how this data would be retired to the communities. It also meant that the research team was accountable to the communities through frequent information updates. A transparent process where communities are involved and informed is in line with the intentions of OCAP<sup>TM</sup> (Hughes and Shmon, 2005). Dieter and colleagues' (2018) following of OCAPTM principles led to a research agreement with clear protocols and procedures on who would hold the data at the end of the project; how participants and the community would be protected throughout data collection, analysis, storage and dissemination. The First Nations Information Governance Centre (2020) ensured that research assistants who contacted participants for a health survey had received OCAPTM training.

Dieter and colleagues (2018) note how outlining details for data protocols and procedures was "essential in guaranteeing that a reciprocal relationship existed and provided a solid foundation to move the research project forward" (p. 8). Brussoni and colleagues (2012) found that the use of OCAP<sup>TM</sup> as a central guiding framework for data collection, analysis, and management helped mitigate distrust; fostered a sense of community control; helped support self-determination; and provided opportunity for culturally relevant and sensitive implementation of findings. Applying

OCAP<sup>™</sup> builds respect and ethics in the research process, and can build community capacity as they draw on their knowledge and expertise (Hughes and Shmon, 2005; Salerno et al., 2021).

# Additional Data Management Considerations

Several articles did not refer specifically to OCAP<sup>TM</sup> but included additional details on data management practices to foster local and community ownership, control, access and/or possession (Gwynn et al., 2015; Henderson et al., 2018; Jacklin and Kinoshameg, 2008). Gwynn and colleagues (2015) detailed in a formal agreement that data would be kept under the control of the partner organization, alongside details for permission for external data access, the length of permission and the date of destruction of the data. For Jacklin and Kinoshameg (2008), community control meant opting out of statistical tests that excluded community members' participation in the analysis process, and choosing a combination of descriptive statistics and qualitative data to provide valid and reliable findings. Local ownership of data created a strong sense of self-determination over the matter being studied (Sawatzky et al., 2020), and is an important part of decolonizing research (Jacklin and Kinoshameg, 2008).

Partner organizations were frequently the stewards of the data (e.g., Gwynn et al., 2015). Certain articles stated that datasets resulting from the study were not publicly available but provided contact information for receiving "reasonable requests" of the data (e.g., Ogenchuk et al., 2022; Tremblay et al., 2018). In certain cases, bodies of people were made in charge of ensuring protocols and procedures adhered to community control and ownership of the data, including the Mi'kmaq Ethics Committee (Lewis et al., 2016) and a Community Advisory Group (Cornect-Benoit et al., 2020). Other data principle guides were also applied, including the Manitoba Métis Federation's Ownership, Control, Access and Stewardship Principles (Kyonn-Achan et al., 2021c).

# **Feature: Data Ethics Information Briefs**

As part of their community mapping workshops for recording Inuit knowledge on culturally significant marine use areas, Dawson and colleagues (2020) worked with attendees of the workshop to create tailored data ethics information briefs. These briefs were to be agreed upon and signed by any groups receiving the knowledge shared at this workshop. These briefs outlined requirements such as the following:

- 1. Proper acknowledgements should be made when using the data to the communities, local researchers, and local knowledge holders that were involved in and that were leaders in the project, as well as to the university's research team.
- 2. The experts whose knowledge and perspectives are documented within this data, their communities, and representative bodies (i.e., Inuit organizations) all retain ownership, control and possession of this knowledge and are guaranteed access to it.
- 3. The experts, the local communities, and representative bodies (i.e., Inuit organizations) retain ownership of the data as it is their cultural knowledge. Inuit, as a community and their representative bodies, own this information collectively in the same way that an

individual owns his or her personal information. Interviews and focus group discussions are confidential.

- 4. The experts, their communities, and representative bodies (i.e., Inuit organizations) have access to this information regardless of where it is held. They also have the right to manage and make decisions regarding access to their collective information.
- 5. If there is uncertainty about data ownership, the OCAP<sup>™</sup> regulations, the National Inuit Strategy on Research, and the university research team should be consulted.
- 6. All individuals working with the data must be made aware of the ethical requirements of using the data (p. 13).

In addition, when data was shared with a recipient (e.g, the Government of Canada), the respective brief clearly outlined the intended purpose for this sharing (e.g., for the purpose of supporting decision-making for sustainable and respectful shipping in Inuit Nunangat).

# 2.7.4 Research Approval and Ethics Review Processes

Additional points must be considered for the ethics approval process when conducting research by, with and for Indigenous communities. Generally, researchers in the reviewed articles consulted with community members or organizations prior to seeking formal ethics approval (see Busija et al., 2020). Community-level bodies that provided research approval or ethics review included local research ethics review bodies (Charania et al., 2014); band councils (Maar et al., 2019); community advisory boards (Khayyat Kholghi et al., 2018); local health authorities (Ritchie et al., 2013); and community Elders (Kurtz et al, 2014). Often, research was approved by both a university-based ethics review body and a community-based ethics review body (see Maar et al., 2019), or drafted according to a community organization's code of research ethics before being approved by a university faculty review board (Khayyat Kholghi et al., 2018). If there is no formal community ethics review, study protocols can be developed and approved in a participatory manner following institutional ethics policies, as was done by Arbour and colleagues (2008).

Brunger and Wall (2016, as cited in Murphy et al., 2021) suggest that institutional research ethics bodies should assume the responsibility of ethics review, ensuring that projects are relevant to communities needs and in line with OCAP<sup>TM</sup> principles. While it is beneficial for communities to have their own research review process to ensure accountability and that community goals are represented, having community review as a requirement may be burdensome to the community.

# **2.7.5 Consent Processes**

Free, prior, and informed consent is listed in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) as "an inherent right of Indigenous peoples and helps ensure their survival, dignity and well-being" (Chung-Tiam-Fook, 2022 p. 102). Establishing a clear process for how consent will be given is an important aspect of an assessment process (Gibson, 2018).

#### Community and Individual Consent

In most articles, both community-level and individual consent was sought (in that order) before research began. In the context of genomics research, Taniguchi and colleagues (2021) describe the need for both individuals and community consent. This process could consist of first seeking community approval through a community organization (e.g., a local health board), then from Chief and Council, and finally from individuals (Kacklin and Kinoshameg, 2008). Kyoon-Achan and colleagues (2021a) first had their research approved by each participating community through Band Council Resolutions, before obtaining free, prior, and informed consent from each participant.

#### Written or Verbal Consent

Collective or individual consent was obtained in *written form* (as in Sanderson et al., 2021; Lukaszyk et al., 2018; Young et al., 2018; Oster et al., 2016; Patel et al., 2022; Vaughan et al., 2018; McCalman et al., 2020; Simpson et al., 2021; Haynes et al., 2019; Kyoon-Achan et al., 2021a; Kildea et al., 2012), *verbally* (as in Charania et al., 2014; Lewis et al., 2016; Jacklin and Kinoshameg, 2008; Ritchie et al., 2013; Ziabakhsh et al., 2016), or in *both forms* (as in Lopresti et al., 2022). In other cases, while consent was given, it was not stated in what format this took place (as in McElhaney et al., 2021; Neufeld et al., 2020; Ogenchuk et al., 2022; Rizkalla et al., 2020; Shea et al., 2013; Watson et al., 2012).

The choice to obtain consent verbally was described as culturally appropriate for certain regions or communities (e.g., as in Charania et al., 2014). Lewis and colleagues (2016) describe verbal consent as "a more reasonable form of consent in Indigenous communities" (p. 201). Jacklin and Kinoshameg (2008) attribute this preference to cultures that have oral traditions based on the Seven Grandfather Teachings, and a mistrust of signature-related processes such as historical Treaty-making between Indigenous and colonial powers. As a result, researchers in this study obtained verbal consent from participants, noting the time, date, and location of consent.

#### Communication for Consent

Part of the consent process may include generating awareness of the research and awareness of participants' roles and rights. In certain cases, researchers provided participants with letters of information, and generally also verbally explained study details to participants (Jacklin and Kinoshameg, 2008; Sawatzy et al., 2020; Kyoon-Achan et al, 2021c). To inform each individual of whether or not to participate, participants in these studies were informed about study objectives, their rights as research participants, data use and management, and confidentiality.

In three studies with youth, parents or legal guardians provided written or verbal consent on their child's behalf (McCalman et al., 2020; Simpson et al., 2021; Watson et al., 2012). Young and colleagues (2018) deemed that children themselves should be the ones who chose whether to participate in the study. Therefore, they reached out directly to children ages eight to eighteen using information and recruitment letters, booths at community events, and individual invitations.

Listed in the Author's Summary below, several researchers outlined how they communicated the research and provided opportunities for informed consent in a way that was accessible for participants, including language and cultural considerations.

## 2.7.6 Concluding Remarks on Protocols for Ethical Research and Assessment Processes

Research agreements, governance processes, clear guidelines on data ownership and governance, and culturally and contextually appropriate consent processes help contribute to ethical research by ensuring clear communication, expectations, responsibilities, and benefit sharing between and among researchers, participants, and communities.

# Author Summary: Sample Means of Communicating Research for Consent Processes

- Respecting community partners' preferences, both in advance of and throughout their research, Jacklin and Kinoshameg (2008) publicized their research with posters, flyers, advertisements on local TV and a monthly advertisement in a local newspaper, as well as informing staff of local agencies of the research through meetings.
- Simpson and colleagues (2021) provided an illustrated booklet with key research details and a Plain Language Statement to assist with recruitment.
- Language considerations: Charania and colleagues (2014) explained the study in English or Cree as requested, and Romain and colleagues (2015) developed simplified informed consent forms and questions in both English and Inuktitut, alongside considerations for participants with low educational and literacy levels.
- In McCalman and colleagues (2020) and Simpson and colleagues (2021), community members hired as cultural liaisons were involved in the process of obtaining consent to ensure that participants were adequately informed.
- In Kyoon-Achan and colleagues (2018a), participating First Nations requested frequent updates from the study and access to study data as a continuation of consent throughout the research process.

# 2.8 Practices for Community Engagement and Leadership

Community engagement is essential for research that is culturally safe and in line with community concerns and priorities (Maina et al., 2020). Effective, meaningful approaches to community engagement may encourage a project's success, build community relationships, and strengthen community through engagement in and ownership of the research process (Harper et al., 2012; Maina et al., 2020; Murphy et al., 2021; Lopresti et al., 2022).

Assessments designed by and with community members from the outset allows for high levels of community engagement and ownership as their interests and worldviews are reflected in the research design. Several sources from grey literature are resources and examples of assessments that are created for use by community members to bring about change or build capacity within their own communities (as opposed to assessments conducted by an external researcher). This includes involvement of community members in designing the scope of the assessment itself, such as defining goals for community planning and determining which indicators to measure to determine progress towards these goals.

Community-initiated research projects and calling for research proposals directly from communities lead to research that meets community priorities and provides scientific insight (see Parlee et al., 2021). However, studies initiated by external researchers can meaningfully incorporate community priorities through engagement practices. This is generally an iterative process that allows a project to be, at the very least, tailored to a community's reality, and ideally, leads to community ownership over a project through significant involvement and buy-in (e.g., Carter et al., 2019, in which hired youth researchers became "project champions" in their social networks). Providing funding directly to communities can also support community abilities to address their own local priories and research gaps (Harper et al., 2012).

In projects with high levels of community engagement, certain factors contributed to successful partnerships. A *relationship-focused approach* positively affected the ability of researchers and community members to communicate and collaborate, at times allowing for highly collaborative research processes (see Angelbeck et al., 2014; Lucier et al., 2020; Kandasamy et al., 2017; and Ogenchuk et al., 2022). *Open communication* with discussion of roles and responsibilities early in the project prevented misunderstandings (as described in Carter et al., 2008). As well, Harper and colleagues (2012) recommend setting a *shared vision* between all project participants and taking a *strengths-based approach* to facilitate successful partnerships (see Section 2.4).

While meaningful community engagement throughout the research process is desirable, there are challenges and limitations to this engagement, including logistical challenges, resource constraints, skill gaps, and the level of capacity and interest of community members (Murphy et al., 2021). In cases like this, organizations with a presence in the community may play a role in representing community interests and priorities (see Ford et al., 2012). At other times, the limitations resulted from the researcher. While researchers may perceive or describe their community-based research as meaningful and beneficial, this may not be participants' actual experiences (Ford et al., 2018). The roles of community members may be unnecessarily limited by research assumptions. For example, while many projects engage Indigenous community members in data collection, participation in shaping research questions or in data interpretation and meaning-making is less common (Murphy et al., 2021). In a scoping review on Indigenous

participatory health research by Murphy and colleagues (2021), despite researchers describing studies as influenced by community members, very few studies were community led or owned.

Researchers hold a responsibility to work with the community to determine what level of engagement is desired, as well as outline possible approaches for a particular research project. These decisions should be made based on input from community members themselves, not researcher assumptions (Murphy et al., 2021). The following sections reviews the multitude of ways in which community members were engaged in and led research and assessment activities in the selected literature. We begin with common community engagement practices, followed by a review of the specific roles fulfilled by community members in the reviewed studies. We end this section with a review of practices that researchers can apply to facilitate community engagement.

# 2.8.1 Common Community Engagement Practices

## **Openings and Introductions**

Prior to community engagement, introductions and openings will take place in some form. The Canadian Aboriginal Aids Network (CAAN) (n.d.) outlines the importance of a traditional opening for bringing hearts and minds together, fostering good thoughts, and establishing a safe atmosphere. Introductions allow people to get to know each other and foster a sense of belonging, purpose, and teamwork. CAAN provides the following outline for opening a community engagement session with the participation of a willing Elder or Traditional Person:

# Feature: CAAN's Guide to Openings and Introductions

- 1. "Prior to the session, it is your responsibility to determine the culturally appropriate manner in which to open the session. Once determined, approach the Elder/Traditional Person and if possible, welcome him/her to participate in the training. Full participation will allow the opportunity for the Elder/Traditional Person to offer his/her input and if agreed, counsel a participant if required.
- 2. Start the session by briefly introducing yourself and welcoming the participants.
- 3. Introduce the Elder/Traditional Person, briefly explaining [their] role. Invite [them] to open the session (as predetermined)" (CAAN, n.d., p. 9)

# Meetings, Round Tables, and Workshops

Meetings, round tables, and/or workshops with project stakeholders provided platforms for participants to share concerns, priorities, relevant local information, and provide feedback on project scope, tools, and direction (as in Isaak et al., 2010; Morton Ninomiya et al., 2020; Shea et al., 2013). They were a common starting point for relationship-building, and throughout projects they facilitated establishing research objectives, project planning, feedback, and results sharing with community members, other stakeholders, and/or experts (e.g., Parlee et al., 2021; Isaak et

al., 2010; Plaganyi et al., 2020; Kandasamy et al., 2017; Charania et al., 2014; Morton Ninomiya et al., 2020; Shea et al., 2013). Three elements of ethically and culturally safe meetings are face-to-face interactions, storytelling, and Elders holding roles in decision-making (Dieter et al., 2018).

## Community Liaisons

Several studies took place with community members acting liaisons between researchers and communities. Community members hired as liaisons in Isaak and colleagues (2010) were vital for initiating research with the community, and Kyoon-Achan and colleagues (2021c) describe how community liaisons helped establish trust amongst researchers and community members.

The responsibilities of community liaisons included recruiting study participants (Carter et al., 2019; Henderson et al., 2018; Isaak et al., 2010); providing logistical support (Kyoon-Achan et al., 2021c; Simpson et al., 2021); facilitating events (Isaak et al., 2010); clearly communicate research objectives and obtain informed consent (McCalman et al., 2020; Simpson et al., 2021); and advising researchers on local cultural considerations (Kyoon-Achan et al., 2021b; Kyoon-Achan et al., 2021c). In studies where researchers and research participants were already interacting, local liaisons were cultural interpreters, enabling effective communication and a culturally safe participant experience (Carter et al., 2019; Einsiedel et al., 2013; Kyoon-Achan et al., 2021b; Nagy et al., 2020; Simpson et al., 2021).

Liaisons could be individuals in the community who researchers had contact with (e.g., Kyoon-Achan et al., 2021c), councils tasked with communication and logistical support between researchers and communities of focus (e.g., Wendt et al., 2019), or hired research assistants who also aided with cultural interpretation, logistical support, and participant recruitment (e.g., Carter et al., 2019; Patel et al., 2022; Simpson et al., 2021). Isaak and colleagues (2010), who had to periodically hire replacements for community liaisons who could no longer participate, note that it can be difficult to make new connections and find replacements. They found that asking for liaison recommendations from a local health director was an effective means of finding a replacement.

#### Indigenous Peer Researchers and Facilitators

Many studies trained local community members as peer researchers and research assistants for research projects. This helped build capacity, promote community dialogue (see Flicker et al., 2007), and contribute to study quality and culturally tailored research methods (see Carter et al., 2019). Peer researchers (often working with a research coordinator) were hired and trained to recruit participants; facilitate focus groups in their own communities; participate in data analysis, in knowledge translation, in co-creation and refinement of knowledge documentation tools (Carter et al., 2019; Flicker et al., 2007; Kildea et al., 2012; Sanderson et al., 2021).

Lukaszyk and colleagues (2018) integrated community members into the project by hiring Aboriginal research assistants and site managers. Among other criteria, site managers were required to be active members of their local community. Program Facilitators did not need to be Aboriginal, but had to be i) an allied health professional; ii) have experience working with Aboriginal people, and receive cultural competency training provided the project's Aboriginal Steering Committee (Lukaszyk et al., 2018, p. 197). Hiring local peer researchers and research assistants provided mutual benefits for both parties. Local researchers and assistants participated in research training and gained transferable skills, building local research capacity (e.g. Flicker et al., 2007; Elliott et al., 2015). Some trained researchers did go on to have consistent employment in research because of the training they participated in through these projects (as in Elliott et al., 2015; Kildea et al., 2012). Meanwhile, local researchers provided critical feedback to external researchers on research practices and insight into local context, leading to improvements. There is a tendency to forget that external researchers can also learn from locally hired researchers; however, external researchers should also learn from locally hired researchers. This bi-directional capacity building – where each party learns from the other – contributes to sovereignty and self-determination (Murphy et al., 2021).

Challenges may occur when hiring local peer researchers and facilitators. In Carter and colleagues (2019), community members hesitated to answer questions they knew youth facilitators already knew the answers to, and youth facilitators also struggled not to interject their own answers in interview activities. Researchers should consider that English literacy and numeracy could act as a barrier for Indigenous peer researchers and make adjustments to roles accordingly (as in Carter, 2008). Two examples of studies with in-depth information on peer researcher hiring and training are included in the feature box below.

# **Feature: Two Examples of Studies Employing Peer Researchers**

**Example 1:** Hiring people who had previously been involved in research as subjects, researchers in Elliot and colleagues (2015) developed a flexible, interactive, attendance-based training model with an hourly wage designed to train peer researchers to undertake their own research projects in the future. They found they had to address other barriers, at times providing food, housing, transportation to appointments, and other support to allow peer researchers to succeed, noting that "it was impossible for the [research assistants] to be focused at work if they were worrying about where they were going to sleep that night" (p. 29).

**Example 2:** In Dawson et al.'s (2020) participatory mapping study, 59 Inuit and Northern youth (ages 15-45) were trained as community research associates. Key training exercises (covered extensively on pages 6-8) included:

- Researchers read draft questions aloud, adjusting questions to ensure they were "easily understood, non-technical, and relevant to the community" (p. 7). With the help of a skilled interpreter, community research associates translated questions into Inuktitut, then translated them back into English to ensure original meanings were preserved.
- Researchers trained community research associates by providing sample final products (e.g., maps and community reports), hands-on demonstrations, and activities such as tasking associate researchers to map familiar routes as interviewer-interviewee pairs.
- Community research associates practiced the data collection methods they had just been trained in through a half-day practice run of data collection. Following this test run, community research associates reflected on their experience. They strategized ways to improve their techniques for the upcoming workshop, decided on their respective roles in the workshop, and refined research questions as necessary.

## Advisory Groups and Project Teams

Creating project advisory groups and project teams is a common practice for engaging communities and promoting culturally appropriate research practice. These guiding bodies, also referred to as Community Reference Group, Community Advisory Group, Project Reference Group, Project Team, and Steering Committee, are composed of community members and knowledgeable individuals, with membership reflective of research purposes. Members included local Elders and Knowledge Carriers (Prince et al., 2019), health care workers (Patel et al., 2022), staff from social services departments (Oster et al., 2016), teachers (Ogenchuk et al., 2022), and members of Indigenous governing bodies (Murphy et al., 2021). Composition depends on the focus and purpose of the study. In some cases, researchers were also included to ensure the projects met academic priorities (e.g. Satawzky et al., 2020), but it is recommended that they be composed mainly of local Indigenous individuals (Carter et al., 2019; Gwynn et al., 2015). These groups generally engage through consistent meetings to discuss issues and provide feedback and guidance on the research process (Isaak et al., 2010; Kholgi et al., 2018).

Group responsibilities varied between studies. Their roles included approving research before it took place; guiding and designing the research process; providing support and guidance regarding culturally sensitive issues and emerging problems; providing knowledge on their respective communities; recruiting participants for data collection; deciding how to disseminate results; providing feedback on data analysis and resulting knowledge products; and implementing policies and strategies (Charania et al., 2014; Cornect-Benoit et al., 2020; Isaak et al., 2010; Kildea et al., 2012; Turner et al., 2020). In Tremblay and colleagues (2019), the Community Advisory Board was responsible for supervising all aspects of the project, from design through to implementation and assessment. While these groups were mostly for community engaged research (e.g. Benoit et al., 2020; Dieter et al., 2018; Gwynn et al., 2015), they also guided literature review research processes and outcomes (Maina et al., 2020). Advisory groups played key roles in community engagement, ensuring beneficial research outcomes, and in driving partnerships between communities and institution-based researchers (Gwynn et al., 2015; McElhaney et al., 2021).

# Key Information: The Important Roles of Community Groups

Gwynn and colleagues (2015) believe that all projects and projects should establish Community References Groups (CRGs). They describe their importance by stating:

"The CRGs have been described by community members as 'the tree from whose branches hangs (sic) all aspects of the research'. These enable communities to be engaged proactively, and are vital in enabling community benefit. The CRGs and Aboriginal and Torres Strait Islander employees hold the project together, manage risks to the study and support the translation of research results into practical benefits to the community. Together they ensure community priorities are addressed at each step and have an 'ear' to the community and its issue on a daily basis. They guide research programs on each community's ways of 'doing business' and on managing research activity with sensitivity to local issues." (p. 240)

#### Partnering with community leaders and local organizations

In some studies, notably in research focused on health services delivery, researchers partnered with leaders, local residents, and existing community structures or organizations. They used existing social networks to structure research initiatives and meaningfully engage community members to build local capacity (Kyoon-Achan et al., 2021c; Wendt et al, 2019). For example, Kyoon-Achan and colleagues (2021c) worked with community structures and leaders to improve caregiver knowledge, attitudes and behaviours toward early childhood oral health. This was an effective approach due to community member knowledge of local issues, allowing for the identification of areas of need and for research to be translated into appropriate action.

# 2.8.2 The Role(s) of Community Members in General Research and Assessments

There are several ways that community members in general were engaged in and throughout academic research processes (see Table 5). While not comprehensive, this table illustrates general trends and examples across studies of where community members were involved, and who was likely to be involved in what capacity.

	Activity	Participant	Sample source
	Learning about local culture and context; engaging warmly and respectfully; ensuring that research aligns with community needs and ethical principles	External researcher	Kandasamy et al., 2017
	Feedback, oversight, assistance in and approval of all or most aspects of research, including considerations for local culture	Advisory council	Khayyat Kholghi et al., 2018
		Elders	Farrant et al., 2019
	Facilitating Ceremony	Elders	Dawson et al., 2020
	Logistical support; troubleshooting problems	Community liaison	Simpson et al., 2021
		Other community partners	Carter et al., 2019
	Supporting communication between research team and community	Advisory council	Wendt et al., 2019
		Community liaisons Youth community liaisons	Henderson et al., 2018 Carter et al., 2019

Table 5: Summary of Engagement	Activities and Community Roles

Initiating research project; idea generation; identification of community priorities	Advisory council	McElhaney et al., 2021
	Community liaison	Isaak et al., 2010
	Elders	Tremblay et al., 201
	Result of long standing relationship between community and researcher	Angelbeck et al., 2014
Collaboratively writing and reviewing research proposals, funding applications, and ethics applications	Advisory council	Kyoon-Achan et al. 2018a
	Elders	Kurtz et al., 2014
	Peer researchers	Harper et al., 2012
	Advisory council	Wendt et al., 2019
	Community advisors	Brooks-Cleator et a 2019
	Community liaisons	Einsiedel et al., 201
Creating, reviewing, modifying and approving data collection methods and tools	Community members (general) Elders Youth	Irving et al., 2017 Kurtz et al., 2014 Hampton et al., 200
	Peer researchers	Dawson et al., 2020
	Staff of partner organizations	Neufeld et al., 2020
Participant recruitment	Community leader	Ogenchuk et al., 2022
	Community liaison	Kyoon-Achan et al. 2021c
	Peer researchers Youth peer researchers	Sawatzky et al., 2020; Carter et al., 2019
	Community liaison	Fitts et al., 2019

Obtaining free, prior and informed consent from participants	Peer researchers	Kyoon-Achan et al., 2021a
Interpretation into other languages	Community advisor	Brooks-Cleator et al., 2019
	Community liaison	Simpson et al., 2021
	Peer researchers	Jacklin and Kinoshameg, 2008
Data collection	Peer researchers (including Elder and youth peer researchers)	Kyoon-Achan et al., 2021b; Farrant et al., 2019; Dawson et al., 2020
Data analysis and interpretation	Advisory council	Cornect-Benoit et al., 2020
	Peer researchers	Kyoon-Achan et al., 2021b
Knowledge dissemination and implementation; developing and sharing outputs of research	Advisory council	Oster et al., 2016
	Community leaders	Harper et al., 2012
	Elders	Ziabakhsh et al., 2016
Preparing manuscripts for peer-reviewed publication; co-authoring paper	Community advisor	Brooks-Cleator et al., 2019
	Community members (general)	Harper et al., 2012
	Peer researchers	Haynes et al., 2019
Development of recommendations resulting from research	Advisory council	Charania et al., 2014
Ongoing activities evolving from study	Community members (general)	Kurtz et al., 2014

## 2.8.3 The Role(s) of Elders in Research and Assessment Processes

Elders (or Knowledge Keepers, as is the preferred term in certain regions) holding roles in decision-making is one of the key elements of ethically and culturally safe community meetings, including gatherings for research or assessment purposes (Dieter et al. 2018). Elders are seen as significant guides and teachers in their communities (Lickers, 2017). Their sharing of wisdom through stories can shape research that is respectful, relevant, culturally safe, and builds on the strengths of Indigenous culture (Hampton et al., 2007; Farrant et al., 2019). Elders not only provide insight into history (Islam and Berkes, 2016), they can also "provide a link between past and present, creating a sense of cultural continuity" (Hulko et al., 2010 as cited in Dieter et al., 2018 p. 6), and contribute to a study's validity (Carter et al., 2019; Neufeld et al., 2019). Hampton and colleagues (2007) say it is important to include Elders throughout the research process.

The literature includes examples of Elders being involved at all stages of a research process. In certain cases, they hold unique positions of influence in these settings, as they are looked to as guides and decision-makers in their communities (Carter et al., 2019; Dieter et al., 2018; Lickers, 2017). In Carter and colleagues (2019), youth co-researchers advised that inclusion of Elders was essential so that other community members would not feel "cultural disconnect, discomfort, and reluctance" to participate (p. 395). Farrant and colleagues (2019), who included Elders as coresearchers on their project, found that it was important to allow ample time for these groups to reach consensus in decision-making, in line with Indigenous ontologies and epistemologies. Workshops and project meetings often began with Ceremony conducted by Elders in the form of prayers and blessings, the presenting of tobacco, smudging, or other depending on the customs and traditions of each particular community (see Dawson et al., 2020; Dieter et al., 2018; Flicker et al., 2014; Hampton et al., 2007; Jackson et al., 2015; Kyoon-Achan et al., 2018a; Kyoon-Achan et al., 2021c; Lucier et al., 2020). As well as a symbol of a project's commitment to honouring cultural knowledge and traditions (Dieter et al., 2018), the inclusion of Ceremony may be critical for supporting the well-being of community members who are participating in studies (as in Sanderson et al., 2021). Elders can provide support in other ways depending on context, as demonstrated in the work of Nasir and colleagues (2019) where Elders provided counselling support.

# 2.8.4 The Role(s) of Youth in Research and Assessment Processes

Youth involvement in research is described as "an important factor in the success of research initiatives" (Carter et al., 2019 p. 392). Leadership development and capacity building is particularly emphasized in studies involving youth (Carter et al., 2019; Dawson et al., 2020; Flicker et al., 2014; Jacklin, 2008). Involvement in research can be an empowering process for youth, allowing them to take ownership over the research process and contribute positively to community engagement and study quality (as in Carter et al., 2019). Youth were engaged in different stages of research, most notably in participant recruitment and data collection as corresearchers - roles aided by their knowledge of and familiarity with their community (Flicker et al., 2014; McCalman et al., 2020; Carter et al., 2019; Dawson et al., 2020; Hatala et al., 2019; Hampton et al., 2007; Parlee et al., 2021; Wray et al., 2020). Wray and colleagues (2020)

recommend hiring youth researchers as it helps ensure research projects are beneficial for communities.

Brascoupé and Waters (2009, as cited in Flicker et al., 2014) found that additional support may enable youth who have not yet developed leadership qualities to take on these roles. Other community members, including Elders, play an important part in fostering youth leadership through encouraging youth and passing on knowledge (Lickers, 2017). There are potential challenges to consider when engaging youth in the research process. Youth may be constrained by their availability; in Carter and colleagues (2019), research obligations took more time than expected, and youth had significant family, school, and community commitments, leading to fluxes in participation. Perceptions of what ages are considered 'youth' may differ between regions (FNIGC, 2006 as cited in Hayward et al., 2021).

#### Key Information: The Importance of Bridging Knowledge between Generations

The importance of passing down knowledge is underlined in the research. Research can be beneficial for promoting dialogue between Elders and youth. In Carter and colleagues (2019), youth co-facilitators relished the opportunity to interact with and learn from Elders, and Elders were glad that their knowledge of hunting, camping, and fishing was being documented by youth for future generations. Maina and colleagues (2020) found that students' self esteem and attitudes towards school improved when Elders taught about culture and community knowledge in their schools. Youth found the input and support of Elders significant, seeing them as significant guides and teachers (Carter et al., 2019; Lickers et al., 2017).

# 2.8.5 The Role(s) of Researchers in Indigenous Community Research and Assessments

We've reviewed several ways that community members can be engaged in research. However, researchers also have roles to consider outside of *doing the research*. Some articles provided key ways in which researchers can re-think their interactions with participants and community throughout research and assessment processes.

#### Researchers as Participants

While researchers are generally trained to act as impartial listeners, researchers can also take part in data collection as participants when the community is in agreement. In Bennett and colleagues 2019 study using photovoice, participants asked researchers to contribute their own images to break down hierarchies between researcher and participant, and let participants get to know them on a personal level. Researchers felt it was important to maintain a "low profile" in group discussions, coining the term "discreet participants" (Bennett et al., 2019, p. 7). In Isaak and colleagues (2010) study using sharing circles as a method, a participant later expressed desire for researchers to participate in the discussion rather than just listen. In this case, researchers' absence from the discussion was perceived by the community as a lack of trust. Being engaged as participants in the research process itself can build trust and break down power relations.

#### Researchers as Learners: Co-learning

The concept of co-learning is described by Murphy and colleagues (2021) as a dynamic transfer of knowledge from researchers to community members, and from community members to researchers. Authors also referred to multidirectional learning (Benoit et al., 2020), 'both-way' or 'two-way' learning (Haynes et al., 2019), and multi-directional capacity building (Murphy et al., 2021). While participants can learn from researchers, this is not a one-way process – researchers also have much to learn from community members while doing research. Kyoon-Achan and colleagues (2021c) describe a practice of 'embodied learning,' where non-Indigenous researchers learn by observing and interacting in community-based contexts. According to Dawson and colleagues (2020), co-learning is "known to elicit stronger research outcomes" (p. 2), and Benoit and colleagues (2020) found it contributed to non-hierarchical research processes.

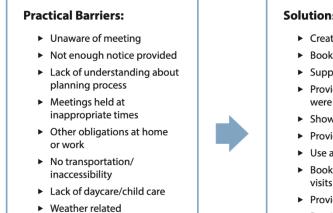
Co-learning took the form of facilitating cross-cultural knowledge and skills exchanges (Dawson et al., 2020); participating in sharing circles (Benoit et al., 2020); and planning events in a participatory manner (Carter et al., 2019). Along with learning from researchers' experiences, community member participants appreciated researchers' willingness to learn about cultural traditions and protocols in these settings (Benoit et al., 2020). Co-learning is reflective of the collaborative approach of CBPR (Hayward et al., 2020), and Haynes and colleagues (2019) state that it "values Indigenous knowledge systems and the reciprocal co-creation of knowledge" (p. 40). Murphy and colleagues (2021) observe that capacity-building is often only discussed when transferring skills and knowledge to community members, despite the potential for research processes to also build capacity for non-Indigenous researchers. This is discussed further below.

# Feature: Bi-Directional Capacity Building or Co-Learning

"Indigenous Peoples have been researchers since time immemorial, collecting and analyzing information from the land, and from one another, to support and provide for the well-being of all their relations; thus, this knowledge has always existed. Furthermore, some Indigenous Peoples argue that capacity-building is needed at least as much by researchers, whereby there should be an onus of responsibility placed upon non-Indigenous researchers to learn more about Indigenous perspectives before ever entering into a research relationship with Indigenous partners. Additionally, should capacity-building be mentioned in the context of Indigenous communities, it should capture the need for greater self-determination and sovereignty over research rather than leading with the assumption that Indigenous peoples simply require more Euro-western research skills." (Murphy et al., 2021, p. 16).

# 2.8.6 Considering Obstacles to Community Engagement

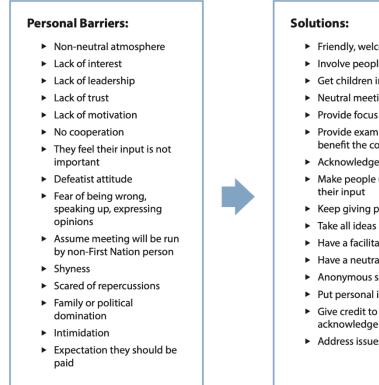
Practitioners involved in the publications of grey literature provide insight into common barriers to community engagement, and how to anticipate and avoid these barriers. Indigenous Services Canada (2018) outlined practical and personal barriers to community engagement (see Figure 9 and Figure 10).



#### Solutions:

- Create a communications strategy
- Book meeting at set time and dates
- Supply agendas to show meeting content
- Provide minutes or notes for those who were unable to attend
- Show progress with newsletters, posters
- Provide information to the public
- Use a survey rather than a meeting
- Book individual meetings, lunches, home visits at flexible times
- Provide transportation to meetings
- Provide childcare services ►
- Hold meetings indoors

Figure 9: Practical Barriers and Solutions (Indigenous Services Canada, 2018, p. 5)



- Friendly, welcoming attitude
- Involve people on a personal level
- Get children involved
- Neutral meeting place
- Provide focus group sessions or home visits
- Provide examples of how planning will benefit the community
- Acknowledge and appreciate participation
- Make people understand the importance of
- Keep giving positive feedback
- Take all ideas into consideration
- Have a facilitator
- Have a neutral chairperson
- Anonymous suggestion box
- Put personal issues aside
- Give credit to community members and acknowledge their accomplishments
- Address issues and look for solutions

Figure 10: Personal Barriers and Solutions (Indigenous Services Canada, 2018 p. 6)

With consideration to obstacles in community engagement, researchers should be well aware of consultation fatigue, or rather, the result of "too much talking and not enough action," (Australian Government, 2010, p. 24). This lack of concrete outcomes can lead to stakeholders losing interest, negatively impacting future engagement strategies.

Through all stages of community engagement, researchers should recognize and celebrate community members' contributions. This can take many forms, from organizing a community barbecue to providing references. Regardless of the ways in which appreciation is demonstrated, it is crucial to affirm that the work of the community is recognized and valued.

# 2.8.7 Concluding Remarks on Practices for Community Engagement and Leadership

This section outlined common methods of community engagement in the selected literature, showcasing how engagement can occur at different stages of research, with various levels of responsibility. Common themes include:

- Engaging community members in as many stages of the research as possible.
- Inviting community members to shape and interpret research, not just in data collection.
- Hiring community members to conduct different aspects of the research, with a focus on building research capacity in the community.
- Ensuring cultural practices are honoured Elders are part of all stages of the research.
- Ensuring research questions, processes and methods are reflective of community needs and practices, and seeking and incorporating feedback iteratively throughout research.
- Forming advisory groups and hiring local researchers are recommended practices.
- Creating flexible processes that encourage community and individual engagement.
- Integrating bi-directional capacity building for two-way learning.
- Anticipating and addressing potential barriers to effective community engagement.

As always, practices should be adapted to the research context and according to community decisions and capacities.

# 2.9 Research Paradigms: Knowledge Systems, Theories and Methodologies

# 2.9.1 Indigenous Ontologies, Epistemologies and Theory-Principles

Ontological and epistemological assumptions about what knowledge is and how knowledge is understood lay the foundation for approaching and choosing appropriate theories, methodologies, and methods. This section reviews how Indigenous ontologies, epistemologies, and theory principles derived from Indigenous knowledge systems were put into practice.

#### Indigenous Knowledge Systems and Worldviews

Indigenous knowledge systems are described as fluid (as cited in Beveridge et al., 2021), interconnected (Kyoon-Achan et al., 2021c), and as wholistic (also spelled holistic) (Haad et al., 2019; Kandasamy et al., 2017; Nagy et al., 2020). Wholism is discussed frequently within healthcare, where physical and mental wellbeing can include culture, spirituality, language, connection to land, and social, emotional, and cultural wellbeing for the individual, family, and community (Farrant et al., 2019). In certain contexts, a medicine wheel provides a visual representation of this wholistic worldview of health (Ritchie et al., 2015).

Authors often contrasted Indigenous worldviews with Western worldviews – which generally support individualist and dichotomous ways of knowing (Farrant et al., 2019; Flicker et al., 2014). Differing worldviews lead to differing assumptions; for example, while authority in Western systems is acquired through specific roles, authority in Indigenous communities is generally based on age, cultural knowledge, and relationships (as cited in Farrant et al., 2019). Failing to acknowledge and discuss differences in understanding can lead to misunderstandings. Understanding knowledge systems at play and their ontologies, epistemologies, and value principles is important for ensuring that research objectives are aligned with research design.

#### **Ontologies and Epistemologies**

Researchers working with Indigenous communities should be aware of their own ontological and epistemological assumptions – especially considering that University structures and research processes have been rooted in more Western worldviews. Awareness of why processes have historically been completed a certain way and the assumptions interrelated with these ways of knowing and doing is part of the process for creating better research practices moving forward.

Common Indigenous epistemologies include relational ways of knowing (Beveridge et al., 2021; Hatala et al., 2019), and an understanding of accountability towards the world (Kovach, 2010 as cited in Nagy et al., 2020). Epistemologies and ontologies differ across Nations and communities – understanding of how knowledge is known and understood should be discussed with communities to assist with research design decisions.

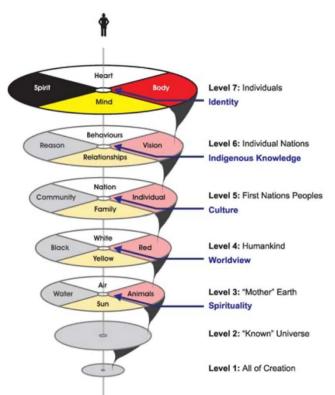
# Feature: Example of How Worldviews Underlie Design

Explicitly or implicitly, core teachings can be encoded in design choices. For example, the following principles may be encoded within the symbology of the Medicine Wheel:

- "The circle symbolizes wholeness, inclusion, feminine energy (womb), and eternity.
- The four directions of a healing journey (South, West, North, East).
- The four basic elements of Mother Earth (earth, water, fire and air).
- The four dimensions of the human condition and wellbeing (physical, mental, emotional and spiritual).
- Natural laws are based on observations of and interrelationships with the natural world, and are aligned with the sacred laws bestowed by the Creator (e.g. love, respect, truth, reconciliation and peace).
- The four stages of the life cycle (child, youth, adult, Elder)" (Chung-Tiam-Fook, 2022 p. 57).

Similarly, the way research and assessments are conducted and implemented is directly connected to the worldviews underlying these processes.

The Regional Health Survey conducted by the First Nations Information Governance Centre was based on a framework designed to



reflect commonalities between diverse Indigenous worldviews. The framework (the diagram on the right from FNIGC, 2005 p. 4), shows seven levels connecting the individual to all of creation, forming a complex and layered picture of First Nations identity. This framework determined the health survey's design and distribution, using the concept of Balance between the different levels as a foundation for First Nation wellness.

## Feature: Example of Differing Ways of Knowing Knowledge

While researchers from a Western knowledge system commonly view knowledge from a positivist perspective (i.e., knowledge exists independently from us and is discovered), Indigenous epistemologies are different. Knowledge learning in Anishinaabe culture has been described by Rheault (1998, as cited in Ritchie et al., 2015) through the **four stages of feeling**, **observing**, **reflecting**, **and doing**: "These stages seem to support the temporal changes or transition from connecting with creation as a first-order sensory learning process (feeling and observing), and connecting with self as a second order process (reflecting). Doing simply refers to the process of applying the knowledge to new situations" (Ritchie et al., 2015, p. 12).

Research processes often bring together people from diverse ontological and epistemological backgrounds, including beyond the binary of Western and Indigenous worldviews. Tensions arising from the merging of divergent epistemologies and ontologies are part of the process and should be expected. Researchers were able to navigate these tensions in ways that honoured members in the group and led to good outcomes. For example, Benoit and colleagues (2020) navigated tensions through ongoing reflection and consistent and open communication with community representatives. Having members of the community as team members and in leadership roles helps put the community's epistemologies and ontologies at the forefront (see Beveridge et al., 2021). In line with Australian Aboriginal epistemologies and ontologies, Farrant and colleagues (2019) set aside plenty of time for consensus to be reached and allowed decision-making processes to unfold naturally.

#### Theory-Principles

Kovach (2017) uses the term Indigenous theory-principles to describe teachings, including "philosophy values (e.g., respect, reciprocity) and practices (Indigenous laws, ethics, protocols) that guide relationships" (p. 222). The term itself was only used by few to describe how values were integrated into the research process (see Beveridge et al., 2021), but teachings, philosophy values and relational practices and how they guided research practices was discussed by many.

Among the noted theory principles were the 3 R's of respect, reciprocity, and relationality (Bennett et al., 2019), and the 4 R's of respect, reciprocity, relevance and responsibility (Nagy et al., 2020). Certain theory principles were more community specific. In Jacklin and Kinoshameg's participatory health research with Anishinaabek members of the Wikwemikong Unceded Territory in Ontario, the Anishinaabe seven grandfather teachings of wisdom, love, honesty, respect, humility, bravery and truth guided the research process alongside principles of participatory action research. For the Kahnawake Schools Diabetes Prevention Project, the Haudenosaunee values of collective thinking, shared responsibility, listening. As well, those involved were taking into account the impact of current decisions on future generations, consensus decision-making, and a wholistic view of health informed the community-based participatory approach taken for this project with the Kahnawake community (Tremblay et al., 2018). Chung-Tiam-Fook (2022) describes the *Seventh Generation principle*, which is common to many Indigenous Nations, as an ancient philosophy which guides decision-making and can

also guide relationships to be "generative and mutually respectful and beneficial for many generations to come" (p. 55). This principle can also be integrated into research processes.

These principles overlap with ones we reviewed under *Principles for Research and Assessment Processes*. This overlap showcases how Indigenous value principles have already been translated into research practice, and that this can be done with community-specific values as well.

# **Feature: Translating Value Principles into Research Action**

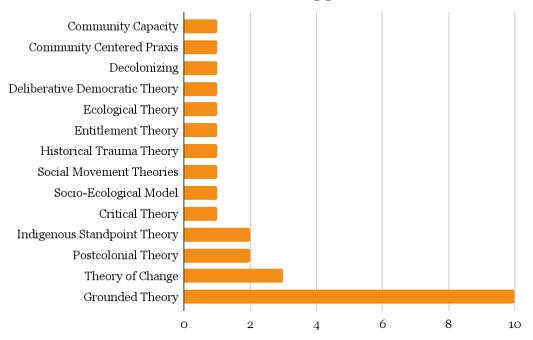
As part of their research framework, Kandasamy and colleagues (2017) upheld and translated values of Indigenous research into action throughout the research process. For example, the value of *respect for individuals and community* was translated into action through researchers being considerate of the diversity found within a community. This consideration took the shape of:

- Exploring the cultural, artistic, economic, and political diversity of the community through several years of relationship building and community immersion where researchers spent time with different community groups.
- Participating in training programs and events to learn more about the community and to share the study with a diversity of people and community organizations.

Other Indigenous research values reflected in their research included Indigenous control over research; reciprocity and responsibility; respect and safety; deep listening; reflective nonjudgement; self-awareness; subjectivity; and honouring what is shared. The way these principles were translated into actions can be found in Table 1 of Kandasamy and colleagues (2017).

# **2.9.2 Theoretical Perspectives**

Certain articles in this review noted the theories informing their research. This provides a glimpse into the array of theoretical frameworks used to inform research by, with and for Indigenous communities (Figure 11). That being said, many of the articles provided minimal detail for how these theories were applied. The following summary reviews the information that was present on how these theories were applied, and reasoning for choosing these theories.



# **Theoretical Approaches**

**Figure 11**: Theoretical approaches employed in the reviewed articles. Articles that used more than one theoretical approach are represented more than once in this diagram.

Grounded theory was the most commonly applied theory, having been discussed in ten (37.0%) articles, was grounded theory (see Davies et al., 2011; Friendship and Furtal, 2012; Hatala et al., 2019; Kandasamy et al., 2017; Kyoon-Achan et al., 2018b; Kyoon-Achan et al., 2021a; Patel et al., 2022; Rizkalla et al., 2020; Romain et al., 2015; Sawatzky et al., 2020). For some researchers, grounded theory meant that data collection and analysis were performed in parallel (Rizkalla et al., 2020; Sawatzky et al., 2020); for Patel and colleagues (2022), this was an iterative and cyclical process, where data collection and analysis continued until there were no new emerging themes (when saturation was reached). Contrary to the common process of conducting a literature review before collecting data, Kyoon-Achan and colleagues (2018b) grounded theory approach meant they only looked at literature on their topic after the data analysis was already complete. Grounded theory was applied (in some cases, uniquely) to the data analysis process to identify inductive themes and principles (Davies et al., 2011; Friendship and Furgal, 2012; Romain et al., 2015). For Kyoon-Achan and colleagues (2018b), data analysis took place with both researchers and community partners providing interpretations of and validating the findings through data feedback sessions in weekly teleconferences scheduled for this purpose. Researchers chose grounded theory for its ability to accommodate different ways of knowing, different ways of sharing knowledge, and for interpreting data while considering its specific temporal, cultural and structural contexts (Kandasamy et al., 2017; Patel et al., 2022). For example, Hatala and colleagues (2019) combined grounded theory and Indigenous methodologies for data generation, interpretation, and analysis through implementing a two-eyed seeing framework, which allowed room for integrating aspects of Indigenous methodologies not aligned with grounded theory.

*Theory of change* was the second most frequent applied theory, having been discussed in three (11.1%) articles (Couzos et al., 2020; Kelley et al., 2018; Wendt et al., 2019). This model includes four phases to represent a gradual transformative process for palliative care: "1) having necessary antecedent community conditions; 2) experiencing a catalyst for change; 3) creating a palliative care team team; and 4) growing the palliative care program" (Kelley et al., 2018, p. 54). Its application varied widely and was often altered to be more culturally appropriate in its application. Kelley and colleagues (2018) Developing Rural Palliative Care Model was modified and applied as a culturally appropriate theory of change with the purpose of guiding program and policy development to improve end-of-life care in First Nations communities. Couzos and colleagues (2020) applied a theory of change model to help understand factors, both within and outside of project control, on pharmacist interventions for chronic diseases (see p. 1434). Wendt and colleagues (2019) applied the Yup'ik Indigenous theory of change in substance use research with Indigenous communities, which informed the identification and measurement of intervention outcomes.

Several other applied theories exist and were applied in relation to colonialism. This includes decolonizing theory (see Haynes et al., 2019; Henderson et al., 2018), postcolonial theory (see Brooks-Cleator et al., 2019; Henderson et al., 2018), historical trauma theory (see Rizkalla et al., 2020), and Indigenous standpoint theory (see Fitts et al., 2019; Haynes et al., 2018).

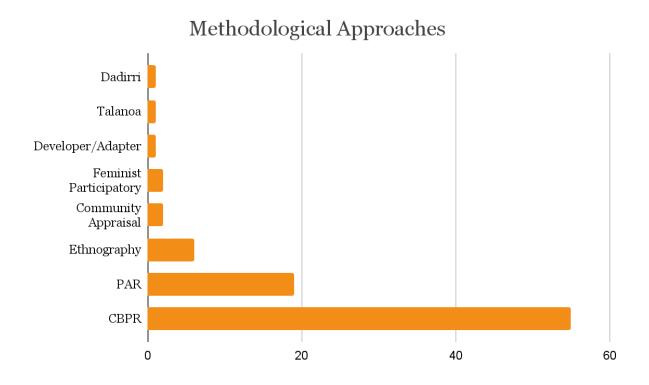
Decolonizing theory was created in intentional and constructive response to the damages created by colonisation. This theory was applied by Haynes and colleagues (2019) alongside standpoint theory (reviewed shortly), and in Henderson and colleagues (2018) alongside postcolonial theory. Postcolonial theory is a framework that allows researchers to "consider the histories of those who have experienced colonialism and to connect their present-day material and social conditions with the injustices of colonization" (McEwan, 2009 as cited in Brooks-Cleator et al., 2019, p. 52). It challenges dominant Western discourses and is particularly useful when understanding the experiences of folks who have experienced colonization (Brooks-Creator et al., 2019). This framework is applied by Brooks-Creator and colleagues (2019) in their study with older First Nations and Inuit adults about how supported they feel to age well in a Canadian city. Henderson and colleagues (2018) used both decolonizing and post-colonial theory to guide their data analysis with the purpose of prioritizing First Nations voices and understanding how colonization has shaped healthcare experiences. *Historical trauma theory* was another theoretical lens applied to consider the impacts of colonization on health care experiences. Rizkalla and colleagues (2020) define it as a theory that "aims to explain how colonial policies have promoted and propagated the use of violence against Indigenous Peoples, and cause unmeasurable intergenerational grief" (p. 2). They apply it in their study on improving the response of primary care providers for rural First Nations women experiencing intimate partner violence. More on this theoretical framework can be found in Evans-Campbell (2008, as cited in Rizkalla et al., 2020). Indigenous standpoint theory is defined as "a decolonizing approach that enables Indigenous people to maintain/regain or learn their own epistemological standpoint that has been lost due to colonisation and to adopt ethnocentric Western forms or approaches to knowledge" (Foley, 2006 as cited in Fitts et al., 2019, p. 139). This approach, which prioritizes Indigenous

and marginalized voices (Haynes et al., 2019), engages community members in each step of the research and encourages capacity building (Fitts et al., 2019).

Eight additional theoretical frameworks and perspectives were included in projects throughout this systematic review. Community capacity development sees communities as having the capacity to address their problems through collective problem-solving (Kelley et al., 2018). Community centred praxis places ethical actions as a central feature of research and engages in specific research principles, including continuing discussion with community, research that reflects community concerns, and the transfer of research skills to community members (Jacklin and Kinoshameg, 2008). Deliberative democratic theory was employed in Khayyat Kholghi et al.'s (2018) evaluation of a diabetes prevention project, and informed deliberative elements in public engagement methods to ensure participants were informed about the topic and were encouraged to discuss and consider different viewpoints to arrive to a list of recommendations. Ecological theory was applied by Rowley and colleagues (2015) as it recognizes the social and physical environment's impact on wellbeing - a perspective that is more aligned with a holistic view of health. In a similar manner, Neufeld and colleagues (2020) employed a socio-ecological model to explore Elder womens' relationships with foods, as the model considers levels of influence at an intrapersonal, interpersonal, institutional, community, and public policy level to better understand human behaviour. Entitlement theory was applied alongside the concept of food sovereignty by Islam and Berkes (2016) to understand reasons behind experiences of food insecurity. A social movement theories framework was employed by Tremblay and colleagues (2018) to examine community-based participatory research processes and understand how they can lead to systemic change. Finally, critical theory, which "seeks to understand and explain deficits with the current social situation by empowering those affected" (Jacklin and Kinoshameg, 2008, p.65) was applied alongside community centered praxis to understand health needs in Wikwemikong Unceded Indian Reserve in Ontario.

# 2.9.3 Methodologies

Eight different culturally relevant methodologies were applied in these studies (see Figure 12). Of these, community-based participatory research (CBPR) was the most commonly referenced, followed by participatory action research (PAR). There are also Indigenous methodologies present, including Talanoa and Dadirri (both based out of Australia), as well as the Developer/Adapter Method which was designed in collaboration with First Nations communities.



**Figure 12**: Culturally relevant methodological approaches employed in the reviewed articles. Articles that used more than one theoretical approach are represented more than once in this diagram.

*Dadirri* is identified throughout Smith and colleagues (2020) literature review as a recommended methodology for Australian Indigenous community members' perceptions of health needs. It is an Indigenous methodology rooted in a language of the Ngangikurungkurr people, though it is also applicable for Indigenous groups in Australia (West et al., 2012). Principles of Dadirri include reflection; community; reciprocity; equal interaction; returning resources to community to empower community; deep listening of others - which is at the core of spirituality; and taking enough time to truly understand (West et al., 2012). In practice, it is a "process of listening, reflecting, observing the feelings and actions, reflecting and learning, and in the cyclic process, re-listening at deeper and deeper levels of understanding and knowledge-building" (Atkinson, 2002, p. 19 as cited in West et al., 2012). West and colleagues (2012) explain it as a process of rich and meaningful communication which results in a better understanding of self, and that it can be linked with critical theories in order to develop an Indigenous research framework.

*Talanoa* was applied in Vaughan and colleagues (2018) to evaluate a community-based program focused on chronic disease prevention among Maori and Pacific Islanders in Queensland, Australia. Talanoa is a Pasifika form of informal communication and dialogue which brings people together to share views, and participants' perspectives can be challenged or legitimized by others (Vaughan et al., 2018). Its principles of respect and trust guided data collection through interviews and focus groups (Vaughan et al., 2018). Both Talanoa and Dadirri aim to address power dynamics between participants and researchers by reducing distance through dialogue.

*The Developer/Adapter method* was created in collaboration with First Nations communities in Northern Ontario to have an intervention/control approach that was consistent with Indigenous principles (McElhaney et al., 2021). This methodology addresses community health issues identified by a community. Communities can either choose to participate as a Developer (identify, develop, enact and evaluate new opportunities to tackle issues) or as an Adapter (adapt successful strategies to their local context), both of which contribute to a "toolbox" that can be applied to newly identified issues (McElhaney et al., 2021). It was developed "to support community engagement, the community-based identification of the needs of Elders, and community partnerships with Indigenous health service agencies in the development of community-based interventions" (McElhaney et al., 2021). It can also contribute to improving the quality of existing services and be employed for knowledge mobilization.

Coppola and McHugh (2018) took a *feminist participatory approach* to enhance cultural humility in their research partnership. Nagy and colleagues (2020) took this approach as well; in combination with PAR, they were able to emphasize values of agency, self-determination, resilience, resistance, and empowerment when conducting workshops with participants.

*Community Appraisal* was applied through the work of Ens and colleagues (2017), as they took a rapid, collaborative community-based appraisal approach to identify potential factors causing the decline of a locally culturally and ecologically important tree genus utilizing both local and western ecological knowledge. Jackson and colleagues (2015) used participatory appraisal (PA) to produce knowledge about violence in Indigenous women's lives and communities. PA aims to improve hierarchies between researchers and participants by "putting the first last", and the collective production of knowledge can catalyze community-based action (Jackson et al., 2015). In practice, PA activities took the form of a spider net exercise, a causal-impact exercise, a matrix exercise, and a community mapping exercises, all related to improving domestic violence services for Indigenous women.

*Ethnography* was applied in several ways in the reviewed research. In Bennett and colleagues (2019) project, the lead author followed the *immersive experience of ethnography* as a learning tool by living in and frequently visiting partnered communities in the research. This immersion showed commitment, helped in the development of trust with community members, and provided context for research questions (Bennet et al., 2019). Elliot and colleagues (2015) took an *imaginative ethnographic* approach in their project Aboriginal Health and Healing. They note that while applying an ethnographic approach can be messy, there is also room to develop ethnographic research methodologies that are inclusive and collaborative, addressing the "structural inequities and oppressive ideologies in academia, medicine and scientific research" (Elliot et al., 2015, p. 37). Institutional ethnography (IE), applied by Morton Ninomiya and colleagues (2020), "aims to produce evidence that maps how peoples' activities and labour are invisibly coordinated by institutional texts" (Morton Ninomiya et al., 2020, p. 223). The IE approach helps to identify how people's everyday lived experiences are connected to institutional practices. It was adapted to fit the local context through face-to-face meetings and consultation with community leaders, key community members, and stakeholders. In Oster and colleagues (2016), ethnography was chosen by the Community Advisory Group as the most appropriate research approach to understand effective prenatal care for First Nations women in a Cree First Nation in Alberta. They were able to identify the role of structural issues in affecting healthcare relationships (Oster et al., 2016). Ritchie and colleagues (2015) took a focused ethnography

approach by focusing on a 10-day, outdoor adventure and leadership expeditions for youth ages 12-18 from Wikwemikong Unceded Indian Reserve. This approach resulted in all data collection occurring during the expeditions through interviews, journal entries, focus groups, and Elder teachings and discussion. Ritchie and colleagues (2015) also employed the critical ethnography principles of positionality and reflexivity. Finally, ethnography can also be used in the form of ethnographic description (Wendt et al., 2019). Each of these ethnographic studies integrated community-based research principles in their approaches.

#### Participatory Action Research and Community-Based Participatory Research

Both participatory action research (PAR) and community-based participatory research (CBPR) were the most common methodologies. Though they are separate, they overlap in their participatory approaches under the umbrella of collaborative, community-based research (Wray et al., 2020), and their distinction was not always clear in the reviewed articles. As a result, they will be considered together in this section.

PAR and CBPR approaches provide pathways for community engagement in research processes. This takes the form of (research) partnerships and collaborations between researchers and community leaders, partners, stakeholders, organizations, program representatives, specific members of a community (e.g., youth), and communities as a whole (Brooks-Clear et al., 2019; Carter et al., 2019; Castleden et al., 2016; Flicker et al., 2017; Kelley et al., 2018; Murray et al., 2014; Ogenchuk et al., 2022; Ritchie et al., 2015). In the reviewed articles, these approaches were utilized in the collection of both quantitative and qualitative data. Either methodology can also be applied in evaluations; in fact, evaluations are suggested in PAR and CBPR approaches to assess collaborations and partnerships (Haynes et al., 2019; Hickey et al., 2019).

In certain projects, CBPR and PAR approaches meant that community had control over and lead all aspects of the research, including research questions, study design, data collection and analysis (Brussoni et al., 2012; Kyoon-Achan et al., 2021b; Lavalley et al., 2020; Prince et al., 2019). In other articles, community members were involved and engaged in the design and research process through mediums such as consultation and discussion (Charania and Tsuji, 2012; Davies et al., 2015). In certain cases, policy makers and service providers were also invited to participate in the research design and execution processes; this facilitated uptake and changes in policy and practice (Farrant et al., 2019). These partnerships and collaborations generally resulted in locally relevant research questions directly addressing community concerns and creating community benefits (Charania et al., 2014; Dawson et al., 2020; Jackson et al., 2015; Rizkalla et al., 2020). They can also help create research processes that are culturally tailored and safe (Brussoni et al., 2012; Farrant et al., 2019; Vaughan et al., 2018). PAR and CBPR approaches are generally strength-based (Smith et al., 2020). When intentionally designed, they can result in beneficial outcomes such as capacity building (Flicker et al., 2007; Kyoon-Achan et al., 2018a), empowerment (Cornect-Benoit et al., 2020), knowledge co-creation that will benefit communities (Kyoon-Achan et al., 2018a; Prince et al., 2019), and contributions towards self-determination (Dieter et al., 2018). PAR and CBPR can also facilitate social change and transformation for research participants (Kelley et al., 2018; Kyoon-Achan et al., 2018a). In practice, PAR and CBPR both aim to develop community benefits such as knowledge and evidence that is useful to the community (Isaak et al., 2010). To ensure participants received these benefits in a timely manner, Kyoon-Achan and colleagues (2018a) determined beforehand how the results would translate into beneficial projects and programs for the community.

Collaborative and participatory research requires making space for an iterative research process. Initial plans should be flexible to change as dialogue continues with community members and new understandings emerge (Woodward and Marrfurra McTaggart, 2016). Since community members contribute meaningfully to these approaches, their time and effort should be reciprocated. In Kyoon-Achan et al., this looked like i) hiring locally (e.g., research assistants) to provide work experience, training, skill development, and networking opportunities; ii) compensating Elders by offering customary tobacco or honoraria for their services; iii) providing or covering the costs of meals at community meetings and presentations; and iv) covering travel and accommodation costs for First Nations partners for team workshops, national meetings, and conferences. Another important practice is that of flexibility with meeting times and timelines and to be open to unexpected changes (Kyoon-Achan et al., 2018). Flexibility is particularly important since CBPR and PAR approaches also have challenges. For example, locally hired researchers and local supporters may move away and frequent changes in leadership can create gaps (e.g., Kyoon-Achan et al., 2018a). Continuously building relationships throughout the research process may help address some of these challenges.

Authentic relationship building and trust are central components of PAR and CBPR and the partnerships and collaborations required for these methodologies. Commitment to relationship building in the research process is required (Woodward and Marrfurra, 2016). This includes prioritizing time and resources to connect – including face-to-face interactions before and throughout the research process (Farrant et al., 2019; Lopresti et al., 2022) and facilitating open communication channels for community members to reach the research team with any questions and concerns (Kyoon-Achan et al., 2018a). Meaningful community engagement, encouraging community ownership, and respecting community ethics and protocols also contribute to relationship and trust-building (Kyoon-Achan et al., 2018; Kyoon-Achan et al., 2021c). Combining CBPR and PAR methodologies with Indigenous methodologies for a project can also contribute to this important principle of relationship building (Rix et al., 2014).

Applying collaborative and community-based methodologies may not be sufficient to conduct culturally relevant research with Indigenous communities. Though PAR and CBPR can align with Indigenous research paradigms (see Lickers, 2017; Hickey et al., 2019; Lucier et al., 2020) and they overlap with Indigenous principles (e.g., relationality), they come from a different epistemological source (see Beveridge et al., 2021). At the same time, it is not necessarily appropriate for non-Indigenous researchers to utilize Indigenous methodologies. Researchers are beginning to address this by combining community-based approaches with Indigenous ways of knowing alongside community engagement and leadership. In application, this looks like utilizing principles of CBPR to engage community members in order to expand the application of Indigenous ways of knowing, values and beliefs into research design, data collection, data analysis, and/or research dissemination (Rix et al., 2014; Kyoon-Achan et al., 2021a; Lavalley et al., 2021; Lewis et al., 2016). Lickers and colleagues (2017) describe their combination of PAR and Indigenous methodologies as "research that engages research participants in directing the research on a facet of their own lives; it generally involves using collective critical thinking to find ways to solve an issue or problem that is of critical importance to the participants," (p. 73).

The significant take away from these authors' discussions on the topic is the importance of community engagement in, and leadership and control over the research process. This

engagement and leadership, facilitated by CBPR and PAR, leads to integration of Indigenous ways of knowing into the research itself, allowing for a more culturally appropriate process.

Applying these methodologies does not ensure meaningful engagement: researchers have the responsibility to ensure their work is truly participatory (Jacklin, 2008). Murphy and colleagues (2021) found that although studies with Indigenous communities often cited participatory methods, the levels of engagement of communities varied. They suggest that baseline expectations of what participatory research is ought to be defined, and that researchers should aim to exceed this baseline and aim for research that is owned and led by Indigenous communities.

Overall, CBPR and PAR encourage the building of authentic relationships, which also aligns with Indigenous value principles. PAR and CBPR have a wide-ranging application and can be complementary to other research methodologies. When done with a commitment to the "participatory," they facilitate community engagement and leadership, leading to a more culturally appropriate process and more relevant and beneficial outcomes.

#### Indigenous Methodologies

Additional practices were described as Indigenous methodologies. Benoit and colleagues (2020) explain their Indigenous methodology as "prioritizing Indigenous worldviews, knowledge, histories, and realities as well as privileging Indigenous voices, peoples, and lands" (p. 462). This meant including Ceremony and cultural activities throughout the research. Hickey and colleagues (2021) also take a similar approach. Farrant and colleagues (2019) and Rix and colleagues (2014) describe Indigenous methodology as one that understands knowledge as created and shaped through relationships with other people and the world, making relationships between researchers and community an important part of the research process. Indigenous methodologies also support collaboration (Rix et al., 2014), self-determination and Indigenous leadership (Smith et al., 2020).

Lickers (2017) notes: "Indigenous methodology does not mean and has not meant a total rejection of all theory, research, or Western ways of knowing. Rather, it is about centring Indigenous concerns and worldviews, being committed to knowing and understanding Western theory and research, and coming to know and understand theory and research from an Indigenous perspective and for an Indigenous purpose" (p. 72).

As the examples above show, pairing Indigenous and Western methodologies can be successful. The process of choosing the appropriate methodology should centre the community's worldviews, research priorities, and should be reflective of the research question that flows from worldview and priorities.

# 2.9.4 Concluding Remarks on Research Paradigms: Knowledge Systems, Theories and Methodologies

This section provides a brief overview of Indigenous ways of knowing, epistemologies and ontologies, and theory principles. Works by scholars Margaret Kovach and Shawn Wilson are listed in the further reading section for additional information on this topic. Ensuring Indigenous epistemologies and ontologies are adequately considered and integrated has important consequences (e.g., creating more effective health care approaches as in Lavalley et al., 2021).

To ensure research genuinely meets the needs of the communities involved, the ontological and epistemological base from which the research is planned and designed needs to be clear and understood. When that awareness is there, choosing theoretical approaches, methodologies, and data collection and analysis methods can be done more consciously and in alignment with a community's worldview and research goals. For example, Beveridge et al.'s (2021) recognition of Nuxalk knowledge systems meant they chose visual, narrative, and practical sources and materials (e.g., family photos) to gather knowledge and engage community members. Tools such as ethical space and two-eyed seeing can help guide this work, but no matter what, this work is done consciously and deliberately, and is facilitated through genuine relationships and trust.

# **2.10 Culturally Relevant Data Collection and Knowledge Documentation** Tools

Understanding ontological and epistemological roots and choosing the appropriate theories and methodologies is an important process preceding choosing appropriate knowledge documentation tools for data collection. A total of eighteen culturally relevant data collection and knowledge documentation methods were employed in the reviewed articles. A description of these methods and examples of their application are provided below.

In this section, we also review how the common methods of surveys, interviews, and focus groups are applied in these studies, discuss situations when quantitative data is most appropriate, and review how researchers adapted existing data collection methods to be more culturally relevant and safe.

# 2.10.1 Conversational and Narrative Methods

#### Conversational Methods

Conversational methods part of the research design for four studies (Cornect-Benoit et al., 2020; Firestone et al., 2019; Hatala et al., 2019; Sawatzky et al., 2020). These conversational methods took place through community dialogue, sharing circles, focus groups, and interviews such as conversational storytelling interviews (Cornect-Benoit et al., 2020; Firestone et al., 2019; Hatala et al., 2019). Conversational methods are noted as being aligned with an Indigenous worldview and practices of oral knowledge sharing through storytelling.

#### Storytelling

Aligned with oral knowledge sharing, storytelling occured independent of and in combination with other data collection methods. Storytelling was elicited through yarning circles (e.g., Patel et al., 2022), collages and photovoice (Shea et al., 2013), focus groups (Cornect-Benoit et al., 2020), shawl making (Jackson et al., 2015), and through interviews (e.g., Romain et al., 2015). For storytelling to occur in interviews, interview guides were designed with broad, loose questions to provide opportunity for storytelling (Kandasamy et al., 2017). Storytelling through these methods means it was important to consider how to appropriately conduct data analysis. Hudson and Vodden (2020) ensured that the interpretation of data sets was validated by participants during focus groups, conversations and gatherings.

Storytelling was present in other formats as well. Ford and colleagues (2018) used a monitoring and evaluation method called 'most significant change' - a story-based approach where participants evaluate a project through sharing their stories of most significant change in relation to this project. Gomes and colleagues (2014) applied a storytelling format to present information in their clinical practice guidelines. Graeme and Mandawe (2017) co-constructed narratives of their own experiences with conducting community-based Indigenous geography research by asking themselves general questions about their own experiences as researchers.

Smith and colleagues (2020) note that storytelling, alongside yarning, is the most commonly recommended data collection format for research with Indigenous Australians. Storytelling can help subvert assumptions and biases of researchers and other practitioners that could affect data interpretation (Kyoon-Achan et al., 2021c).

## Digital Storytelling

Digital storytelling is an emerging data collection and knowledge dissemination method. Its narrative structure and storytelling purpose makes it a well suited method for research by and with Indigenous peoples. It is defined as a process of illustrating personal narratives through multimedia where the digital stories themselves are the data (Harper et al., 2012). Since the data emerges from participants with minimal researcher interference, it is the participants who decide which information is important to include in their narratives (Harper et al., 2012).

In McElhaney and colleagues (2021), persons at risk of and living with dementia and their caregivers told their stories through digital storytelling, with the purpose of raising awareness on this issue in their communities. They noted the method as effective for community engagement as it gave people the chance to tell their stories (McElhaney et al., 2021). Kandasamy and colleagues (2017) utilized digital storytelling as a form of knowledge dissemination by creating a short digital story in collaboration with Tahnee Wilson, a Spoken Word artist and filmmaker, to communicate research findings about knowledge on perinatal care in a culturally significant way. This story was made available online and was also distributed via DVD to folks who were not able to access it online.

Digital storytelling was also chosen as a data collection method in Harper et al.'s (2012) study to understand climate change impacts on Inuit health. Week-long workshops were held in the community where members created their own digital stories. A total of 37 digital narratives created 3-5 minute first-person narrative videos. Interviews, focus groups, surveys, and a photovoice workshop were also conducted alongside digital storytelling. This method was impactful for studying this complex and nuanced topic; the multiple narratives showcased how community members experienced the impacts of climate change in different ways. The digital stories captured experiences that could not have been captured just through interviews (Harper et al., 2012). This method also became an intervention of sorts and helped promote community health by promoting the stories as public health campaigns. The stories also contributed to preserving and promoting language, culture and ways of life (Harper et al., 2012).

# 2.10.2 Circle Methods

#### Talking Circles

Talking circles are a culturally relevant method of data collection for research by and with Indigenous people that aligns with storytelling and collective listening (Khayyat Kholghi et al., 2018; Ritchie et al., 2015). Khayyat Kholghi and colleagues (2018) describe them as "based on respect for everyone present, active listening, learning and stating personal beliefs without arguing, debate or denigrating other opinions" (p. 82). Though this is not shared by all articles with this method, Tremblay and colleagues (2018) describe talking circles as a means of consensus, where participants discuss specific topics until consensus is reached. Similarly, Khayyat Kholghi and colleagues (2018) note talking circles aligned with the consensus-building model of the Haudenosaunee.

Talking circles were present in eight studies covering diabetes prevention (Khayyat Kholghi et al., 2018); health care experiences and health reform (Kurtz et al., 2014); experiences with substance use treatment (Lavalley et al., 2020); experiences of living with HIV (Lavalley et al., 2021); youths' experiences in an outdoor adventure leadership program (Ritchie et al., 2015);

and diabetes prevention (Tremblay et al., 2018). Talking circles were also integrated into health programs. Through the work of Maina and colleagues (2020), talking circles were part of a 10-week intervention for students in the early stages of substance use. In this program, talking circles took place once a week for 45 minutes to provide a culturally appropriate setting for discussions on substance use and for participants to "come together, accept each other, and share stories respectfully" (Maina et al., 2020, p. 10). For some programs, talking circles were specifically organized for sharing information on a health issue. Ziabakhsh and colleagues (2016) integrated talking circles in their culturally relevant heart health pilot program for Indigenous women at risk for heart disease. This holistic alternative to "being told what to do" proved successful as it created this "sacred space of transformation," allowing women to choose health changes feasible for them (Ziabakhsh et al., 2016, p. 823).

These circles are seen as safe and respectful places to share stories. It is common practice for participants to pass around a feather (Ziabakhsh et al., 2016; Lavalley et al., 2020; 2021), a rock (Kurtz et al., 2014), or another meaningful item to signify who's turn it is to speak – and for participants to pass on their turn if they choose (Lavalley et al., 2020; 2021). In the work of Ziabakhsh and colleagues (2016), the facilitators also participated in the talking circle by sharing their own experiences. The facilitators were often one of the researchers, though Elders also fulfilled this role (Kurtz et al., 2014). Talking circles took place in community spaces (e.g., Tremblay et al., 2018) or another place safe to participants. In some cases, hosting a meal with the participants was mentioned as good practice; according to Kurtz and colleagues (2014), meal sharing before the talking circle allowed for trust building between participants. Kurtz and colleagues (2014) also provided childcare for the children of the women who were asked to attend the talking circle.

#### Sharing Circles

Seven articles noted the use of sharing circles. Sharing circles facilitated discussion for processes of Indigenous engagement in epidemiology (Benoit et al., 2020), drivers of HPV infections (Henderson et al., 2018), suicide issues and prevention (Isaak et al., 2010), early childhood oral health (Kyoon-Achan et al., 2021c), experiences and knowledge with human trafficking (Nagy et al., 2022), perceptions of health and body image (Shea et al., 2013), and youth asthma (Watson et al., 2012). Sharing circles are described as comparable to focus groups, but they have a sacred meaning in many Indigenous cultures. It is a method more in line with Indigenous values, that diminishes hierarchies, and emphasizes equality (Henderson et al., 2018; Watson et al., 2012). Sharing circles generally involve formal turn-taking for dialogue, non judgemental and respectful communication and listening, and Ceremony (Isaak et al., 2010; Watson et al., 2012). They consist not only of sharing of knowledge, but of sharing of the whole, resulting in potential for individual growth and change (Lavallée, 2009 as cited in Isaak et al., 2010; Watson et al., 2012). While one study notes the terms sharing circles and talking circles as interchangeable (Khayyat Kholghi et al., 2018), sharing circles are understood as deeper spiritual processes, while talking circles are described as more surfaced in comparison.

Through the work of Kyoon-Achan and colleagues (2021c), sharing circles took place in community centres with participants seated on flat cushions or on chairs, while the facilitator and note-takers remained standing. The sessions opened with prayers, and an eagle feather was held by the person who's turn it was to speak to reduce interruption and ensure respect for each speaker (Kyoon-Achan et al., 2021c). The feather was passed in a systematic manner to ensure

everyone had the chance to share, though there was no obligation for participants to speak (Kyoon-Achan et al., 2021c). As a follow up to photovoice activities, Shea and colleagues (2013) hosted sharing circles to further discuss and develop findings. Sharing circles were also employed at the end of a workshop day as a means of reflecting and debriefing (Nagy et al., 2022). Participants in Isaak and colleagues (2010) suggested that researchers participate in sharing circle discussion, which would have contributed to building mutual trust - something that is necessary for sharing circles.

Sharing circles are not culturally relevant to all Indigenous communities. In Kyoon-Achan and colleagues (2021c), while sharing circles took place with First Nations participants, Métis communities opted for focus groups as a comparable method for sharing knowledge. The same questions were used across both sharing circles and focus groups (Kyoon-Achan et al., 2021c). Watson and colleagues (2012) held both a sharing circle and a focus group with the same participants, with each method focusing on a different topic. The authors tried these methods with youth as well but this proved ineffective. Instead, they opted for arts-based methods (more on this under arts-based methods).

## Yarning Circles

Engaging in yarning circles is noted as a culturally appropriate data collection method for Australian Indigenous folks (Rix et al., 2014; Smith et al., 2020). Yarning, which signifies 'let's have a chat,' refers to an often informal conversational method that uses storytelling to gather information (Hickey et al., 2021; Rix et al., 2014). It places value on the participants' knowledge and expertise and its reciprocal nature between researcher and participants mitigates hierarchical power relations (Patel et al., 2022; Smith et al., 2020).

A total of nine studies referred to yarning circles. These studies focused on the role of Elders in Indigenous communities (Busija et al., 2020), reproductive health (Hickey et al., 2021), mental health services for youth (McCalman et al., 2020), oral health education and prevention (Patel et al., 2022), and experiences of haemodialysis (Rix et al., 2014). Like talking circles, yarning circles are also utilized in health services, including one for mental health (Nasir et al., 2021), and as an educational component of a fall-prevention program (Lukaszyk et al., 2017).

Yarning was integrated into research processes in various ways. Before research began, Busija and colleagues (2020) organized a yarning circle between researchers and a local Indigenous community in order to establish a working relationship with the community, determine issues of importance, and refine research aims to ensure community relevance. The yarning circle also informed interview questions for data collection later on.

Yarning also goes beyond circle form. Rix and colleagues (2014) conducted interviews in which a 'yarning' technique was integrated. They described this as "an informal and reciprocal exchange of information" (p. 2); yarning took place before the interview on non-research topics to build rapport, the interviews themselves had no set guide, and participants were encouraged with prompts (Rix et al., 2014). Kildea and colleagues (2012) created a 'Yarning Circle' paper-based survey, however, no additional information on this is provided.

Smith and colleagues (2020) systematic review on recommended methodologies for Australian Indigenous community perceptions of health needs found yarning, alongside storytelling, to be

the most recommended data collection with Indigenous Australians. They utilize the terms storytelling and yarning interchangeably. They note that there are four types of yarning:

- 1. Social yarning is informal, unstructured conversation in which trust usually develops; the researcher is accountable to the participant.
- 2. Collaborative yarning can involve sharing similar ideas; sharing research findings can lead to new discoveries and understandings.
- 3. Research topic yarning occurs in un/semi-structured interviews to gather information relating to the research question.
- 4. Therapeutic yarning occurs when the participant discloses traumatic, intensely personal or emotional information where the researcher's role is to listen empathically; this can empower and support the participant to re-think their understanding of their experience in new and different ways (Bessarab and Ng'andu, 2010, p. 40–41 as cited in Smith et al., 2020).

Patel and colleagues (2022) note their use of both social yarning and diagnostic yarning before conducting the yarning interviews, though no definition of diagnostic yarning is provided.

## Learning Circles

Learning circles are part of Bennett and colleagues (2019) culturally safe photovoice method. Bennett and colleagues (2019) defined a learning circle as an adapted version of the Sharing Circle Ceremony of the Anishinaabek. This was then referred to as "a circle of research and healing that allows for stories and substantive information of a group to be retold" (p. 4). Though it is comparable to a focus group or group discussion, this method differs in that it emphasizes participants sharing their perspectives rather than participants becoming a means of collecting data (Bennett et al., 2019). Learning circles were central to creating a more culturally safe photovoice method (Bennett et al., 2019). Orientation, data collection, participant feedback, and discussion on outcomes all took place in learning circles, and their structure and etiquette were established before they took place.

## Story Circles

Story circles were employed in Hanson (2018) alongside the use of art and material artifacts to facilitate storytelling through eliciting the experiences of textile artists. Hanson (2018) describes their design as similar to a talking circle. The process went as follows: An Elder opened and closed the circles, introductions were provided, an understanding of intergenerational relationships was established among participants, and the researcher asked questions to which each participant responded in turn, utilizing the art and material artifacts to facilitate this process. This process facilitated sharing embodied, intellectual, and spiritual knowledge (Hanson, 2018).

## 2.10.3 Visual and Arts-Based Methods

Visual and arts-based methods are highly participatory methods that facilitate participant engagement and align with Indigenous epistemologies (Sanderson et al., 2021). Several data collection and knowledge documentation methods had an art and/or visual component to them. These included arts-based methods, photovoice, participatory mapping methods, participatory whiteboard creation, and the creation of documentaries. In many cases, the visual products of these methods also contributed to knowledge mobilization and knowledge translation.

#### Arts-Based Methods

Arts-based methods were employed in eight articles throughout this review. In these articles, "art" took the shape of music (Anthony et al., 2018), textiles and artifacts (Hanson, 2018), shawl-making (Jackson et al., 2015), art collages (Sanderson et al., 2021; Shea et al., 2013), dance (Mayo and Tsey, 2009), and drawing (Watson et al., 2012), with some studies allowing participants to choose artistic expressions of their choice (Flicker et al., 2014). Arts-based methods align with

Authors referred to arts-based methods as decolonizing and as aligned with Indigenous epistemologies due to their overlap with storytelling (Flicker et al., 2014; Sanderson et al., 2021). They allow participants space to express and discuss difficult experiences and give participants control in determining how their experiences are expressed (Sanderson et al., 2021). Arts-based methods can also contribute to capacity-building by teaching new skills (Flicker et al., 2014).

Hanson's (2018) study with textile artists integrated art and material artifacts into the story circle to conduct an arts-based inquiry into their research topic. Participants brought artifacts (e.g., fur, beads, beaded items) which were set at the centre of the circle, and when it was their turn to speak, participants had access to the artifacts to explain, detail, and amplify their stories (Hanson, 2018). The decision to add art and artifacts to the circles emerged from conversations with participants as part of the community-based. In a similar fashion, Jackson and colleagues (2015) hosted weekly sessions that combined storytelling and shawl making (shawl making and wearing are part of Blackfoot knowledge and cultural practices) to improve local domestic violence services for Indigenous women. According to the authors, the knowledge created from the combination of shawl making and storytelling was "a powerful spirit of hope and strength with impacts far beyond the initial research encounter" (Jackson et al., 2015, p. 12). Arts-based methods were also combined with photovoice (Sanderson et al., 2021).

Many studies that took an arts-based approach wanted to learn more about the experiences of Indigenous youth (Anthony et al., 2018; Flicker et al., 2014; Shea et al., 2013, Watson et al., 2012), and women and girls (Hanson, 2018; Jackson et al., 2015; Shea et al., 2013). Watson et al.'s (2012) original plan of hosting a sharing circle and focus group activity with youth to learn about their experiences living with asthma was not successful - instead, they found that youth were more comfortable sharing their experiences through drawing.

Shea and colleagues (2013) undertook collage-making with their participants. While it was successful, they noted a limitation of their collage activity - they were unable to locate magazines directed at Aboriginal readers, and as a result, the ones they used for the collages featured predominantly white women. Materials offered for collage-making should be chosen considerately.

## Feature: An Example of an Arts-Based Approach

Flicker et al.'s (2014) research project, named "*Taking Action! Building Indigenous leadership in HIV prevention using arts-based methods*", took arts-based approaches to engage Indigenous youth across Canada in discussions about their health. Art-making activities differed across the six communities involved in the study. They included hip-hop, painting, throat singing, photography, carving, film and video making, graffiti, and theatre.

Through interviews conducted after the events, youth participants shared their experiences and noted the following points about participating in these arts-based processes:

- It was preferable to other modes of information sharing such as sitting there and listening.
- It was an opportunity to learn about traditional art forms, and in some cases, facilitated reclaiming parts of their heritage.
- The art-making process provided an emotional outlet which was healing for some participants.
- Participants got to develop new technical skills (e.g., filmmaking).
- Participants felt proud about their final products and were aware of the potential positive impacts their art could have on others.

They see arts-based methods as decolonizing because they empower and centre participant voices, and facilitate inquiry while creating room for complex and intersectional identities.

## Photovoice

Photovoice was applied as a data collection method for capturing relationships between climate change and health (Harper et al., 2012); perspectives on healthy lifestyles (Khayyat Kholghi et al., 2018); personal experiences of criminalization of HIV nondisclosure (Sanderson et al., 2021); health and body image (Shea et al., 2013); and intimate partner violence (Bennett et al., 2019). Photovoice consists of four general steps involving participants and facilitators:

- 1. Convening to establish research topics, which speak to the needs of the community, and guide the photography of participants
- 2. Instructions on how to use a camera (if required)
- 3. Allotting time for participants to take photographs
- 4. Reconvening to discuss the photographs participants feel are most significant to the research topic" (Bennett et al., 2019, p. 2)

Photovoice is referred to as an empowering, participant-led, culturally appropriate method that is aligned with Indigenous ways of knowing (Bennett et al., 2019; Sanderson et al., 2021; Shea et al., 2013). Through the work of Sanderson and colleagues (2021), participants shared the meaning of the photos they took through narrative interactions, while in Khayyat Kholghi and colleagues (2018) the group shared their photos in a talking circle (instead of the more common practices of interviews or focus groups).

## Feature: A Culturally Adapted Photovoice Method

Bennett and colleagues (2019) sought to further culturally adapt photovoice for research with Indigenous peoples by co-creating a culturally safe Anishinaabek version of photovoice. A significant change to the original photovoice method to create the Gaataa'aabing Research Method was the choice to utilize learning circles to present and discuss photos, in place of the more conventional photovoice practices of interviews, focus groups, or presentations. Participants also created cultural protocols for the learning circles, including i) having a ceremonial opening; ii) establishing a process of group sharing at the learning circles; iii) sharing a meal at each learning circle; and iv) establishing group guidelines unique to the community (Bennett et al., 2019). Additional changes were to include various forms of art created at any time (not only images taken recently), including researchers as discreet participants in the process, and holding a final learning circle as a last check-in or reflection (Bennett et al., 2019). This culturally safe adapted method resulted in both personal and social change in participants' lives. The Gaataa'aabing method is adaptable to other Indigenous communities.

## Participatory Mapping

Participatory mapping describes the "creation of spatial maps of certain phenomena that represent what the community perceives to be important to them, including natural and sociocultural features" (Dawson et al., 2020). Participatory mapping was utilized to create a community-based map of knowledge for the protection of marine areas (Ban et al., 2009; Carter et al., 2019; Dawson et al., 2020), to educate healthcare providers (Prince et al., 2019), and to map out the role of Elders in an Indigenous communities (Busija et al., 2020). In Carter and colleagues (2019), participatory mapping was applied to document Inuit knowledge and use of marine areas - this knowledge documentation was accompanied by focus groups, interviews, conversations, and results validation and sharing exercises.

For spatial mapping, Carter and colleagues (2019) note the importance of choosing the appropriate base map (e.g., topographic scale) to facilitate participants' communication of knowledge. Other types of mapping included asset- and capacity-mapping, group concept mapping, and journey mapping - all of which are reviewed below.

*Asset and capacity-mapping* was conducted in three studies (Hampton et al., 2007; Hudson and Vodden, 2020; Kikkert and Lackenbauer, 2021). Hampton and colleagues (2007) conducted assets-mapping to identify community-based service agencies that were preferred by Aboriginal youth. This approach allowed them to start from a place of "what works" in the community. Kikkert and Lackenbayer (2021) held capacity-mapping workshops to "determine local assets and resources, identify untapped or unrecognized resources, and register collective and individual capacities" related to search and rescue (p. 261). This exercise allowed the right assets to face potential search and rescue missions.

Busija and colleagues (2020) did *group concept mapping* (GCM) to conceptualize the role of Elders in an Australian Indigenous community. GCM follows steps to "collect ideas on a topic, structure ideas into major themes, prioritize ideas based on their relative importance, create

visual representation of the ideas on a two-dimensional concept map, and discuss and amend concepts on the map to arrive at a group consensus on a topic" (Busija et al., 2020, p. 515). The participant-generated data created a participant-led process that minimized the role of the researcher (Busija et al., 2020), which aligns well with community-based participatory research.

*Journey mapping* is a culturally appropriate mapping tool referred to by Kelley and colleagues (2018) and Prince and colleagues (2019). Not much information is provided other than it is a tool used for quality improvement of health services, and that a journey mapping toolkit exists on the EOLFN website (Kelley et al., 2018).

## Participatory whiteboard video

One study co-created a whiteboard video with Rigolet community members with the purpose of disseminating a health message on acute gastrointestinal illness. Whiteboard videos depict hand-drawn images on a whiteboard accompanied by narration, sound effects and music (Saini et al., 2020). This method was chosen in collaboration with community members, local public health practitioners and government representatives because of its alignment with Inuit culture (Saini et al., 2020). The steps followed to create this video are as follows:

- 1. Presenting video concept and determining interest in this approach
- 2. Video content planning
- 3. Illustrated storyboard development
- 4. Audio selection
- 5. Video production and post-production editing
- 6. Video dissemination (Saini et al., 2020, p. 52).

The video, produced with a film company, was developed with the help of interviews, focus group discussions and surveys with local Inuit community members.. The end product, a video of 4 minutes and 46 seconds, was an effective tool for delivering the intended health message.

#### Documentary

Documentary and other video-based media can also be utilized as a form of data collection. Borish and colleagues (2021) discuss a case study in which caribou-related knowledge and visual media outputs were co-created with Inuit from Nunatsiavut and NunatuKavut in Labrador, Canada. In this study, qualitative data was collected with filmed in-depth and conversational interviews, with some of the interviews being activity-based (done while the participant is engaging in an everyday life activity) as per participants' request. Data analysis also occurred from the audio-visual data with a video-based qualitative analysis (Borish et al., 2021).

A documentary film was chosen by Inuit leads of the project as a culturally appropriate fit aligned with cultural values of oral tradition of knowledge-sharing (Borish et al., 2021). This method facilitated collaboration and partnerships with diverse groups of people (Borish et al., 2021). Like other narrative methods, the creation of a documentary to share results also ensured participants were speaking for themselves, reducing researcher intervention and interpretation. The method also captured the interview setting – a dimension not captured in traditional interviews, yet is an important part of considering 'place.'

## 2.10.4 Place-Based Methods

Place-based methods are practices that require land (Simpson, 2017 as cited in Hatala et al., 2019). Four of the reviewed articles discussed place-based and land-based methods in research. These examples do not provide clear data collection methods, but review how land and place are considered in the reviewed articles.

Isogal and colleagues (2012) facilitated place-based education activities to test out a geomatics informatics tool with youth during two environmental outreach camps in Fort Albany. This experience was combined with semi-directed interviews, participant observation and field notes to capture youth experiences (Isogal et al., 2012). Kelley and colleagues (2018) took a place-based approach to a palliative care program development by developing it specifically to the local context and culture. They found that considering place in this sense allowed for the success of the program.

Hatala and colleagues (2019) decided to centre place-based notions of wellness in their process for health research. They integrated land as a determinant of health, consequently exploring how urban Indigenous youth engage with land and how land contributes to perceived health and wellness. Land-based activities for data collection did not occur for this study; instead, conversational interviews were utilized to discuss land as a determinant of health. To document knowledge, Beveridge and colleagues (2021) abandoned the initially planned interviews in favour of informal exchanges that occurred through participating in land-based practices. This contributed to their learning, their relationship building with community, and community engagement in general. Beveridge and colleagues (2021) retroactively noted how regular landbased activities would have allowed for more opportunity for collective reflexive processes.

## 2.10.5 Additional Means of Data Collection

## Community Consultations and Roundtables

Community consultations are an important community engagement practice. While they are an appropriate means of choosing and refining data collection and knowledge documentation methods (e.g., Gould et al., 2014; Jacklin and Kinoshameg, 2008), in certain cases, they can act as a tool to design a 'product.' For example, in Dutton and colleagues (2020) information was collected via community consultation to design a new health care service model. Through the work of Plaganyi and colleagues (2020), community consultation served to design and develop a fish Harvest Strategy.

A roundtable is a means of consultation that may bring together multiple parties. They also provide a place for data collection. Kikkert and Lackenbauer (2021) held a roundtable to elevate their work to the regional level. This occasion allowed for free flowing discussion and a scenario exercise with several stakeholders involved in search and rescue, all of which were documented and published in a summary report (Kikkert and Lackenbauder, 2021).

#### Community Workshops

Community workshops were both a data collection and knowledge documentation tool, and a facilitator of other data collection methods. The term workshop was generally used to describe

large centralized gatherings with multiple stakeholders participating in knowledge sharing, skill building, and/or capacity-building exercises. In Hudson and Vodden (2020), a workshop included strength-based decision making and planning; community visioning exercises; community asset mapping; community engagement; and proposal writing. The term workshop was also used to describe the small group discussion sessions in Mayo and Tsey (2009), which focused on participants' experiences in a family well-being program. These discussions followed a 4Rs guideline:

- Recall details of the experience.
- Relive program highlights and challenges,
- Reinterpret experiences to consider what was learned about self and others.
- Respond to lessons and formulate future directions.

In-depth interviews were also conducted alongside these small group discussion workshops.

## 2.10.6 When Quantitative Data is Needed

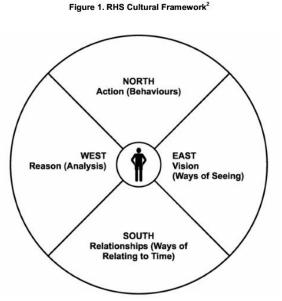
A majority of culturally relevant methods lead to the collection of qualitative forms of data. Qualitative data has significant strengths, including the ability to capture diverse community perspectives (Wendt et al., 2019). Some researchers, however, note that quantitative forms of data are at times more appropriate to meet research objectives. Quantitative data is most appropriate when communicating information to certain bodies (e.g., government) (Wray et al., 2020) and to inform decision-making in domains such as healthcare (Hayward et al., 2021). Wray and colleagues (2020) note that short surveys enabled them to engage with many more community members, particularly youth who are less likely to use narrative to share knowledge. Hayward and colleagues (2021) propose that by i) taking a strength-based approach; ii) contextualizing through positionality; iii) taking a community-based participatory research approach; and iv) ensuring Indigenous data sovereignty, quantitative data collection methods have the opportunity to be decolonized and Indigenized. These approaches have the potential to be applied to various data collection methods, with the overall purpose to incorporate and centre Indigenous worldviews into the entirety of the research process. An example of a culturally appropriate form of quantitative data collection is provided below.

## Key Information: The First Nations Regional Health Survey

The First Nations Regional Health Survey (RHS) is an example of quantitative data collection done in a culturally appropriate way. The RHS was initiated by the Government of Canada in 1997 in response to three major national longitudinal health surveys launched in 1994 that excluded First Nations. The RHS was taken over by a National Steering Committee comprising members of First Nations and Inuit partner organizations (FNIGC, 2007). The way the RHS was conceived and conducted "fundamentally changed the way that research on and with First Nations was conducted in Canada" (FNIGC, 2022 p. 139), and processes and principles guiding this survey are now associated with OCAP<sup>TM</sup> (FNIGC, 2022).

The survey, which "sought to balance First Nations content with content from comparable Canadian surveys while remaining culturally and scientifically valid," (FNIGC, 2016 p. 147) is based on a Cultural Framework that discusses how to act with Indigenous Intelligence, which means "exercising the total capacity of body, mind, heart and experience in total responsiveness and total relationship to the whole environment" (Dumont, 2005 p. 6). Acting with Indigenous Intelligence includes analyzing and interpreting statistical data in relation to the community's own vision and standards of what health means for their community (Dumont, 2005).

The survey was conducted four times over twelve years, with each cycle focused on one part of the four-directions model in the Cultural Framework. As seen in the diagram to the left (FNIGC, 2005), these four cycles are 1) East: envisioning First Nations wellness; 2) South: interpreting relationships; 3) West: reflecting on determinants of health; and 4) North: acting for positive change (FNIGC, 2005). This model communicates the survey intentions, and draws connections between wellness and culture, language, worldview, and spirituality



Fieldworkers hired from each region facilitated surveys on a laptop in respondents' homes. The RHS included distinct youth surveys to capture issues uniquely faced by Indigenous youth. Youth generally completed the survey themselves, with a fieldworker in the room to offer assistance as needed all the while respecting privacy. Adults completed their own surveys, and children were interviewed by someone who knew them well, usually their mother (FNIGC, March 2007). The survey used regional definitions (e.g., of youth), and data collected from the surveys was interpreted according to a holistic interpretive framework which acknowledges the complex and layered nature of First Nations health (FNIGC, March 2007). According to the FNIGC (2005), Since the survey is based upon First Nations understanding of health and wellness and collected and interpreted by First Nations, risk of misinterpretations is eliminated.

## 2.10.7 Conventional Methods

In addition to what we've defined as "culturally relevant data collection methods", authors also used more conventional forms of data collection. Of the reviewed studies, 37 used surveys, 71 used interviews, and 36 used focus groups as a method for data collection. Interviews and focus groups were more frequently one of the primary methods of data collection, while surveys were more likely to complement other forms of data collection. Some studies included recommendations and lessons learned about how to adapt these conventional methods to be more culturally relevant - these recommendations and lessons are explored in this section.

#### Uses of Surveys

Surveys often complemented other methods and were distributed as a follow-up to determine the effectiveness of an intervention, or even as a method of community engagement early on in the research process (see Harper et al., 2012; VanderBurgh et al., 2014).

While authors acknowledge surveys as an effective tool for gathering number-based data (e.g. Hampton et al., 2007; Prince et al., 2019), many mentioned limitations with conventional survey methods. For example, Islam and Berkes (2016) found that follow-up interviews revealed more nuance and different understandings than their follow-up survey questions. There can also be issues with survey responses. For example, in Lucier and colleagues (2020), some surveys were returned blank while other surveys intended to be answered at the individual level submitted on behalf of a household. Surveys were often coupled with other methods such as focus groups or interviews (e.g., Hampton et al., 2007; Islam and Berkes., 2016) to assist with appropriate interpretation of survey results and explore emerging themes in more depth. In some cases, participants could choose between a survey or more conversational methods (see Kildea et al., 2012).

There is no consensus on whether a self-administered or an interviewer-assisted survey is preferable. A self-administered survey may lead to more truthful answers, particularly on sensitive topics. However, interviewer-assisted surveys were essential in many cases for ensuring that survey questions were accessible for participants and for making sure the survey was completed (Irving et al., 2017). In one study that used surveys across several communities, researchers felt that a survey felt too impersonal in a particular community "given the nature of researcher and community relationships" (Hudson and Vodden, 2020 p. 16). Instead, they shifted to using methods such as focus groups. Survey fatigue is also a reality - in Jacklin and Kinoshameg (2008), their partnered community already had five surveys circulating. As a result, they either limited the use of surveys or made surveys as comprehensive as possible to limit participant fatigue. For Ford and colleagues (2018), despite efforts to contextualize survey questions, they still did not always resonate with partner communities.

Surveys described as culturally appropriate were generally developed in partnership with individuals or organizations from the community of study, or at the very least, reviewed by community members/organizations before being administered (Charania et al., 2014; Hayward et al., 2021; Irving et al., 2017; Islam and Berkes, 2016; Jacklin and Kinoshameg, 2008; Kelley et al., ; Kyoon-Achan et al., 2018; Munro et al., 2017). At times this led to re-wording questions to make the language more familiar to participants, or to use terms that were considered more

culturally appropriate. Munro and colleagues (2017) used visuals such as tick boxes, circling pictorial symbols and open-ended questions to make the survey more approachable for community members. Others noted that certain conventional scales may need to be adapted, as in Dutton and colleagues (2020), who found that a scale of 1-5 was not always understood by participants. Many surveys offered the presence of a researcher, local Elder, or translator so that questions could be explained in more depth or translated when necessary (see Charania et al., 2014; Irving et al., 2017; Jacklin and Kinoshameg, 2008; Lucier et al., 2020).

Participant recruitment was also addressed in locally-defined ways. Hampton and colleagues (2007) note that their conventional survey recruitment process, which relied on consistent school attendance and a signature from a parent or guardian, needed to be adapted to recruit Indigenous youth. In this case, a partner organization with existing trust with youth was crucial for youth recruitment for the survey. Lucier and colleagues (2020) offered an incentive for survey completion (community members were entered into a raffle for a tablet computer at the request of the community).

## Feature: Lessons Learned for Improving Survey Responses

Outlined below are some key Lessons Learned summarized from Lewis et al.'s (2016) study on increasing response rates on face-to-face surveys with Indigenous communities in Canada. Their process led to a 59% response rate on a community-wide environmental health survey.

- Use CBPR to develop survey instruments reflective of community-specific worldviews and practices.
- Develop a culturally appropriate survey protocol (e.g., verbal vs written consent).
- Use culturally relevant variables (or indicators). For example, variables in this study reflect traditional practices of gathering foods and medicines.
- Conduct a participatory and formative evaluation of design and delivery of service instruments.
- Share results on a regular basis.
- Ensure representation of households is achieved. Reflective of crowded housing in Pictou Landing, all adults over 18 completed their own surveys and, unless otherwise requested, female heads of households answered on behalf of their underage children.
- Include building community capacity as a tenet of CBPR.
- Ensure Flexibility in arranging interview times and locations.
- Local research assistants recommended using the names of the local community organization and researcher for advertising the research project. They believed this would result in higher response rates since they were familiar to community members.

## Uses of Focus Groups and Interviews in Studies

Cornect-Benoit and colleagues (2020) describe the conversational methods of interviews and focus groups as "valid form[s] of sharing that foster Indigenous Ways of Knowing" (p. 268). Dieter and colleagues (2018), Hampton and colleagues (2007), and Kyoon-Achan and colleagues (2021c) found that focus groups allowed the community to come together and share, resulting in community dialogue about dementia; relationship-building between Elders and youth; and encouraging positive oral health behaviours, respectively. Researchers followed-up surveys with focus groups and/or interviews to validate results or to build on emerging themes (see Islam and Berkes, 2016).

Interviews and focus groups were often used in tandem (see Haag et al., 2019). At times, participants were given the option to participate in a focus group or an interview depending on their preferences (see Hanson et al., 2018; Kildea et al, 2012; Kandasamy et al., 2017; Prince et al., 2019). In Brooks-Cleater and colleagues (2019) study, Inuit participants preferred focus groups, while First Nations participants preferred interviews. Isaak and colleagues (2010) found that interviews were preferable over focus groups for discussion of suicide because a focus group format generated a "ripple effect of despair within the group" (p. 268). The choice of focus group facilitator was important in a study by Flicker and colleagues (2014); youth became enthusiastic to participate in a focus group when it was directed by a younger, more locally engaged facilitator. In another case, a focus group with youth was unsuccessful, and youth were more comfortable sharing their experiences with asthma through drawing (Watson et al., 2012). Prior existing relationships improved recruitment and participation for interviews and focus groups (see Isaak et al., 2010).

Interview and focus groups were conducted in a location selected by the participant or participants were given the choice between several locations (e.g., homes, cafes, on the land) to ensure comfort, cultural safety, and/or confidentiality (Brooks-Cleator et al., 2019; Cornect-Benoit et al., 2020; Dawson et al., 2020; Heard et al., 2022; Fitts et al., 2019; Flicker et al., 2014; Kandasamy et al., 2017; Lewis et al., 2016; Rix et al., 2014). Participants in Fitts and colleagues (2019) could choose to have a support person present for the interview. Some interviews began with smudging and tobacco offerings (Hatala et al., 2019; Lucier et al., 2020).

Some studies did not audio record interviews and focus groups, but opted for taking handwritten notes, often with multiple notetakers to ensure accuracy (Brussoni et al., 2012; Kandasamy et al, 2017; Kikkert and Lackenbauer, 2021). Castleden and colleagues (2016) and Fitts and colleagues (2019) supplemented focus group recordings with field notes, observations and personal reflections to capture conversations that were not recorded and to augment interviews with their own reflections. Firestone and colleagues (2019) read and coded interview and focus group transcripts until they reached consensus and gave participants an opportunity to adjust and add to emerging themes. In both interviews and focus groups, it is noted that in small communities, individual community members may be easily identifiable by story content, so anonymity cannot be guaranteed. As a result, Cornect-Benoit and colleagues (2020) told participants to only share stories they were comfortable with the community being aware of.

While most studies using interviews mentioned that they offered to conduct them in the language of the participant's choice, this option was often not preferred by participants (see Kandasamy et al., 2017). There were certainly cases, however, when translation services were needed, or where

use of local languages enriched data collection by allowing for nuance of expression and interpretation of phrases used for emphasis (see Einsiedel et al., 2013; McDermott et al., 2015).

The main recommendation for how to make both interviews and focus groups more culturally appropriate is to prioritize semi-structured, conversational and unstructured styles. These methods elicit more in-depth answers and give participants more control over how the conversation progresses and which points are emphasized (see Dieter et al., 2018; Firestone et al., 2019; Isogai et al., 2012; Kyoon-Achan et al., 2018a; Murray et al., 2014; Oster et al., 2016; Rix et al., 2014). In Kandasamy and colleagues (2017), unstructured interviews in the participant's home environment allowed Elders to speak comfortably and they could use photographs, newspapers and personal experience and storytelling to support knowledge sharing. Styles such as these emphasize relationship and trust-building, and are described as "flexible, purposeful, and collaborative" (Firestone et al., 2019 p. 407). Isaak and colleagues (2010) state the importance of making clear to participants the differences between focus groups and Indigenous sharing circle traditions, as expectations for participants and researchers are different between these methods.

While interviews and focus groups can align with Indigenous ways of knowing, they may still not be the best method for the study at hand. In Lewis and colleagues (2016), even a very flexible interview style was described as merely "bearable" by a participant (p. 203). Shea and colleagues (2013) found that interviews were the least favourite part of the day for female youth participants. Hudson and Vodden (2020) said that "action-oriented data collection" that engaged participants in group settings "were much more conducive to collecting rich data and in engaging participants throughout the research" (p. 7). While the culturally relevant methods reviewed earlier may address these concerns, researchers should also consider adapting a method to be more culturally relevant. The following section reviews how this was done in the reviewed studies.

## 2.10.8 Cultural Relevance, Adaptation, and Creation of Research Tools

Choosing which research approaches, theoretical frameworks, methodologies, and data collection tools are used within a research process will have significant impacts on research outcomes. The various approaches described above are not universally culturally relevant: choices for which ones to employ and what this looks like in practice must be grounded in contextual considerations. Researchers should consider three important steps when designing research: i) choice; ii) adaptation; and iii) creation of new frameworks or tools.

#### Choice

Choosing data collection and knowledge documentation methods alongside community is important, as researchers do not necessarily know which methods align best with community values and ways of knowing. For example, in Brooks-Cleator and colleagues (2019), while Inuit adults in their study identified that they would prefer focus groups, the First Nations adults with whom they worked preferred participating in interviews. Providing space for this type of community input generally improved research processes for both researchers and community members.

## Feature: Balancing Western Science and Aboriginal Ways of Knowing

A randomized controlled trial (RCT) is a traditional research approach for determining the effectiveness of health interventions. In a health study involving Aboriginal children, however, Young and colleagues (2018), opted for an alternative approach termed a prospective cohort design. They chose this approach because:

- It was better aligned with the purpose of the study
- It was more aligned with existing community capacities
- It was more aligned with Indigenous worldviews and values, addressing some of the ways in which RCTs did not align with Indigenous ways of knowing.

## Adaptation and Transformation

Researchers may find that adapting existing tools works well in certain contexts. For example, Hampton and colleagues (2007) and Lewis and colleagues (2016) adapted survey questions to meet specific community needs and ways of knowing. In Kandasamy and colleagues (2017), the original interview questions were redesigned to be more broad and loose, allowing more space for storytelling. Participants were also able to bring additional sources of knowledge such as family photos, newspaper articles, and magazine publications to add to the oral conversations (Kandasamay et al., 2017).

Adaptation is a process that continuously evolves throughout a research project. Beveridge and colleagues (2021) continued to adapt knowledge documentation methods as they went along. In this case, their methods became increasingly open-ended and reciprocal. Ziabakhsh and colleagues (2016) adapted their methods by extending the time of their talking circles from 10 to 50 minutes, and by modifying educational materials shared about smoking cessation to be culturally appropriate. It is also possible to adapt ways of recording data. For example, Brussoni and colleagues (2012) switched to handwritten notes instead of audio recordings for their interviews and focus groups.

Examples of culturally adapted programs and health interventions in the reviewed articles also provide insight into cultural adaptation. Though program development can be done alongside community to ensure cultural relevance (Maina et al., 2020), adaptation of existing projects and programs is also an option (see Kelley et al., 2018; Lavalley et al., 2021; Nasir et al., 2021; Wendt et al., 2019). Maina and colleagues (2020) scoping review provides examples of how larger structures of service delivery can be adapted successfully; Johnson and colleagues (as cited in Maina et al., 2020) adapted a project on three levels: i) surface adaptation (idioms, language, and phraseologies); ii) deep adaptation (integrating participants' culture, history, mores, physical environment, and spirituality); and iii) evidential adaptation (using empirical information about participants). As always, community members should be involved in these decisions.

## Feature: Key Components for Culturally Safe Transformation of a Method

Bennett and colleagues (2019) determined seven key components for the culturally safe transformation of the method photovoice, which resulted in the Gaataa'aabing method. These components could potentially be adapted to the transformation of other methods:

- 1. The research method and cultural protocols are adapted to the respective Indigenous community context.
- 2. Community immersion of the academic team grounds the researchers in the day-to-day realities and culture of the community.
- 3. Participants define what visual media to include, in order to deepen participant involvement in the research process.
- 4. Academic researchers support participants in their technology use, thus facilitating participation from a variety of tech comfort levels.
- 5. The research team works to diminish/confront social hierarchies common in academic research by including researchers as "discreet" participants.
- 6. A focus on participant aspirations forms the basis for intended research outcomes, reaffirming the objectives of CBPR.
- 7. A final group learning circle provides an opportunity for reflection and concluding remarks.

## Co-Creation

At times, culturally appropriate frameworks and tools do not yet exist and the co-creation of something new is required to ensure cultural safety and relevance. This is what McElhaney and colleagues (2021) did when they developed the Developer/Adapter method. These tools can go on to be used by other communities as well.

The process of co-creation, however, is not limited to the creation of tools. It occurs as researchers and community members work together to create knowledge (Prince et al., 2019). Kelley and colleagues (2018) describe the repetitive process as "identifying a problem, planning a change, acting and observing the process and consequences of the change, reflecting on these processes and consequences, and preplanning, acting, observing and reflecting" (p. 26). Co-creation can be embedded throughout a project and guide how knowledge is created in the research process.

Co-creation can allow community partners to go beyond an advisory capacity (Carter et al., 2019) and be part of developing aspects of a project including research objectives and questions (Carter et al., 2019; Dawson et al., 2020). This can help to ensure that a project and its outputs are culturally relevant and in line with community priorities (Dawson et al., 2020; McCalman et al., 2020; Prince et al., 2019; Saini et al., 2020). Co-creation can further build local capacity (McCalman et al., 2020) and influence change in policy and practice (Prince et al., 2019). Trust is essential for co-creation, and its absence can undermine knowledge creation activities (Ford et al., 2018). Co-creation is achieved through flexibility and collaboration (Kyoon-Achan et al., 2018a). Ensuring there are opportunities for co-creation at all stages of the research process may influence the success of a CBPR project (Wray et al., 2020).

Coppola and McHugh (2018) developed a list of potential questions to ask when co-creating an activity-promoting community research agenda. These are listed in the box below.

## Feature: Potential Questions and Reflections for Co-Creating an Activity-Promoting Community Research Agenda (Coppola and McHugh, 2018, p. 22)

Building relati	ionships and consulting the community
How can we	promote stronger interagency work to support culturally relevant activity-promoting programming?
What are our	roles and responsibilities in supporting each other to achieve our project goals?
How can we a	all promote a democratic process of decision-making?
How can we	engage in continued dialogue to co-create project outcomes?
What is our p	partnership philosophy?
How will we a	address conflicts that arise?
Incorporating	culturally relevant practices
Is the term 'co	ulturally relevant' or 'cultural relevance' appropriate within our group? And how are we exploring or understanding
how the com	munity's culture is honoured?
Who should b	be involved in conducting culturally relevant activity-promoting programming?
How do we e	engage youth leaders in culturally relevant activity-promoting programming?
Are we promo	oting culturally relevant practices for all members of the group?
Are we using	terms that are appropriate and non-offensive within the group?
Sharing Know	ledge
How can we	promote on-going meetings?
What is the b	est way for our group to communicate?
What does th	e community group need to know about sharing outside the group?
How do you l	begin a discussion about sharing information outside of the group?
	willing to share about the project?
How many pe	eople need to agree on what is shared, and how will decision-making occur?
	creating opportunities for networking?
	creating a safe space for growth and support for our partners?
Have we cons	sidered how and when we will translate knowledge to other groups or partners, and who should receive this
knowledge?	

## 2.10.9 Developing Community-Specific Indicators

Talking about what brings about success, rather than focusing on why one person has something when another doesn't, gets people thinking in a positive way.

— Larissa Grant, Musqueam First Nation (as cited in Geddes, 2015 p. 2)

Community indicators are a key part of community assessments. While some assessments use pre-determined indicators, the grey literature suggests developing community-specific indicators. In line with the theme of how research should be co-designed with partner communities, community indicators can also be developed specific to community contexts.

The indicators used for assessments are essential for determining the relevance (including cultural relevance) of research to a particular community and its needs. Indicators measure specific aspects of a particular population or community. While these measurements are often quantitative (e.g., statistics), they can also be qualitative (e.g., stories) (Geddes, 2015). Not only do indicators measure information, they both reflect what is valued and create values as they determine what is being measured (Meadows, 1998 as cited in Geddes, 2015 p. 7). For

measuring health, indicators must "have a cultural fit", and "[reflect] people's positive view of themselves" according to their own vision of what health means (Geddes, 2015 p. 3). The importance of thoughtfully selecting indicators is expressed in the following quote:

"Too often, indicators of community wellness actually measure the absence of something negative, rather than the presence of something positive. For example, when tracking educational success, why track numbers of drop-outs when you could track the number of graduates? Why not track literacy instead of illiteracy, strengths instead of needs (Kretzman and McKnight, 1993)? While collecting information on things like sickness and environmental damage do raise awareness of real challenges, they can also become discouraging, self-fulfilling prophecies, lowering the expectations of community members of what is possible (Kishk Anaquot Health Research, 2008)" (Geddes, 2015 p. 2).

Developing indicators in partnership with communities can help ensure that assessment design is strengths-based and based on particular communities' understandings of health and well-being. This can allow communities to take ownership over assessment processes as they see their concerns reflected in what is being measured. (Geddes, 2015). Geddes's (2015) recommends using existing determinants of health (e.g., education) as a reference for discussing with communities what "success" would look like in each area. They recommend including a representative sample of community members in all stages of indicator development, from discussing the reasons for developing indicators to testing the selected indicators (FNIGC, 2020). This process may result in more indicators that focus on interrelationships between different social, cultural, environmental, and health factors. For example, following an interview-based consultation process in which community members identified things that made them healthy, an additional indicator of 'Community Connection' was added which reflects a non-physical understanding of health (Gibson, 2017).

# **2.10.10** Concluding Remarks on Culturally Relevant Data Collection and Knowledge Documentation Tools

While this section holds a large amount of information, the lessons are clear: To make the best research design choices for research by, with and for Indigenous communities, an awareness of knowledge systems, and epistemological and ontological assumptions underlying the origins and purpose of the research process is needed. When this awareness is present, deciding on which data collection and knowledge documentation methods to adopt can be done more consciously and in the genuine interest of the research purpose. Decisions determining the research design are not separate from other processes, including relationships building and community engagement. In fact, meaningful relationships and community engagement will only improve research design decisions and, generally, lead to improved outcomes.

# 2.11 Additional Practices for Research and Assessments by, with and for Indigenous Communities

## 2.11.1 Communication and Language Considerations

Culturally centred communication skills are essential for programs and projects to be appealing and successful (Vaughan et al., 2018). Even with a focus on relationships and education on local culture, outside researchers still bring their own values to the research process (Kyoon-Achan et al., 2018a). This can lead to communication difficulties such as wariness to express sacred beliefs and stories with external researchers (Wendt et al., 2019). It is therefore important to maintain open communication and to "continually clarify nuances, meanings, and intentions to prevent possible feelings of confusion or frustration" (Kyoon-Achan et al., 2018a p. 1044).

Recognizing that cultural misunderstanding can occur, Mayo and Tsey (2009) created an atmosphere of openness and understanding by recruiting people who were reflective about their roles in research. In several studies, locally hired research assistants and community liaisons played the role of cultural interpreters, enabling effective communication (particularly in institutional settings as in Einsiedel et al., 2013; Nagy et al., 2020; Simpson et al., 2021). Two examples of culturally tailored communication strategies are described below.

## Feature: Two Examples of Culturally-Tailored Communication

**Example 1:** In Haynes and colleagues (2019) metaphors were a preferred means of communication for speakers of an Australian Aboriginal language (Yolŋu Matha). Consequently, they used metaphors to communicate unfamiliar concepts such as a canoe journey as a metaphor for action research and the eye of a crocodile to represent critical thinking. The co-creation of these metaphors resulted in a meaningful reciprocal translation process.

**Example 2:** In Carter and colleagues (2019), youth research assistants helped researchers understand underlying meanings of Elders' stories and their connection to research questions, which at times was otherwise unclear to researchers.

#### The Use of Indigenous Languages

Using local languages may help facilitate communication as well as expand the reach of a project (Carter, 2008; Wray et al., 2020). Carter (2008) found that speaking the local language was beneficial for relationship building and described training in local languages as an emergent theme of participatory environmental research. Taking courses in local language and culture may play a role in relationship building, as locals are provided with opportunities to explain place-based protocols to newcomers (Carter, 2008). Language may not only facilitate communication between speakers of different languages, but it may also facilitate understanding between different worldviews as it is "ultimately an exercise in cross cultural understanding" (Carter et al., 2019 p. 392). Kyoon-Achan and colleagues (2018b) found that profound insight and meaning were communicated when participants used their local languages, suggesting that meaning can

be lost if language is not understood. In Henderson and colleagues (2018), community members both young and old found the integration of Indigenous languages in messaging to be "empowering," or noteworthy, even for those who did not speak the language (p. 98). In Young and colleagues (2017), perceptions of the relevance of research increased when their survey was given an Ojibwe name by children in the community who were taking the survey.

Having translation services available was important in some studies, particularly to document the knowledge of Elders who may require or prefer an interview conducted (even partially) in their Indigenous language (Carter et al., 2019; Einsiedel et al., 2013; Hanson et al., 2018; Islam and Berkes, 2016; Kyoon-Achan et al., 2018a). Authors also flagged the need for sensitivity regarding bilingualism and translation, as limits to language fluency caused by the residential school system may be an area of discomfort (Carter et al., 2019). As in Carter et al.'s (2019), skilled interpreters may need to be hired to accurately document Elders' knowledge. This took more time and was more expensive, but it was important for participants to have the option to respond in the language of their choice for accurate knowledge documentation. In some cases, participants used Indigenous languages only for emphasis or to communicate certain phrases (see Hanson et al., 2018; Kyoon-Achan et al., 2021a). In other cases, participants preferred to communicate in English (see Kandasamy et al., 2017; Romain et al., 2015).

When translation is used, The World Health Organization (as cited in Davies et al., 2015) recommends hiring one interpreter for forward translation (i.e., English to Yolŋu Matha) and another interpretation for back translation (Yolŋu Matha to English) to check the accuracy of translations. Carter and colleagues (2019) found that key words involved in the research project (such as "impact" and "season") had no direct translation in Inuktitut; using a back-and-forth translation process helped ensure the same meanings were communicated. As metaphors are a preferred means of communication in certain languages, context in translations between literal and conceptual interpretations is crucial. Reviewing data collection tools with community members is recommended to adjust language use or methods so that they are more understandable and culturally appropriate (see Dawson et al., 2020; Kelley et al., 2018).

## 2.11.2 Data Interpretation, Results Verification and Sharing

Interpreting collected data, verifying the interpretation, and sharing results with community members are a continuation of important practices for research by, with and for Indigenous communities. Kyoon-Achan and colleagues (2018a) describe the "two-way learning knowledge exchange" that comes from presenting results and providing space for community feedback as "fundamental to the CBPR process" (p. 1041). This section reviews practices for data analysis and interpretation, results verification and sharing, and considerations for confidentiality when sharing results with community.

#### Data Analysis

The most common analysis and verification practice appears to be researchers developing an initial analysis as a first step, then reviewing emerging themes with community members or other Indigenous partners and incorporating their feedback (e.g. Benoit et al., 2020; Sawatzky et al., 2020; Ziabakhsh et al., 2016). This occurs through discussion (e.g., Benoit et al., 2020), a group activity with participants (Firestone et al., 2019), or facilitating a workshop with project participants (Fitts et al., 2019). Several studies involved Indigenous partners as co-analysts in

results interpretation (e.g., Lucier et al., 2020; Ritchie et al., 2015). Kyoon-Achan et al., 2021a drew partially on the "lived experience of Indigenous research team members" for data analysis and interpretation (p. 3). Consideration of who ought to be involved in results interpretation and verification is important - for example in Hickey at al. (2021), researchers chose to separately code, interpret and validate data between men and women to respect the cultural significance and gendered nature of sexual and reproductive health for First Nations people. Where interpretation of data differed, First Nations interpretations were privileged in the process of finding consensus. More examples of data analysis processes are included in the box below.

## **Feature: Examples of Collaborative Data Analysis Processes**

**Example 1:** Flicker et al.'s (2007) collaborative inductive analysis had several iterative steps: i) conduct a preliminary analysis fo a subsample of transcripts; ii) develop a coding framework based on emerging themes, commonalities and differences; iii) each team member codes transcripts independently and they meet on a weekly basis to review and discuss completed coding, and ; iv) create summary documents to capture common themes, gaps and issues. This process was done with six team members made of faculty, research staff and students, with half the team identifying as Indigenous. This created a transparent and nuanced analysis in line with OCAP<sup>TM</sup> principles.

**Example 2:** Flicker and colleagues (2014) invited all co-investigators and Youth Coordinators involved in their study to a retreat, at which they collaboratively identified key themes from data. They used the DEPICT method (described in Flicker and Nixon, 2014) to analyze the transcripts, which had been de-identified to maintain confidentiality.

**Example 3:** Lucier and colleagues (2020) collaboratively analyzed findings following a Water Ceremony, discussing findings with Chief and Council, Elders and the broader community. They used discussion prompts such as, "Does this make sense?", "What jumps out and why?", and "Why do you think community members said what they said?" (p. 4). They disaggregated data by gender, and by two broad age categories: younger (18-49) and older (50 and above).

**Example 4:** In Benoit and colleagues (2020) statisticians performed data analysis, discussing the analysis plan with members of an Indigenous research team who had expertise in the field of study. Statisticians presented results from the analysis at a Sharing Circle gathering, where their respective research teams provided Indigenous perspectives. They discussed meanings and implications of the findings, and how the findings would be shared.

## **Results Verification**

Consistently checking results and sharing them with communities to provide opportunity for awareness, critique, consensus, and discussion is critically important in community-engaged research (Carter et al., 2019; Jacklin and Kinoshameg, 2008). Data interpretation and results verification with community members not only ensures accuracy, it may increase the impact of research and its uptake (Kyoon-Achan et al., 2021c). Wray and colleagues (2020) found that the additional step of going back to share final results with community members was well-worth the additional cost. Community members expressed gratitude for the researcher's presentation of

findings, saying they "would be much happier with the idea of having research being conducted there" if all researchers undertook this step (Wray and colleagues, 2020, p. 16). Further, Indigenous control of results dissemination communicates respect and reciprocity for Indigenous cultures (Kandasamy et al., 2017). Data validation may also lead to co-authorship, as in Ogenchuk and colleagues (2022), in which a community member who contributed substantial feedback is included as a co-author.

Preliminary findings were publicized and validated through formal or informal in-person meetings, Facebook posts, knowledge documentation workshops, community feedback sessions, conversations, focus groups, one-on-one sessions, the displaying of results in public spaces, community story nights, events such as a dinner or a gala, DVDs, posters and flyers, public presentations or other methods depending what was appropriate for each community (see Carter et al., 2019; Cornect-Benoit et al., 2020; Dawson et al., 2020; Harper et al., 2012; Hatala et al., 2019; Hudson and Vodden, 2020; Islam and Berke, 2016; Kyoon-Achan et al., 2021b; Lewis et al., 2016; Ziabakhsh et al., 2016). Khayyat Kholghi and colleagues (2018) attended the monthly meetings of various partner organizations, providing updates and inviting discussion, interpretation, and recommendations related to the research. Kildea and colleagues (2012) facilitated a World Café style workshop with sixty community participants.

An iterative and cyclical approach to data verification can include researchers providing multiple opportunities for data interpretation and validation (Carter, 2008). In Carter and colleagues (2019), results were first checked by youth co-facilitators, then by available research participants, with feedback progressively incorporated into the interpretation and framing of results before being shared with community partners. Results were also validated through informal discussions of survey results between community members, with a community representative incorporating these perspectives into his discussion of results with researchers (Carter et al., 2019). Hudson and Vodden (2020) validated datasets through conversation, focus groups, and gatherings in accordance with the importance of storytelling. They provided "ample opportunity to reflect, discuss, share what they meant, and what they saw as important for the future" to ensure community voices were central to the direction of and study results (Hudson and Vodden, 2020, p. 8). Ritchie and colleagues (2015) used multiple means of data validation, including comparing results with participant journals and triangulating their data through a process of "constant validity checking" (p. 356). Their analysis process incorporated the perspectives of research team members, staff, youth participants, Elders, and members of local organizations. Lewis and colleagues (2016) held community events every six months to provide updates and answer questions.

To verify information shared at these data verification events, some researchers took audiorecordings and/or notes (Hudson and Vodden, 2020; Ritchie et al., 2015). Others repeated focus groups to ensure accuracy, validity and credibility of stories shared (Cornect-Benoit et al., 2020). Researchers provided follow-up summaries or word clouds to participants for additional verification, with participants invited to provide feedback on emerging themes (Cornect-Benoit et al., 2020; Dawson et al., 2020; Oster et al., 2016). Lickers and colleagues (2017) needed to reengage participants to ensure accurate interpretation of stories before presenting resulting information.

While Carter and colleagues (2019) expected participants to view validating results as "inherently valuable" (p. 397), community partners recommended that researchers give remuneration, such as door prizes or token gifts, as a formal acknowledgement of participants' contributions. Carter and colleagues (2019) found that misunderstanding would have been prevented if they had explained the benefits of research validation for both participants and researchers at research-related meetings. Community members may expect results as fast as within a couple weeks, as this is common practice for things such as school assignments (Cooper and Driedger, 2018). Out of respect for participants and to ensure results reach community members who may be mobile, it is important that results be communicated back as quickly as possible.

#### Confidentiality Considerations when Verifying Data and Results

It is crucial to uphold the confidentiality of participants during the data verification processes described above. This can be done by presenting data at an aggregate level in a way that participating individuals or communities are not identifiable in publicly released results (Couzos et al., 2020). In Hickey and colleagues (2021), quotes in the final management script were only attributed to 'the yarning circle group,' rather than identifying individual participants. Hatala and colleagues (2019) found that youth preferred third person references rather than artificial pseudonyms. Couzos and colleagues (2020) describe the researcher obligation to "broadly disseminate a full account of the process and findings of the study" (p. 1438), while considering intellectual property rights and culturally sensitive data. Researchers should work with research partners to define protocols that respect confidentiality while still providing a transparent data verification process with participants.

#### 2.11.3 Outcomes of Research and Assessment Processes

"By creating products that seek not only to return study information but also to answer questions and address specific challenges identified by participants, it is possible to continue to engage in research that is meaningful and ethical and strengthens relationships with all stakeholders"

(Cooper and Driedger, 2018 p. 61).

#### Knowledge Mobilization and Knowledge Translation (KT)

The Canadian Institutes of Health Research defines knowledge translation as, "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge" which results in a strengthening and improvement of services as research is translated into action (as cited in Charania et al., 2012 p. 2). Similarly, Indigenous knowledge translation is defined as "the process[es] through which knowledge is transformed into strategic action" (Estey et al., 2008 as cited in Dieter et al., 2018 p. 10). Ensuring that the results of research are accessible and useful to communities through appropriate knowledge translation considerations is essential in Indigenous research (Cooper and Driedger, 2018).

Bottom-up involvement of communities in the development of resources is crucial to their success (Davies et al., 2015). Researchers are responsible to work to understand community needs and preferences to determine which methods of research translation to employ (Cooper and Driedger, 2018). One community's code of ethics stated knowledge dissemination had to take place in the community before it could be communicated elsewhere (Khayyat Kholghi et al., 2018). Knowledge mobilization, however, does not need to wait until the final stages of a project; it can be incorporated throughout all stages, particularly when there is significant

community engagement shaping research processes (e.g., Morton Ninomiya et al., 2020). Cooper and Driedger (2018) developed a list of considerations for developing research dissemination products, included below.

## Feature: Seven key considerations for developing research dissemination products

Cooper and Driedger (2018) outline seven key considerations for developing research dissemination products in research with, by and for Indigenous communities:

- Can the community easily make copies of the resource?
- Are there aspects of the product which do not require any written literacy skills?
- Is there a component of the message which is strengths based and hopeful?
- Is the product interactive?
- Has the knowledge from participants and/or communities been acknowledged?
- Is there an active learning component that spans beyond encounters with the research team?
- Has the product been returned to the community quickly (under 6 weeks)? (p. 62)

Additionally, stakeholders should consider the target age range, gender, and geographic reach for their dissemination product.

Knowledge dissemination products should be reflective of Indigenous Knowledge Keepers and knowledge users (Cooper and Driedger, 2018). Methods of delivery are also key for accessibility and community uptake (Vaughan et al., 2018). For example, documents generated in high-level English may be perceived as a "secret language" by community members, who may prefer oral or visual methods of delivery (Davies et al., 2013 p. 13).

Knowledge translation can occur through a variety of mediums that incorporate and communicate research findings in an accessible way for participants. Besides traditional academic outputs, this includes the use of art, activity sheets, videos and documentaries, plain-language reports, newsletters and pamphlets, television and radio broadcasts, websites, storybooks, board games, and social events (Benoit et al., 2020; Borish et al., 2021; Brooks-Cleator 2019; Cooper and Driedger, 2018; Fanian et al., 2015 as cited in Athony et al., 2018; Isaak et al., 2010; Shea et al., 2013; Wendt et al., 2019). Davies and colleagues (2015) describe good knowledge products as "user-friendly, interactive, tactile, and aesthetically appropriate" (p. 2).

## Feature: Examples of culturally-tailored communication and KT products

**Example 1:** Upon discussion of community priorities, including purpose and target audience for dissemination products, community members chose to use findings from Woodward and Marrfurra McTaggart (2016) to create a seasonal calendar as an educational tool for use in local schools. This calendar used Ngan'gi (an Australian Aboriginal language) species names to describe the socio ecological reasons for Ngan'gi resource use and management, allowing "the way of the ancestors" (p. 138) to be communicated in a school setting alongside other knowledge systems. The calendar went on to be distributed regionally, nationally and internationally to a variety of audiences including educational institutes, Indigenous community organizations, government and research bodies, and members of the public.

**Example 2:** In Kandasamy and colleagues (2017), a Six Nations filmmaker was brought onto their project to communicate research findings so that these findings would be "culturally meaningful and significant" (p. 7).

**Example 3:** In Munro and colleagues (2017), a radio message on substance abuse developed through community consultation was found to be a relevant and well-trusted form of media. This message was delivered over the radio through the voice of an Elder, leading to high recall of these messages.

Although Indigenous individuals and communities may prefer oral or visual forms over written documents, more traditional academic outputs have important audiences such as government agencies, community service organizations, and researchers (Davies et al. 2013). Davies and colleagues (2013) describe a common practice of generating "a suite of documents for different audiences and purposes" (p. 13) by creating, for example, a main picture and map-rich plan supplemented by other documents containing relevant scientific and technical information. Even when intended for non-Indigenous audiences, documents that incorporate Indigenous knowledge and visuals can have the benefit of communicating and validating the presence and knowledge of local Indigenous individuals to outsiders, while promoting the confidence of traditional owners interpreting these documents (Davies et al., 2013). Morton Ninomiya and colleagues (2020) identify that building strategic partnerships with target audiences (particularly policy and decision-makers) is often included in effective knowledge translation strategies.

#### Additional Action Resulting from Research and Assessments

Sources from grey literature (notably, documents on community assessments and community planning) focused on using community assessments as a springboard for action and positive community change. While data is important in these assessments for identifying issues, this information can also be leveraged to rally community and grow towards a common vision.

In their Community Readiness Manual, Plested and colleagues (2016) outline a process for building capacity in Indigenous Nations to "recognize and build on the strengths from within to begin a healing process of healthy change" (p. 3). The manual provides a framework for conducting a community readiness assessment and is a guide for progressively building capacity in communities to address a specific issue (e.g., youth suicide). They outline nine stages of community readiness (below). Following a research or assessment process, awareness of an issue might not be sufficient for communities to take action to move towards positive change; however, as communities move into higher stages of community readiness, we can build towards high levels of community ownership that create conditions for positive, strengths-based action. Initiating processes of change emerging from a community assessment may be a complex, integrative and imaginative process involving an entire community and its assets.

STAGE	DESCRIPTION
1. No Awareness	(THE ISSUE) is not generally recognized by the community/leaders as an issue (or it may truly not be an issue).
2. Denial / Resistance	At least some community members recognize that (THE ISSUE) is a concern, but there is little recognition that it might be occurring locally.
3. Vague Awareness	Most feel that there is local concern, but there is no immediate motivation to do anything about it.
4. Preplanning	There is clear recognition that something must be done, and there may even be a group addressing it. However, efforts are not focused or detailed.
5. Preparation	Active leaders begin planning in earnest. Community offers modest support of efforts.
6. Initiation	Enough information is available to justify efforts. Activities are underway.
7. Stabilization	Activities are supported by administrators or community decision makers. Staff are trained and experienced.
8. Confirmation/ Expansion	Efforts are in place. Community members feel comfortable using services, and they support expansions. Local data are regularly obtained.
9. High Level of Community Ownership	Detailed and sophisticated knowledge exists about (THE ISSUE) prevalence and consequences. Effective evaluation guides new directions. Model is applied to other issues.

**Table 6**: Table Stages of Community Readiness (Plested et al., 2016 p. 10)

## 2.12 Reconciliation in Research, Research in Reconciliation

The impacts of colonization and the ways in which research can contribute to decolonization are a focus of the reviewed studies and of this report. Colonizing research has had negative effects on Indigenous peoples, in part by portraying them as "sick and inherently unable to care for themselves" (Mosby, 2013 as cited in Lopresti et al., 2022 p. 2). Health research done "in a good way" has the potential to support reconciliation in Canada (Murphy et al., 2021 p. 2). Research can be used as a tool for "decolonization, reconciliation and democratization of knowledge toward growth" (Kyoon-Achan et al., 2018a p. 1037). Decolonizing research is central to reconciliation, and applying the Wise Practices reviewed in this report can contribute to this.

Simms and colleagues (2016) reference the report from the Truth and Reconciliation Commission (TRC) as "perhaps the best resource" (p. 24) for building trust and capacity for collaboration. With colonization recognized by the WHO as "the single most significant social determinant of health among Indigenous peoples worldwide" (Neufeld et al., 2020 p. 1), the TRC consists of 94 Calls to Action aimed at narrowing disparities in health and well-being between Indigenous and non-Indigenous groups in Canada (Neufeld et al., 2020). The ultimate goal of reconciliation, according to the TRC, "must be to transform our country and restore mutual respect between peoples and nations" (Simms et al., 2016, p. 23).

Bloomfield (2006 as cited in Graeme and Mandawe, 2017) describes two general approaches to reconciliation: structural, which focuses on the roles of political structures in building adequate working relationships; and cultural, a deeper process which takes place at the interpersonal level and may lead to harmonious relationships between Indigenous and non-Indigenous people or groups. According to Murphy and colleagues (2021), community-directed research is an appropriate means for Western-based researchers to begin to "unlearn colonial research practices, re-learn, and accept the inherent value of Indigenous-led research" (p. 19). Reconciliation can be furthered through research that is useful to the communities, culturally relevant, oriented toward relationship and trust building, respects collaboration, respects traditional knowledge, and is contextually situated and owned by the communities (Kyoon-Achan et al., 2021c). The TRC report considers mutually respectful relationships that acknowledge and redress past harms as central to reconciliation (Lopresti et al., 2022). Researchers clearly have a role to play in reconciliation by forming these relationships and adhering to these research recommendations.

At the structural level, further work is recommended to make these practices more common across research practices. Graeme and Mandawe and colleagues (2017) recommend that funding agencies encourage academics to reflect on their roles in reconciliation by prioritizing and funding research that promotes relationship-building with Indigenous communities, particularly in disciplines where this is not typically emphasized. Researchers could demonstrate their commitment by providing strategic plans or formal responses to the TRC's recommendations. While there is danger that such guidelines would not be enacted, Graeme and Mandawe (2017) propose "there is much room for conversations about how researchers can do more to support reconciliation in Canada through both their research and their relationships" (p. 15).

Some authors in the systematic review drew connections between their projects and the TRC report. Kyoon-Achan and colleagues (2018a) described their research as promoting consultation and establishing measurable goals in response to Call to Action number 19, and Kyoon-Achan and colleagues (2021a) found that recognizing and respecting traditional healing, healers, medicines, and therapies in their project addressed the legacy and impacts of assimilative policies. Kyoon-Achan and colleagues (2021c) and Young and colleagues (2018) connected their work to closing health disparities in Indigenous oral health and child emotional health, respectively. Authors also experienced reconciliation in action on an interpersonal level with conflict and reflection in the participatory research process leading to trust and meaningful relationships (Graeme and Mandawe, 2017). Siyám and Raphael created a comprehensive guide for (economic) reconciliation which includes background context, tools for personal reflection, further reading, and other practical steps and resources to commence a journey of reconciliation in one's own context.

The principles, protocols, and practices reviewed in this report support research that continues to be increasingly useful to communities, culturally relevant, oriented towards relationship and trust building, is collaborative, respects and reflects traditional knowledge, and is contextually situated and community-owned. It is with these characteristics that how research and assessments are conducted can contribute to reconciliation.

## **Section 3 – Limitations**

There are key limitations to note about our methods for this review and our results.

In our search process, our peer-reviewed literature search was systematic but our grey literature search was not. This decision was made due to project time constraints. While our grey literature sources provided important information, most of our sources were focused on Canada. The sources located from Australia seemed less relevant to the purpose of this review (e.g., government publications). Since we are performing this research as Canadians in Canada, we may not have had enough contextual knowledge to locate pertinent Australian sources, despite consulting a librarian.

In our analysis process, we did not divide findings based on Canadian and Australian sources. We also did not conduct our analysis based on Indigenous groups (First Nations, Inuit, Métis). While this information was provided in case-study examples presented throughout the report, certain nuances about country and group-specific approaches to research may have been lost in our analysis process.

Certain limitations exist due to the scope of our research. In our sections on research paradigms and knowledge documentation tools, we did not include methodologies related to health practices as they are out of our own scope and understanding as social science researchers.

The construction of this document has its limitations. We founded our review, and this document, on findings from peer-reviewed literature, integrating findings from grey literature afterwards. This may have privileged language and experiences of academic practitioners over other types of practitioners engaged in research and assessment with Indigenous communities. The shape of this document and its emphasis may have differed had it prioritized grey literature first.

## Section 4 – Glossary: Terminology

## **Indigenous Peoples**

Indigenous peoples refers to the original inhabitants of a territory (Siyám and Raphael, 2022). In the Canadian context, this includes First Nations, Métis, and Inuit peoples. In Australia, this includes Aboriginal and Torres Strait Islander peoples.

Aboriginal and Torres Strait Islander Peoples: Aboriginal and Torres Strait Islander Peoples refers to peoples Indigenous to what is now known as Australia. Unless otherwise stated, in this text, the term "Aboriginal" is *only* used to refer to Indigenous peoples of Australia.

*First Nation:* "Any of the groups of [I]ndigenous peoples of Canada officially recognized as an administrative unit by the federal government or functioning as such without official status. The term is generally understood to exclude the Inuit and Métis" (Siyám and Raphael, 2022, p. 12)

*Inuit:* "The Inuit are Indigenous Peoples of Arctic Canada. Inuit communities are located in regions based on modern land claims known as the Inuvialuit Settlement Region (the Northwest Territories), Nunavut, the northern Québec region of Nunavik, and the northern Labrador region of Nunatsiavut" (Siyám and Raphael, 2022, p. 147).

*Métis:* In accordance with the Métis National Council (2022), "'Métis' means a person who selfidentifies as Métis, is distinct from other Aboriginal peoples, is of historic Métis Nation Ancestry and who is accepted by the Métis Nation."

## People

*Elder:* In accordance with the texts in this review, Elders are individuals who are "recognized because they have earned the respect of their community through wisdom, age and balance of their actions in their teachings" (Siyám and Raphael, 2022, p. 146). Knowledge Keeper is a preferred term in some communities, including in Treaty Four Territory (Dieter et al., 2018).

*Researcher:* Refers to anyone conducting a research or assessment process. While in many texts 'researcher' often refers to someone external to a community, this may also be someone who is local to a community where research is occurring.

*Settler:* In accordance with Siyám and Raphael, 2022, 'settler' refers to non-Indigenous folks whose ancestors (or themselves) have "voluntarily came and settled on land that had been inhabited by [I]ndigenous people" (p. 12).

*Youth:* Refers to younger people in a community. Who is considered "youth" varies between studies; in Flicker and colleagues (2014), youth were ages 13-29; in Dawson and colleagues (2020), ages 15 to 45; and the First Nations Information Governance Centre (n.d.) considers youth to be ages 12-17.

## **Additional Terms**

*Community:* The term 'community', unless otherwise stated, is used to refer to Indigenous communities. 'Community' was used by many authors, yet was not defined throughout the articles. We understand community as a group of people with a shared aspect of life. In the articles analyzed in this report, this shared aspect of life includes (but is not limited to) geographical location, belonging to a particular Nation, shared cultural practices and identities, and other aspects interrelated with Indigenous identity.

*Colonization:* Colonization occurs when a new group of people migrates to, takes over, and begins to control Indigenous peoples who occupy those territories. This control includes "settlers impos[ing] their own cultural values, religions, and laws, seizing/stealing land and controlling access to resources and trade" (Siyám and Raphael, 2022, p. 145).

*Decolonization:* In accordance with Siyám and Raphael (2022) decolonization refers to deconstructing colonial ideologies, unprivileging Western thoughts and approaches, and in turn "valuing and revitalizing Indigenous knowledge and approaches, and rethinking Western biases or assumptions that have impacted Indigenous ways of being" (p. 146).

*Protocols:* In the context of this report, protocols are "ways of interacting with Indigenous people in a manner that respects traditional ways of being" (Siyám and Raphael, 2022, p. 149). Protocols differ across each culture and are a representation of a culture's ethical system and beliefs.

*Reconciliation:* The Truth and Reconciliation Commission of Canada (2015) defines reconciliation as "establishing and maintaining a mutually respectful relationship" between Indigenous and non-Indigenous peoples, which requires "acknowledgement of the harm that has been inflicted, atonement for the causes, and action to change behaviour" (p. 7). Similarly, Siyám and Raphael (2022) describe reconciliation as "addressing past wrongs done to Indigenous Peoples, making amends, and improving relationships between Indigenous and non-Indigenous people to create a better future for all" (p. 149). Improved relationships between Indigenous and non-Indigenous peoples, and truth, are key to reconciliation. The Truth and Reconciliation Commission of Canada (2015) further states "the importance of truth telling in its own right should not be underestimated; it restores the human dignity of victims of violence and calls governments and citizens to account. Without truth, justice is not served, healing cannot happen, and there can be no genuine reconciliation between Aboriginal and non-Aboriginal peoples in Canada" (p. 12). Both relationships and truth hold their place in how researchers choose to do research by, with and for Indigenous communities.

## References

#### **Systematic Literature Review Articles**

- Alexander, S. M., Provencher, J. F. Henri, D. A., Taylor, J. J., Immanuel, J., Nanayakara, L, Johnson, J. T., Cooke, S. J. (2019). Bridging Indigenous and Science-based Knowledge in coastal and marine research, monitoring, and management in Canada. *Environmental Evidence*, 8(1). https://doi.org/10.1186/s13750-019-0181-3
- Angelbeck, B., and Grier, C. (2014). From paradigms to practices: pursuing horizontal and longterm relationships with indigenous peoples for archaeological heritage management. *Canadian Journal of Archaeology / Journal Canadien D'archéologie*, 38(2), 519–540.
- Anthony, B., Weston, D., and Vallen, S. (2018). Thumbs up: the effective use of music in health and well-being education for Australian Aboriginal youth in remote communities. *International Journal of Canadian Music*, 11(1) p. 71-89. doi: 10.1386/ijcm.11.1.71\_1
- Arbour, L., Rezazadeh, S., Eldstrom, J., Weget-Simms, G., Rupps, R., Dyer, Z., Tibbits, G.,
  Accili, E., Casey, B., Kmetic, A., Sanatani, S., and Fedida, D. (2008). A KCNQ1 V205M missense mutation causes a high rate of long QT syndrome in a First Nations community of northern British Columbia: A community-based approach to understanding the impact. *Genetics in Medicine*, 10(7), 545–550. https://doi.org/10.1097/GIM.0b013e31817c6b19
- Aslam, M., Ogunnaike-Cooke, S., Boulos, D., Archibald, C. P. (2010). Establishing a sentinel surveillance system for HIV-associated risk behaviour among Aboriginal populations in Canada. *A-Track HIV Surveillance in Canada*, 7, 552-555. https://www.tandfonline.com/doi/pdf/10.1080/22423982.2010.11864609#page=553
- Ban, N. C., Picard, C. R., and Vincent, A. C. J. (2009). Comparing and integrating communitybased and science-based approaches to prioritizing marine areas for protection. *Conservation Biology*, 2(4), 899–910. https://doi.org/10.1111/j.1523-1739.2009.01185.x
- Bennett, B., Maar, M., Manitowabi, D., Moeke-Pickering, T., Trudeau-Peltier, D., and Trudeau, S. (2019). The Gaataa'aabing visual research method: A culturally safe Anishinaabek transformation of photovoice. *International Journal of Qualitative Methods*, 18, 1-12. https://doi.org/10.1177/1609406919851635
- Benoit, A. C., Jaworsky, D., Price, R., Whitebird, W., Benson, E., Nowgesic, E., Nicholson, V., Ranville, F., Loutfy, M., Beaver, K., Zoccole, A., Nobis, T., Kellman, C., Jackson, R., O'Brien-Teengs, D., Walsh, T., Keshane, M., Tom, J., Tynes, T., ... Masching, R. (2020). Building bridges: Describing process for Indigenous engagement in epidemiology. *Progress in Community Health Partnerships: Research, Education, and Action, 14*(4), 461–470. https://doi.org/10.1353/cpr.2020.0051
- Beveridge, R., Moody, M. F., Pauly, B., Murray, G., and Darimont, C. T. (2021). Applying community-based and Indigenous research methodologies: Lessons learned from the Nuxalk Sputc Project. *Ecology and Society*, 26(4), art21. https://doi.org/10.5751/ES-12702-260421

- Borish, D., Cunsolo, A., Mauro, I., Dewey, C., and Harper, S. L. (2021). Moving images, moving methods: Advancing documentary film for qualitative research. *International Journal of Qualitative Methods*, 20, 1-14. https://doi.org/10.1177/16094069211013646
- Brooks-Cleator, L. A., Giles, A. R., and Flaherty, M. (2019). Community-level factors that contribute to First Nations and Inuit older adults feeling supported to age well in a Canadian city. *Journal of Aging Studies*, 48, 50–59. https://doi.org/10.1016
- Brussoni, M., Olsen, L. L., and Joshi, P. (2012). Aboriginal community-centered injury surveillance: A community-based participatory process evaluation. *Prevention Science*, 13(2), 107–117. https://doi.org/10.1007/s11121-011-0258-x
- Busija, L., Cinelli, R., Toombs, M. R., Easton, C., Hampton, R., Holdsworth, K., Macleod, BPsySc(Hons), A., Nicholson, G. C., Nasir, B. F., Sanders, K. M., and McCabe, M. P. (2020). The role of Elders in the wellbeing of a contemporary Australian Indigenous community. *The Gerontologist*, 60(3), 513–524. https://doi.org/10.1093/geront/gny140
- Carter, J. L. (2008). Thinking outside the framework: equitable research partnership for environmental research in Australia. *The Geographical Journal*, *174*(1), 63-75. https://rgs-ibg.onlinelibrary.wiley.com/doi/full/10.1111/j.1475-4959.2007.00251.x
- Carter, N. A., Dawson, J., Simonee, N., Tagalik, S., and Ljubicic, G. (2019). Lessons learned through research partnership and capacity enhancement in Inuit Nunangat. ARCTIC, 72(4), 381–403. <u>https://doi.org/10.14430/arctic69507</u>
- Castleden, H., Watson, R., Tui'kn Partnership, Bennett, E., Masuda, J., King, M., and Stewart, M. (2016). Asthma prevention and management for Aboriginal people: Lessons From Mi'kmaq Communities, Unama'ki, Canada, 2012. *Preventing Chronic Disease*, 13, 150244. https://doi.org/10.5888/pcd13.150244
- Charania, N. A., and Tsuji, L. J. (2012). A community-based participatory approach and engagement process creates culturally appropriate and community informed pandemic plans after the 2009 H1N1 influenza pandemic: Remote and isolated First Nations communities of sub-arctic Ontario, Canada. *BMC Public Health*, 12(1), 268. https://doi.org/10.1186/1471-2458-12-268
- Charania, N. A., Martin, I. D., Liberda, E. N., Meldrum, R., and Tsuji, L. J. (2014). Bird harvesting practices and knowledge, risk perceptions, and attitudes regarding avian influenza among Canadian First Nations subsistence hunters: Implications for influenza pandemic plans. *BMC Public Health*, 14, 3-11. https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-14-1113
- Conigrave, K., Freeman, B., Caroll, T., Simpson, L., Kylie Lee, K. S., Wade, V., Kiel, K., Ella, S., Becker, K., and Freeburn, B. (2012). The Alcohol Awareness project: Community education and brief intervention in an urban Aboriginal setting. *Health Promotion Journal of Australia*, 23(3), 219–225. https://doi.org/10.1071/HE12219

- Cooper, E. J., and Driedger, S. M. (2018). Creative, strengths-based approaches to knowledge translation within indigenous health research. *Public Health*, *163*, 61–66. https://doi.org/10.1016/j.puhe.2018.06.020
- Coppola, A. M., and McHugh, T.-L. F. (2018). Considering culturally relevant practices and knowledge-sharing when creating an activity-promoting community research agenda. *Sport, Education and Society*, 23(1), 14–27. https://doi.org/10.1080/13573322.2015.1129942
- Cornect-Benoit, A., Pitawanakwat, K., Wiikwemkoong Unceded Territory Collaborating First Nation Community, Walker, J., Manitowabi, D., and Jacklin, K. (2020). Nurturing meaningful intergenerational social engagements to support healthy brain aging for Anishinaabe older adults: Nakaazang wenjishing naagdawendiwin, nji gechipiitzijig Anishnaabek. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, 39(2), 263–283. https://doi.org/10.1017/S0714980819000527
- Couzos, S., Smith, D., Stephens, M., Preston, R., Hendrie, D., Loller, H., Tremlett, M., Nugent, A., Vaughan, F., Crowther, S., Boyle, D., Buettner, P., and Biros, E. (2020). Integrating pharmacists into Aboriginal Community Controlled Health Services (IPAC project): Protocol for an interventional, non-randomised study to improve chronic disease outcomes. *Research in Social and Administrative Pharmacy*, *16*(10), 1431–1441. https://doi.org/10.1016/j.sapharm.2019.12.022
- Davies, J., Campbell, D., Campbell, M., Douglas, J., Hueneke, H., LaFlamme, M., Pearson, D., Preuss, K., Walker, J., and Walsh, F. (2011). Attention to four key principles can promote health outcomes from desert Aboriginal land management. *The Rangeland Journal*, 33(4), 417. https://doi.org/10.1071/RJ11031
- Davies, J., Hill, R., Walsh, F. J., Sandford, M., Smyth, D., and Holmes, M. C. (2013). Innovation in management plans for community conserved areas: Experiences from Australian Indigenous protected areas. *Ecology and Society*, 18(2), art14. https://doi.org/10.5751/ES-05404-180214
- Davies, J., Bukulatjpi, S., Sharma, S., Caldwell, L., Johnston, V., and Davis, J. S. (2015). Development of a culturally appropriate bilingual electronic app about Hepatitis B for Indigenous Australians: Towards shared understandings. *JMIR Research Protocols*, 4(2), e70. https://doi.org/10.2196/resprot.4216
- Dawson, J., Carter, N. A., van Luijk, N., Weber, M., and Cook, A. (2020). Arctic corridors and northern voices project: Methods for community-based participatory mapping for low impact shipping corridors in Arctic Canada. *MethodsX*, 7, 101064. https://doi.org/10.1016/j.mex.2020.101064
- Dieter, J., McKim, L. T., Tickell, J., Bourassa, C. A., Lavallee, J., and Boehme, G. (2018). The path of creating co-Researchers in the File Hills Qu'Appelle Tribal Council. *International Indigenous Policy Journal*, *9*(4). https://doi.org/10.18584/iipj.2018.9.4.1

- Dutton, T., Marjoram, J., Burgess, S., Montgomery, L., Vail, A., Callan, N., Jacob, S., Hawkes, D., Saville, M., and Bailey, J. (2020). Uptake and acceptability of human papillomavirus self-sampling in rural and remote aboriginal communities: Evaluation of a nurse-led community engagement model. *BMC Health Services Research*, 20(1), 398. https://doi.org/10.1186/s12913-020-05214-5
- Einsiedel, L. J., van Iersel, E., Macnamara, R., Spelman, T., Heffernan, M., Bray, L., Morris, H., Porter, B., and Davis, A. (2013). Self-discharge by adult Aboriginal patients at Alice Springs Hospital, Central Australia: Insights from a prospective cohort study. *Australian Health Review*, 37(2), 239. https://doi.org/10.1071/AH11087
- Elliott, D., Krawcyzk, M., Myran, A., and Rockthunder, R. (2015). Reimagining Aboriginality, addictions, and collaborative research in inner city Vancouver, Canada. *Creative Approaches to Research*, 8(1), 22-40, https://www.researchgate.net/profile/Marian-Krawczyk/publication/284644417\_
- Ens, E. J., Bentley-Toon, S., Campion, F., Campion, S., Kelly, J., and Towler, G. (2017). Rapid appraisal links feral buffalo with kunkod (Melaleuca spp.) decline in freshwater billabongs of tropical northern Australia. *Marine and Freshwater Research*, 68(9), 1642. https://doi.org/10.1071/MF16267
- Farrant, B. M., Shepherd, C. C. J., Michie, C., Scrine, C., Wright, M., Ilich, N., Jones, T., and Pearson, G. (2019). Delivering Elder- and community-led Aboriginal early childhood development research: Lessons from the Ngulluk Koolunga Ngulluk Koort project. *Children*, 6(10), 106. https://doi.org/10.3390/children6100106
- Firestone, M., Syrette, J., Jourdain, T., Recollet, V., and Smylie, J. (2019). "I feel safe just coming here because there are other Native brothers and sisters": Findings from a community-based evaluation of the Niiwin Wendaanimak Four Winds Wellness Program. *Canadian Journal of Public Health*, 110(4), 404–413. https://doi.org/10.17269/s41997-019-00192-6
- Fitts, M. S., Bird, K., Gilroy, J., Fleming, J., Clough, A. R., Esterman, A., Maruff, P., Fatima, Y., and Bohanna, I. (2019). A qualitative study on the transition support needs of Indigenous Australians following traumatic brain injury. *Brain Impairment*, 20(2), 137–159. https://doi.org/10.1017/BrImp.2019.24
- Flicker, S., Danforth, J. Y., Wilson, C., Oliver, V., Larkin, J., Restoule, J.-P., Mitchell, C., Konsmo, E., Jackson, R., and Prentice, T. (2014). "Because we have really unique art": Decolonizing research with Indigenous youth using the arts. *International Journal of Indigenous Health*, 10(1), 16–34. https://doi.org/10.18357/ijih.101201513271
- Flicker, S., Larkin, J., Smilie-Adjarkwa, C., Restoule, J.P., Barlow, K., Dagnino, M., Ricci, C., Koleszar-Green, R., and Mitchell, C. (2008). "It's hard to change something when you don't know where to start": Unpacking HIV vulnerability with Aboriginal youth in Canada. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 5(2), 175-200, https://journalindigenouswellbeing.co.nz/media/2018/10/9\_Flicker.pdf

- Ford, J. D., Bolton, K., Shirley, J., Pearce, T., Tremblay, M., and Westlake, M. (2012). Mapping human dimensions of climate change research in the Canadian Arctic. AMBIO, 41(8), 808–822. https://doi.org/10.1007/s13280-012-0336-8
- Ford, J. D., Sherman, M., Berrang-Ford, L., Llanos, A., Carcamo, C., Harper, S., Lwasa, S., Namanya, D., Marcello, T., Maillet, M., and Edge, V. (2018). Preparing for the health impacts of climate change in Indigenous communities: The role of community-based adaptation. *Global Environmental Change*, 49, 129–139. https://doi.org/10.1016/j.gloenvcha.2018.02.006
- Friendship, K.A. and Furgal., C.M. (2012) The role of Indigenous knowledge in environmental health risk management in Yukon, Canada. *International Journal of Circumpolar Health*, 71(1), 19003. <u>https://doi.org/10.3402/ijch.v71i0.19003</u>
- Gilroy, J., Dew, A., Lincoln, M., and Hines, M. (2017). Need for an Australian Indigenous disability workforce strategy: Review of the literature. *Disability and Rehabilitation*, 39(16), 1664–1673. https://doi.org/10.1080/09638288.2016.1201151
- Gomes, T., Leon, A. Y., and Brown, L. (2013). Indigenous health leadership: protocols, policy, and practice. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, *11*(3), 565-578.
- Gould, G. S., Watt, K., Stevenson, L., McEwen, A., Cadet-James, Y., and Clough, A. R. (2014). Developing anti-tobacco messages for Australian Aboriginal and Torres Strait Islander peoples: Evidence from a national cross-sectional survey. *BMC Public Health*, 14(1), 250. https://doi.org/10.1186/1471-2458-14-250
- Graeme, C. S., and Mandawe, E. (2017). Indigenous geographies: Research as reconciliation. *International Indigenous Policy Journal*, 8(2). https://doi.org/10.18584/iipj.2017.8.2.2
- Gwynn, J., Lock, M., Turner, N., Dennison, R., Coleman, C., Kelly, B., and Wiggers, J. (2015). Aboriginal and Torres Strait Islander community governance of health research: Turning principles into practice. *The Australian Journal of Rural Health*, 23(4), 235–242. https://doi.org/10.1111/ajr.12182
- Haag, H. (Lin), Biscardi, M., Pauktuutit Inuit Women of Canada, Smith, N. (Natalia), MacGregor, N., and Colantonio, A. (2019). Traumatic brain injury and intimate partner violence: Addressing knowledge and service gaps among indigenous populations in Canada. *Brain Impairment*, 20(2), 197–210. https://doi.org/10.1017/BrImp.2019.16
- Hammond, M., Rennie, C., and Dickson, J. (2007). Distance education for Inuit smoking counsellors in Canada: A case report. *International Journal of Circumpolar Health*, 66(4), 284–286. https://doi.org/10.1080/22423982.2018.12016713
- Hampton, M. R., McKay-McNabb, K., Jeffery, B., and McWatters, B. (2007). Building research partnerships to strengthen sexual health of Aboriginal youth in Canada. *The Australian Community Psychologist*, 19(1), 28-38,

- Hanson, C. (2018). Stitching together an arts-based inquiry with Indigenous communities in Canada and Chile. *The Canadian Journal for the Study of Adult Education*, *30*(2), 11-22, https://cjsae.library.dal.ca/index.php/cjsae/article/view/5458
- Harper, S. L., Edge, V. L., Cunsolo Willox, A. and Rigolet Inuit Community Government. (2012). 'Changing Climate, Changing Health, Changing Stories' profile: Using an EcoHealth approach to explore impacts of climate change on Inuit health. *EcoHealth*, 9(1), 89–101. https://doi.org/10.1007/s10393-012-0762-x
- Hatala, A. R., Morton, D., Njeze, C., Bird-Naytowhow, K., and Pearl, T. (2019). Re-imagining miyo-wicehtowin: Human-nature relations, land-making, and wellness among Indigenous youth in a Canadian urban context. *Social Science and Medicine*, 230, 122–130. https://doi.org/10.1016/j.socscimed.2019.04.012
- Haynes, E., Marawili, M., Marika, B. M., Mitchell, A. G., Phillips, J., Bessarab, D., Walker, R., Cook, J., and Ralph, A. P. (2019). Community-based participatory action research on rheumatic heart disease in an Australian Aboriginal homeland: Evaluation of the 'On track watch' project. *Evaluation and Program Planning*, 74, 38–53. https://doi.org/10.1016
- Hayward, M. N., Pace, R., Zaran, H., Dyck, R., Hanley, A. J., Green, M. E., Bhattacharyya, O., Zwarenstein, M., Emond, J., Benoit, C., Jebb, M. L., and Harris, S. B. (2020). Closing the indigenous health gap in Canada: Results from the transFORmation of IndiGEnous primAry HEAlthcare Delivery (FORGE AHEAD) program. *Diabetes Research and Clinical Practice*, 162, 108066. https://doi.org/10.1016/j.diabres.2020.108066
- Hayward, A., Wodtke, L., Craft, A., Robin, T., Smylie, J., McConkey, S., Nychuk, A., Healy, C., Star, L., and Cidro, J. (2021). Addressing the need for indigenous and decolonized quantitative research methods in Canada. SSM - Population Health, 15, 100899. https://doi.org/10.1016/j.ssmph.2021.100899
- Heard, T. R., McGill, K., Skehan, J., and Rose, B. (2022). The ripple effect, silence and powerlessness: Hidden barriers to discussing suicide in Australian Aboriginal communities. *BMC Psychology*, 10(1), 23. https://doi.org/10.1186/s40359-022-00724-9
- Henderson, R. I., Shea-Budgell, M., Healy, C., Letendre, A., Bill, L., Healy, B., Bednarczyk, R. A., Mrklas, K., Barnabe, C., Guichon, J., Bedingfield, N., MacDonald, S., Colquhoun, A., Glaze, S., Nash, T., Bell, C., Kellner, J., Richardson, R., Dixon, T., ... Nelson, G. (2018). First nations people's perspectives on barriers and supports for enhancing HPV vaccination: Foundations for sustainable, community-driven strategies. *Gynecologic Oncology*, *149*(1), 93–100. https://doi.org/10.1016/j.ygyno.2017.12.024
- Hickey, S., Couchman, K., Stapleton, H., Roe, Y., and Kildea, S. (2019). Experiences of health service providers establishing an Aboriginal-Mainstream partnership to improve maternity care for Aboriginal and Torres Strait Islander families in an urban setting. *Evaluation and Program Planning*, 77, 101705. https://doi.org/10.1016/j.evalprogplan.2019.101705

- Hickey, S., Roe, Y., Harvey, C., Kruske, S., Clifford-Motopi, A., Fisher, I., Bernardino, B., and Kildea, S. (2021). Community-based sexual and reproductive health promotion and services for First Nations people in urban Australia. *International Journal of Women's Health*, 13, 467–478. https://doi.org/10.2147/IJWH.S297479
- Hinton, R., Kavanagh, D. J., Barclay, L., Chenhall, R., and Nagel, T. (2015). Developing a best practice pathway to support improvements in Indigenous Australians' mental health and well-being: A qualitative study. *BMJ Open*, 5(8), e007938. https://doi.org/10.1136/bmjopen-2015-007938
- Hudson, G., and Maar, M. (2014). Faculty analysis of distributed medical education in Northern Canadian Aboriginal communities. *Rural and Remote Health*, *14*, 1-8, https://doi.org/10.22605/RRH2664
- Hudson, A., and Vodden, K. (2020). Decolonizing pathways to sustainability: Lessons learned from three Inuit communities in NunatuKavut, Canada. *Sustainability*, *12*(11), 4419. https://doi.org/10.3390/su12114419
- Irving, M., Gwynne, K., Angell, B., Tennant, M., and Blinkhorn, A. (2017). Client perspectives on an Aboriginal community led oral health service in rural Australia. *Australian Journal* of *Rural Health*, 25(3), 163–168. https://doi.org/10.1111/ajr.12307
- Isaak, C. A., Campeau, M., Katz, L. Y., Enns, M. W., Elias, B., Sareen, J., and Swampy Cree Suicide Prevention Team. (2010). Community-based suicide prevention research in remote on-reserve First Nations communities. *International Journal of Mental Health* and Addiction, 8(2), 258–270. https://doi.org/10.1007/s11469-009-9250-0
- Islam, D., and Berkes, F. (2016). Indigenous peoples' fisheries and food security: A case from northern Canada. *Food Security*, 8(4), 815–826. https://doi.org/10.1007/s12571-016-0594-6
- Isogai, A. D., McCarthy, D. D., D. Karagatzides, J., Vandenberg, S., Gardner, H., Edwards, V., Cowan, D., and Tsuji, L. J. S. (2012). The collaborative-geomatics informatics tool: Engaging youth using place-based education. *The International Journal of Technology*, *Knowledge, and Society*, 8(1), 131–142. https://doi.org/10.18848/1832-3669/CGP/v08i01/56269
- Jacklin, K., and Kinoshameg, P. (2008). Developing a participatory Aboriginal health research project: "Only if it's going to mean something." *Journal of Empirical Research on Human Research Ethics*, *3*(2), 53–67. https://doi.org/10.1525/jer.2008.3.2.53
- Jackson, E. L., and Coleman, J. (2015). Threading, stitching, and storytelling: Using CBPR and Blackfoot knowledge and cultural practices to improve domestic violence services for Indigenous women. *Journal of Indigenous Social Development*, 4(1), 1-27, <u>https://journalhosting.ucalgary.ca/index.php/jisd/article/view/58475</u>
- Kandasamy, S., Vanstone, M., Oremus, M., Hill, T., Wahi, G., Wilson, J., Davis, A. D., Jacobs, R., Anglin, R., and Anand, S. S. (2017). A case study of a methodological approach to

cocreating perinatal health knowledge between Western and Indigenous communities. *International Journal of Qualitative Methods*, *16*(1), 160940691769674. https://doi.org/10.1177/1609406917696742

- Kelley, M. L., Prince, H., Nadin, S., Brazil, K., Crow, M., Hanson, G., Maki, L., Monture, L., Mushquash, C. J., O'Brien, V., and Smith, J. (2018). Developing palliative care programs in Indigenous communities using participatory action research: A Canadian application of the public health approach to palliative care. *Annals of Palliative Medicine*, 7(S2), S52– S72. https://doi.org/10.21037/apm.2018.03.06
- Khayyat Kholghi, M., Bartlett, G., Phillips, M., Salsberg, J., McComber, A. M., and Macaulay, A. C. (2018). Evaluating an Indigenous health curriculum for diabetes prevention: Engaging the community through talking circles and knowledge translation of results. *Family Practice*, 35(1), 80–87. https://doi.org/10.1093/fampra/cmx068
- Kikkert, P., and Lackenbauer, P. W. (2021). "A great investment in our communities": Strengthening Nunavut's whole-of-society search and rescue capabilities. *ARCTIC*, 74(3), 258–275. https://doi.org/10.14430/arctic73099
- Kildea, S., Stapleton, H., Murphy, R., Low, N. B., and Gibbons, K. (2012). The Murri clinic: A comparative retrospective study of an antenatal clinic developed for Aboriginal and Torres Strait Islander women. *BMC Pregnancy and Childbirth*, 12(1), 159. https://doi.org/10.1186/1471-2393-12-159
- Kurtz, D. L. M., Turner, D., Nyberg, J., and Moar, D. (2014). Social justice and health equity: urban Aboriginal women's action for health reform. *The International Journal of Health, Wellness, and Society.* 3(4), 13-26,
- Kyoon-Achan, G., Lavoie, J., Avery Kinew, K., Phillips-Beck, W., Ibrahim, N., Sinclair, S., and Katz, A. (2018a). Innovating for transformation in First Nations health using communitybased participatory research. *Qualitative Health Research*, 28(7), 1036–1049. https://doi.org/10.1177/1049732318756056
- Kyoon-Achan, G., Philips-Beck, W., Lavoie, J., Eni, R., Sinclair, S., Avey Kinew, K., Ibrahim, N., and Katz, A. (2018b). Looking back, moving forward: A culture-based framework to promote mental wellbeing in Manitoba First Nations communities. *International Journal* of Culture and Mental Health, 11(4), 679–692. https://doi.org/10.1080/17542863.2018.1556714
- Kyoon Achan, G., Eni, R., Kinew, K. A., Phillips-Beck, W., Lavoie, J. G., and Katz, A. (2021a). The two great healing traditions: Issues, opportunities, and recommendations for an integrated First Nations healthcare system in Canada. *Health Systems and Reform*, 7(1), e1943814. <u>https://doi.org/10.1080/23288604.2021.1943814</u>
- Kyoon-Achan, G., Kinew, K.A., Phillips-Beck, W., Lavoie, Josée., and Katz, A. (2021b). Collaborative and systems approach to transforming primary health care in Manitoba First Nations communities. *International Journal of Indigenous Health*, *16*(1). https://doi.org/10.32799/ijih.v16i1.33207

- Kyoon-Achan, G., Schroth, R., DeMaré, D., Sturym, M., Sanguins, J., Chartrand, F., Campbell, R., Edwards, J., Lavoie, J., and Moffatt, M. (2021c). Healthy Smile, Happy Child: Partnering with Manitoba First Nations and Metis communities for better early childhood oral health. *AlterNative: An International Journal of Indigenous Peoples*, *17*(2), 265–274. https://doi.org/10.1177/11771801211016873
- Lambert, M., Luke, J., Downey, B., Crengle, S., Kelaher, M., Reid, S., and Smylie, J. (2014). Health literacy: Health professionals' understandings and their perceptions of barriers that Indigenous patients encounter. *BMC Health Services Research*, 14(1), 614. https://doi.org/10.1186/s12913-014-0614-1
- Latimer, M., Rudderham, S., Lethbridge, L., MacLeod, E., Harman, K., Sylliboy, J. R., Filiaggi, C., and Finley, G. A. (2018). Occurrence of and referral to specialists for pain-related diagnoses in First Nations and non–First Nations children and youth. *Canadian Medical Association Journal*, 190(49), E1434–E1440. https://doi.org/10.1503/cmaj.180198
- Lavalley, J., Western Aboriginal Harm Reduction Society, Livingstone, C., Steinhauer, M., Goodman, A., and Kerr, T. (2021). "I Used to be Scared to Even Like Stand Beside Somebody Who Had It": HIV risk behaviours and perceptions among Indigenous people who use drugs. *The International Indigenous Policy Journal*, 12(3), 1–21. https://doi.org/10.18584/iipj.2021.12.3.10878
- Lavalley, J., Kastor, S., Tourangeau, M., Western Aboriginal Harm Reduction Society, Goodman, A., and Kerr, T. (2020). You just have to have other models, our DNA is different: The experiences of Indigenous people who use illicit drugs and/or alcohol accessing substance use treatment. *Harm Reduction Journal*, 17(1), 19. https://doi.org/10.1186/s12954-020-00366-3
- Leckning, B., Hirvonen, T., Armstrong, G., Carey, T. A., Westby, M., Ringbauer, A., and Robinson, G. (2020). Developing best practice guidelines for the psychosocial assessment of Aboriginal and Torres Strait Islander people presenting to hospital with self-harm and suicidal thoughts. *Australian and New Zealand Journal of Psychiatry*, 54(9), 874–882. https://doi.org/10.1177/0004867420924082
- Lewis, D., Castleden, H., Francis, S., Strickland, K., and Denny, C. (2016). Increasing response rates on race-to-race surveys with Indigenous communities in Canada: Lessons from Pictou Landing. *Progress in Community Health Partnerships: Research, Education, and Action, 10*(2), 197–205. https://doi.org/10.1353/cpr.2016.0021
- Lickers, M., (2017). Giving voice to First Nation youth leadership. *The Canadian Journal of native Studies*, *37*(1), 65-93. https://www.proquest.com/docview/2250519824
- Lopresti, S., Willows, N. D., Storey, K. E., McHugh, T.-L. F., and IYMP National Team. (2022). Indigenous Youth Mentorship Program: Essential characteristics of a Canadian multi-site community-university partnership with Indigenous communities. *Health Promotion International*, 37(1), daab039. https://doi.org/10.1093/heapro/daab039

- Lucier, K. J., Schuster-Wallace, C. J., Skead, D., Skead, K., and Dickson-Anderson, S. E. (2020). "Is there anything good about a water advisory?": An exploration of the consequences of drinking water advisories in an indigenous community. *BMC Public Health*, 20(1), 1704. https://doi.org/10.1186/s12889-020-09825-9
- Lukaszyk, C., Coombes, J., Sherrington, C., Tiedemann, A., Keay, L., Mackean, T., Clemson, L., Cumming, R., Broe T., Ivers, R. (2017). The Ironbark program: Implementation and impact of a community-based fall prevention pilot program for older Aboriginal and Torres Strait Islander people. *Health Promotion Journal of Australia, 29*, 189-198, https://onlinelibrary.wiley.com/doi/full/10.1002/hpja.25
- Maar, M. A., Beaudin, V., Yeates, K., Boesch, L., Liu, P., Madjedi, K., Perkins, N., Hua-Stewart, D., Beaudin, F., Wabano, M. J., and Tobe, S. W. (2019). Wise Practices for cultural safety in electronic health Research and clinical trials with Indigenous people: Secondary analysis of a randomized clinical trial. *Journal of Medical Internet Research*, 21(11), e14203. https://doi.org/10.2196/14203
- Maina, G., Mclean, M., Mcharo, S., Kennedy, M., Djiometio, J., and King, A. (2020). A scoping review of school-based indigenous substance use prevention in preteens (7–13 years). *Substance Abuse Treatment, Prevention, and Policy*, 15(1), 74. https://doi.org/10.1186/s13011-020-00314-1
- Mayo, K., Tsey, K., and the Empowerment Research Team. (2009). The research dance: University and community research collaborations at Yarrabah, North Queensland, Australia. *Health and Social Care in the Community*, 17(2), 133–140. https://doi.org/10.1111/j.1365-2524.2008.00805.x
- McCalman, J., Bainbridge, R., James, Y. C., Bailie, R., Tsey, K., Matthews, V., Ungar, M., Askew, D., Fagan, R., Visser, H., Spurling, G., Percival, N., Blignault, I., and Doran, C. (2020). Systems integration to promote the mental health of Aboriginal and Torres Strait Islander children: Protocol for a community-driven continuous quality improvement approach. *BMC Public Health*, 20(1), 1810. https://doi.org/10.1186/s12889-020-09885-x
- McDermott, R. A., Schmidt, B., Preece, C., Owens, V., Taylor, S., Li, M., and Esterman, A. (2015). Community health workers improve diabetes care in remote Australian Indigenous communities: Results of a pragmatic cluster randomized controlled trial. *BMC Health Services Research*, 15(1), 68. https://doi.org/10.1186/s12913-015-0695-5
- McElhaney, J. E., Helmer, J., Briggs, M. C., Andrew, M. K., McGilton, K. S., Moeke-Pickering, T., Jackson Pulver, L., and McKenna, E. B. (2021). Developer/Adapter Method: A community-based approach to improve health in Indigenous communities. *International Journal of Indigenous Health*, 16(2). https://doi.org/10.32799/ijih.v16i2.33082
- Morton Ninomiya, M. E., Hurley, N., and Penashue, J. (2020). A decolonizing method of inquiry: Using institutional ethnography to facilitate community-based research and knowledge translation. *Critical Public Health*, 30(2), 220–231. https://doi.org/10.1080/09581596.2018.1541228

- Munro, A., Allan, J., Shakeshaft, A., Snijder, M. (2017). Riding the rural radio wave: The impact of a community-led drug and alcohol radio advertising campaign in a remote Australian Aboriginal community. *Aust. J. Rural Health*, 25, 290–297. https://onlinelibrary.wiley.com/doi/full/10.1111/ajr.12345
- Murphy, K., Branje, K., White, T., Cunsolo, A., Latimer, M., McMillan, J., Sylliboy, J. R., McKibbon, S., and Martin, D. (2021). Are we walking the talk of participatory Indigenous health research? A scoping review of the literature in Atlantic Canada. *PLOS ONE*, 16(7), e0255265. https://doi.org/10.1371/journal.pone.0255265
- Murray, M., Bonnell, E., Thorpe, S., Browne, J., Barbour, L., MacDonald, C., and Palermo, C. (2014). Sharing the tracks to good tucker: Identifying the benefits and challenges of implementing community food programs for Aboriginal communities in Victoria. *Australian Journal of Primary Health*, 20(4), 373. https://doi.org/10.1071/PY14038
- Nadin, S., Crow, M., Prince, H., Kelley, M. L. (2018). Wiisokotaatiwin: development and evaluation of a community-based palliative care program in Naotkamegwanning First Nation. *Rural and Remote Health.* 18 (2). https://doi.org/10.22605 /RRH4317
- Nagy, R., Snooks, G., Quenneville, B., Chen, L., Wiggins, S., Debassige, D., Joudin, K., and Timms, R. (2020). Human trafficking in northeastern Ontario: Collaborative responses. *First Peoples Child and Family Review*, 15(1), 80–104. https://doi.org/10.7202/1068364ar
- Nasir, F. B., Brennan-Olsen, S., Gill, N. S., Beccaria, G., Kisely, S., Hides, L., Kondalsamy-Chennakesavan, S., Nicholson, G., and Toombs, M. (2021). A community-led design for an Indigenous Model of Mental Health Care for Indigenous people with depressive disorders. *Australian and New Zealand Journal of Public Health*, 45(4), 330–337. https://doi.org/10.1111/1753-6405.13115
- Neufeld, H. T., Richmond, C., and The Southwest Ontario Aboriginal Health Access Centre. (2020). Exploring First Nation Elder women's relationships with food from social, ecological, and historical perspectives. *Current Developments in Nutrition*, 4(3), nzaa011. https://doi.org/10.1093/cdn/nzaa011
- Ogenchuk, M., St. Pierre, R., Uswak, G., Graham, H., Weiler, R., and Ramsden, V. R. (2021). Community led: Celebrating wellness with a smile. *International Journal of Circumpolar Health*, 80(1), 1962023. https://doi.org/10.1080/22423982.2021.1962023
- Ogenchuk, M., Graham, J., Uswak, G., Graham, H., Weiler, R., and Ramsden, V. R. (2022). Pediatric oral health: Community-based participatory research. *BMC Pediatrics*, 22(1), 93. https://doi.org/10.1186/s12887-022-03153-0
- Oster, R. T., Bruno, G., Montour, M., Roasting, M., Lightning, R., Rain, P., Graham, B., Mayan, M. J., Toth, E. L., and Bell, R. C. (2016). Kikiskawâwasow - prenatal healthcare provider perceptions of effective care for First Nations women: An ethnographic communitybased participatory research study. *BMC Pregnancy and Childbirth*, 16(1), 216. https://doi.org/10.1186/s12884-016-1013-x

- Parlee, B., Huntington, H., Berkes, F., Lantz, T., Andrew, L., Tsannie, J., Reece, C., Porter, C., Nicholson, V., Peter, S., Simmons, D., Michell, H., Lepine, M., Maclean, B., Ahkimnachie, K., King, L. J., Napoleon, A., Hogan, J., Lam, J., Howlett, T. (2021). One-Size Does Not Fit All—A Networked Approach to Community-Based Monitoring in Large River Basins. *Sustainability*, *13*(13), 7400. https://doi.org/10.3390/su13137400
- Patel, J., Durey, A., Naoum, S., Kruger, E., and Slack-Smith, L. (2022). Oral health education and prevention strategies among remote Aboriginal communities: A qualitative study. *Australian Dental Journal*, 67(1), 83–93. <u>https://doi.org/10.1111/adj.12890</u>
- Plagányi, É. E., Murphy, N., Skewes, T., Dutra, L. X. C., Dowling, N., and Fischer, M. (2020). Development of a data-poor harvest strategy for a sea cucumber fishery. *Fisheries Research*, 230, 105635. https://doi.org/10.1016/j.fishres.2020.105635
- Prince, H., Nadin, S., Crow, M., Maki, L., Monture, L., Smith, J., and Kelley, M. L. (2019). "If you understand you cope better with it": The role of education in building palliative care capacity in four First Nations communities in Canada. *BMC Public Health*, 19(1), 768. https://doi.org/10.1186/s12889-019-6983-y
- Richardson, M., Big Eagle, T., and Waters, S. F. (2022). A systematic review of trauma intervention adaptations for indigenous caregivers and children: Insights and implications for reciprocal collaboration. *Psychological Trauma: Theory, Research, Practice, and Policy, 14*(6), 972–982. https://doi.org/10.1037/tra0001225
- Ritchie, S. D., Wabano, M. J., Corbiere, R. G., Restoule, B. M., Russell, K. C., and Young, N. L. (2015). Connecting to the Good Life through outdoor adventure leadership experiences designed for Indigenous youth. *Journal of Adventure Education and Outdoor Learning*, 15(4), 350–370. https://doi.org/10.1080/14729679.2015.1036455
- Ritchie, S. D., Jo Wabano, M., Beardy, J., Curran, J., Orkin, A., VanderBurgh, D., and Young, N. L. (2013). Community-based participatory research with Indigenous communities: The proximity paradox. *Health and Place*, 24, 183–189. https://doi.org/10.1016/j.healthplace.2013.09.008
- Rix, E. F., Barclay, L., Stirling, J., Tong, A., and Wilson, S. (2014). "Beats the alternative but it messes up your life": Aboriginal people's experience of haemodialysis in rural Australia. *BMJ Open*, 4(9), e005945–e005945. https://doi.org/10.1136/bmjopen-2014-005945
- Rizkalla, K., Maar, M., Pilon, R., McGregor, L., and Reade, M. (2020). Improving the response of primary care providers to rural First Nation women who experience intimate partner violence: a qualitative study. *BMC Women's Health*, 20(1), 209. https://doi.org/10.1186/s12905-020-01053-y
- Rogers, A., Ferguson, M., Ritchie, J., Van Den Boogaard, C., and Brimblecombe, J. (2018). Strengthening food systems with remote Indigenous Australians: Stakeholders' perspectives. *Health Promotion International*, 33(1), 38-48. https://doi.org/10.1093/heapro/daw047

- Romain, S. J., Kohler, J. C., and Young, K. (2015). Policy versus practice: A community-based qualitative study of the realities of pharmacy services in Nunavut, Canada. Journal of *Pharmaceutical Policy and Practice*, 8(1), 22. https://doi.org/10.1186/s40545-015-0043-5
- Rowley, K., Doyle, J., Johnston, L., Reilly, R., McCarthy, L., Marika, M., Riley, T., Atkinson, P., Firebrace, B., Calleja, J., and Cargo, M. (2015). Strengths and limitations of a tool for monitoring and evaluating First Peoples' health promotion from an ecological perspective. *BMC Public Health*, 15(1), 1215. https://doi.org/10.1186/s12889-015-2550-3
- IHACC Research Team, Saini, M., Roche, S., Papadopoulos, A., Markwick, N., Shiwak, I., Flowers, C., Wood, M., Edge, V. L., Ford, J., Rigolet Inuit Community Government, Nunatsiavut Government, IHACC Research Team, Wright, C., and Harper, S. L. (2020). Promoting Inuit health through a participatory whiteboard video. *Canadian Journal of Public Health*, 111(1), 50–59. <u>https://doi.org/10.17269/s41997-019-00189-1</u>
- Sanderson, A., Ranville, F., Gurney, L., Borden, B., Pooyak, S., Shannon, K., and Krüsi, A. (2021). Indigenous women voicing experiences of HIV stigma and criminalization through art. *International Journal of Indigenous Health*, 16(2). https://doi.org/10.32799/ijih.v16i2.33903
- Sarin, J., Hunt, J., Ivers, R., and Smyth, C. (2015). Lifting the burden: A coordinated approach to action on Aboriginal tobacco resistance and control in NSW. *Public Health Research and Practice*, 25(3). https://doi.org/10.17061/phrp2531528
- Sawatzky, A. (2018). "The best scientists are the people that's out there": Inuit-led integrated surveillance for place-based health adaptation to climate change [Doctoral dissertation]. University of Guelph.
- Schmidt, B., Wenitong, M., Esterman, A., Hoy, W., Segal, L., Taylor, S., Preece, C., Sticpewich, A., and McDermott, R. (2012). Getting better at chronic care in remote communities:
  Study protocol for a pragmatic cluster randomised controlled of community based management. *BMC Public Health*, 12(1), 1017. https://doi.org/10.1186/1471-2458-12-1017
- Shea, J. M., Poudrier, J., Thomas, R., Jeffery, B., and Kiskotagan, L. (2013). Reflections from a creative community-based participatory research project exploring health and body image with First Nations girls. *International Journal of Qualitative Methods*, 12(1), 272–293. https://doi.org/10.1177/160940691301200113
- Simms, R., Harris, L., Joe, N., and Bakker, K. (2016). Navigating the tensions in collaborative watershed governance: Water governance and Indigenous communities in British Columbia, Canada. *Geoforum*, 73, 6–16. https://doi.org/10.1016/j.geoforum.2016.04.005
- Simpson, S., Eadie, T., Khoo, S. T., Titmuss, A., Maple-Brown, L. J., Thompson, R., Wunungmurra, A., Jeyaseelan, D., Dunham, M., and D'Aprano, A. (2021). The ASQ-TRAK: Validating a culturally adapted developmental screening tool for Australian

Aboriginal children. *Early Human Development, 163*, 105481. https://doi.org/10.1016/j.earlhumdev.2021.105481

- Smith, R. L., Devine, S., and Preston, R. (2020). Recommended methodologies to determine Australian Indigenous community members' perceptions of their health needs: A literature review. Australian Journal of Primary Health, 26(2), 95. https://doi.org/10.1071/PY19078
- Steenkamp, M., Rumbold, A. R., Kildea, S., Bar-Zeev S. J., Kruske, S., Dunbar, T., Barclay, L. (2012). Measuring what matters in delivering services to remote-dwelling Indigenous mothers and infants in the Northern Territory, Australia. Aust. J. *Rural Health*, 20, 228– 237, https://onlinelibrary.wiley.com/doi/full/10.1111/j.1440-1584.2012.01279.x
- Sushames, A., Engelberg, T., and Gebel, K. (2017). Perceived barriers and enablers to participation in a community-tailored physical activity program with Indigenous Australians in a regional and rural setting: A qualitative study. *International Journal for Equity in Health*, *16*(1), 172. https://doi.org/10.1186/s12939-017-0664-1
- Taniguchi, N. K., Taualii, M., and Maddock, J. (2012). A comparative analysis of Indigenous research guidelines to inform genomic research in Indigenous communities. *International Indigenous Policy Journal*, 3(1). https://doi.org/10.18584/iipj.2012.3.1.6
- Tran, T. C., Neasloss, D., Kitasoo/Xai'xais Stewardship Authority, Bhattacharyya, J., and Ban,
   N. C. (2020). "Borders don't protect areas, people do": Insights from the development of an Indigenous Protected and Conserved Area in Kitasoo/Xai'xais Nation Territory. *FACETS*, 5(1), 922–941. https://doi.org/10.1139/facets-2020-0041
- Tremblay, M.-C., Martin, D. H., McComber, A. M., McGregor, A., and Macaulay, A. C. (2018). Understanding community-based participatory research through a social movement framework: A case study of the Kahnawake Schools Diabetes Prevention Project. *BMC Public Health*, 18(1), 487. https://doi.org/10.1186/s12889-018-5412-y
- Turner, J., Holyk, T., Bartlett, K., Rathburn, B., Karlen, B., Ervin, F., Wilson, J., and Camp, P. G. (2020). "Bayis Ilh Tus a strong breath" a community-based research project to estimate the prevalence of chronic obstructive pulmonary disease in remote and rural First Nations communities in Canada: Research protocol. *International Journal for Equity in Health*, 19(1), 123. https://doi.org/10.1186/s12939-020-01240-1
- VanderBurgh, D., Jamieson, R., Beardy, J., Ritchie, S., and Orkin, A. (2014). Community-based first aid: A program report on the intersection of community-based participatory research and first aid education in a remote Canadian Aboriginal community. *Rural and Remote Health.* 1-8, https://doi.org/10.22605/RRH2537
- Van Wagner, V., Osepchook, C., Harney, E., Crosbie, C., and Tulugak, M. (2012). Remote midwifery in Nunavik, Québec, Canada: outcomes of perinatal care for the Inuulitsivik Health Centre, 2000-2007. *Birth*, 39(3), 230–237. https://doi.org/10.1111/j.1523-536X.2012.00552.x

- Vaughan, L., Schubert, L., Mavoa, H., and Fa'avale, N. (2018). 'Hey, we are the best ones at dealing with our own': embedding a culturally competent program for Māori and Pacific Island children into a mainstream health service in Queensland, Australia. *Journal of Racial and Ethnic Health Disparities*, 5(3), 605–616. https://doi.org/10.1007/s40615-017-0406-5
- Watson, R., Castleden, H., Tui'kn Partnership, Masuda, J., King, M., and Stewart, M. (2012). Identifying gaps in asthma education, health promotion, and social support for Mi'kmaq families in Unama'ki (Cape Breton), Nova Scotia, Canada. *Preventing Chronic Disease*, 9, 120039. https://doi.org/10.5888/pcd9.120039
- Wendt, D. C., Hartmann, W. E., Allen, J., Burack, J. A., Charles, B., D'Amico, E. J., Dell, C. A., Dickerson, D. L., Donovan, D. M., Gone, J. P., O'Connor, R. M., Radin, S. M., Rasmus, S. M., Venner, K. L., and Walls, M. L. (2019). Substance use research with Indigenous communities: exploring and extending foundational principles of community psychology. *American Journal of Community Psychology*, *64*(1–2), 146–158. https://doi.org/10.1002/ajcp.12363
- West, M. (2020). Foot health of Aboriginal and Torres Strait Islander Peoples in regional and rural NSW, Australia. *Journal of Foot and Ankle Research*. *13*(27), 2-7, https://jfootankleres.biomedcentral.com/articles/10.1186/s13047-020-00397-w
- Woodward, E., and Marrfurra McTaggart, P. (2016). Transforming cross-cultural water research through trust, participation and place. *Geographical Research*, *54*(2), 129–142. https://doi.org/10.1111/1745-5871.12136
- Wray, K., Soukhaphon, A., Parlee, B., D'Souza, A., Freitas, C., Heredia, I., Martin, C., Oloriz, C., Proverbs, T., and Spicer, N. (2020). Aligning intentions with community: graduate students reflect on collaborative methodologies with Indigenous research partners. *Sustainability*, 12(18), 7534. https://doi.org/10.3390/su12187534
- Young, N., Wabano, M. J., Blight, S., Baker-Anderson, K., Beaudin, R., McGregor, L., McGregor, L., and Burke, T. (2017). Relevance of the Aboriginal children's health and well-being measure beyond wiikwemkoong. *Rural and Remote Health*, 17(2). https://doi.org/10.22605/RRH3941
- Young, N. L., Wabano, M. J., Jacko, D., and Barbic, S. P. (2018). Community-based screening and triage versus standard referral of Aboriginal children: A prospective cohort study protocol. *International Journal of Indigenous Health*, 13(1), https://jps.library.utoronto.ca/index.php/ijih/article/view/30282
- Ziabakhsh, S., Pederson, A., Prodan-Bhalla, N., Middagh, D., and Jinkerson-Brass, S. (2016). Women-centered and culturally responsive heart health promotion among Indigenous women in Canada. *Health Promotion Practice*, 17(6), 814–826. <u>https://doi.org/10.1177/1524839916633238</u>

## **Grey Literature Scoping Review Sources**

- Australian Government. (2010). Community involvement in *National Indigenous infrastructure guide* (p. 17-44). <u>https://static1.squarespace.com/static/5450868fe4b09b217330bb42/t/55879da8e4b062bc</u> 4c659db3/1434951080238/02-A1-community-involvement.pdf
- BC Aboriginal Child Care Society. (2019). A guide to community engagement and planning. <u>http://www.acc-society.bc.ca/wp-</u> <u>content/uploads/2019/12/CLDP\_Planning\_Guide\_v7.pdf</u>
- Calliou, B., and Wesley-Esquimaux, C. (2010). *Best practices in Aboriginal community development: A Wise Practices approach.* The Banff Centre, Indigenous LEadership and Management. <u>https://communities4families.ca/wp-content/uploads/2014/08/Aboriginal-</u> <u>Community-Development.pdf</u>
- The Canadian Aboriginal AIDS Network (CAAN). (n.d.). Assessing community readiness and implementing risk reduction strategies. <u>https://web.archive.org/web/20210301215645/http://caan.ca/wp-content/uploads/2012/05/CR-manual-eng.pdf</u>
- Chung-Tiam-Fook, T. (2022). *Civic-Indigenous placekeeping and partnership building toolkit*. Future Cities Canada. <u>https://futurecitiescanada.ca/portal/wp-</u> <u>content/uploads/sites/2/2022/02/fcc-civic-indigenous-toolkit-final-2022.pdf</u>
- First Nations Information Governance Centre (FNIGC). (March 2007). *First Nations Regional Longitudinal Health Survey (RHS) 2002\03: The people's report.* <u>https://fnigc.ca/wp-content/uploads/2020/09/0bc75bb9e0f03ebc28116a605432f73b\_rhs2002-03-the\_peoples\_report\_afn.pdf</u>
- First Nations Information Governance Centre (FNIGC). (2018). National report of the First Nations Regional Health Survey phase 3: Volume one. <u>https://fnigc.ca/wp-</u> <u>content/uploads/2020/09/713c8fd606a8eeb021debc927332938d\_FNIGC-RHS-Phase-III-</u> <u>Report1-FINAL-VERSION-Dec.2018.pdf</u>
- First Nations Information Governance Centre (FNIGC). (2020). Strengths-based approaches to Indigenous research and the development of well-being indicators. <u>https://fnigc.ca/wp-content/uploads/2021/05/FNIGC-Research-Series-SBA\_v04.pdf</u>
- Geddes, B. (2015). *Measuring wellness: An indicator development guide for First Nations*. <u>https://static1.squarespace.com/static/558c624de4b0574c94d62a61/t/574de5d7ab48de9a7</u> <u>db592da/1464722919928/BCFNDGI\_-\_INDICATOR\_DEVELOPMENT\_GUIDE.PDF</u>
- Gibson, G. (2017). Culture and rights impact assessment: A survey of the field. The Firelight Group. <u>https://firelight.ca/wp-content/uploads/2016/03/MCFN-303\_MAPP-Report\_Final.pdf</u>

- Gibson, G., Hoogeveen, D., MacDonald, A., and The Firelight Group. (2018). Impact assessment in the Arctic: Emerging practices of Indigenous-led review. Gwich'in Council International. <u>https://gwichincouncil.com/sites/default/files/Firelight%20Gwich%27in%20Indigenous%</u> 20led%20review\_FINAL\_web\_0.pdf
- Hughes, J., and Shmon, K. (2005). *Needs assessment guide for Métis communities*. National Aboriginal Health Organization - Métis Centre. <u>https://web.archive.org/web/20171003154544/http://www.naho.ca/documents/metiscentr</u> <u>e/english/MCNeedsAssesmentGuideforMetisCommunitiesFINAL\_June\_07.pdf</u>
- Indigenous Services Canada. (2018). CCP Handbook: Comprehensive Community Planning for First Nations Handbook (4th edition). <u>https://www.sacisc.gc.ca/eng/1377629855838/1613741744194#wha</u>
- Nishnawbe Aski Development Fund (NADF). (2017). Comprehensive community planning toolkit: Finding bimadizowin. <u>http://www.nadf.org/upload/documents/ccp-toolkit-2018-v2.pdf</u>
- Pikangikum First Nation and Beringia Community Planning Inc. (2013). Working it out together: Pikangikum First Nation's community health needs assessment. <u>https://www.cip-icu.ca/Files/Awards/Planning-Excellence/Working-it-out-together-Pikangikum-First-Nation-en.aspx</u>
- Plested, B.A., Jumper-Thurman, P., and Edwards, R.W (2016, March). *Community Readiness Manual*, The National Center for Community Readiness, Colorado State University, Fort Collins, Colorado.
- Salerno, T., Tam, J. Page, J., Gosling, S., and Firelight Research Inc. (2021). Indigenous mental wellness and major project development: Guidance for impact assessment professionals and Indigenous communities. Impact Assessment Agency of Canada. <u>https://www.canada.ca/content/dam/iaac-acei/documents/research/indigenous-mentalwellness-and-ia-en.pdf</u>
- Siyám, S. and Raphael, L. (2022). Step into the river: A framework for economic reconciliation for municipalities, institutions and industry partners. Simon Fraser University Community Economic Development. <u>http://www.sfu.ca/content/sfu/ced/economic-</u> reconciliation/framework-for-economic-reconciliation/frameworkfulldownload/\_jcr\_content/main\_content/download\_256542266/file.res/Step%20into%20 the%20River%20Economic%20Reconciliation%20FULL%20DOCUMENT.pdf

## **Additional References**

- Armat, M. R., Assarroudi, A., Sharifi, H., and Heydari, A. (2018). Inductive and deductive: Ambiguous labels in qualitative content analysis. *The Qualitative Report* 23(1), 219-221. Retrieved from <u>http://nsuworks.nova.edu/tqr/vol23/iss1/16</u>
- Aslam, M., Ogunnaike-Cooke, S., Boulos, D., and Archibald, C. P. (2010). Establishing a sentinel surveillance system for HIV-associated risk behaviours among Aboriginal populations in Canada. *Circumpolar Health Supplements*, 7.
- Australian Bureau of Statistics. (2021). *Estimates of Aboriginal and Torres Strait Islander Australians*. Retrieved November 21, 2022, from https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islanderpeoples/estimates-aboriginal-and-torres-strait-islander-australians/latest-release
- Bartlett, C., Marshall, M., and Marshall, A. (2012). Two-Eyed Seeing and other lessons learned within a co-learning journey of bringing together Indigenous and mainstream knowledges and ways of knowing. *Journal of Environmental Studies and Sciences*, 2, 331-340. DOI 10.1007/s13412-012-0086-8
- Biesbroek, R., Berrang-Ford, L., Ford, J. D., Tanabe, A., Austin, S. E., and Lesnikowski, A. (2018). Data, concepts and methods for large-*n* comparative climate change adaptation policy research: A systematic literature review. *Climate Change*, 9, e548. <u>https://doi.org/10.1002/wcc.548</u>
- Centre for Indigenous Environmental Resources (CIER). (2009). *Climate risks and adaptive capacity in Aboriginal communities: Final Report. An Assessment south of 60 degrees latitude*. Centre for Indigenous Environmental Resources. Retrieved from <a href="https://www.cakex.org/sites/default/files/documents/climate\_risks\_and\_adaptive\_capacity\_in\_aboriginal\_communities-2.pdf">https://www.cakex.org/sites/default/files/documents/climate\_risks\_and\_adaptive\_capacity\_in\_aboriginal\_communities-2.pdf</a>
- Clark, M. J., Cary, S., Diemert, G., Ceballos, R., Sifuentes, M., Atteberry, I., Vue, F., and Trieu, S. (2003). Involve communities in community assessment. *Public Health Nursing*, 20(6), 456-463. <u>https://doi.org/10.9741/23736658.1023</u>
- Dumont, J. (2005). First Nations Regional Longitudinal Health Survey (RHS) Cultural Framework. <u>https://fnigc.ca/wp-content/uploads/2020/09/rhs\_cultural\_framework.pdf</u>
- Ermine, W., Sinclair, R., and Jeffrey, B. (2004). The ethics of research involving Indigenous Peoples: Report of the Indigenous People's health research centre to the Interagency Advisory Panel on research ethics. *Indigenous Peoples' Health Research Centre*. DOI: 10.13140/RG.2.2.23069.31200
- First Nations Development Institute. (2014). Conducting food sovereignty assessments in native communities: On-the-ground perspectives. First Nations Development Institute. Retrieved from <u>https://www.firstnations.org/wp-</u> <u>content/uploads/2018/12/On\_Ground\_Perspectives.pdf</u>

First Nations Information Governance Centre (FNIGC). (2005). First Nations Regional Longitudinal Health Survey (RHS) 2002\03: Results for adults, youth and children living in First Nations communities. <u>https://fnigc.ca/wp-</u> content/uploads/2020/09/6d630af33e986fb89b6f89895e540513\_rhs2002-03technical\_report.pdf

- First Nations Information Governance Centre (FNIGC). (2007) First Nations Regional Longitudinal Health Survey (RHS): Code of research ethics. <u>https://uploads-</u> <u>ssl.webflow.com/5b786757ee914c5f85ba8959/5b7f155e224aeb337334c6ce\_4\_rhs-code-</u> <u>of-research-ethics-2007.pdf</u>
- First Nations Information Governance Centre (FNIGC). (2016). Pathways to First Nations' data and information sovereignty. In T. Kukutai and J. Taylor (Eds.), *Indigenous data Sovereignty: Toward an agenda* (p. 139-155). Australian National University Press. <u>https://library.oapen.org/bitstream/handle/20.500.12657/31875/1/624262.pdf</u>
- First Nations Information Governance Centre. (2023). *The First Nations Principles of OCAP*. The First Nations Information Governance Centre. Retrieved March 6, 2023 from <u>https://fnigc.ca/ocap-</u> <u>training/#:~:text=OCAP%C2%AE%20is%20an%20expression,Nations%E2%80%94not</u>

%20Indigenous%E2%80%94principles.

First Nations Information Governance Centre Regional Health Survey Materials:

Adult questionnaire. (2008, May). FNIGC. <u>https://fnigc.ca/wp-</u> content/uploads/2020/06/First-Nations-Regional-Health-Survey-Core-Questionnaire-Community-Survey.pdf

- Youth questionnaire. (n.d.). FNIGC. <u>https://fnigc.ca/wp-</u> content/uploads/2020/09/11fb67464a61cd87b760eccf5da742e4\_RHS-Youth-Phase-3\_Final.pdf
- *Child questionnaire*. (n.d.). FNIGC. <u>https://fnigc.ca/wp-content/uploads/2020/09/RHS-Child-Phase-3\_Final.pdf</u>

The First Nations regional health survey. (n.d.). FNIGC. <u>https://fnigc.ca/wp-content/uploads/2020/09/fnigc\_rhs-brochure-questions\_finalproof.pdf</u>

Foley, D. (2006). Indigenous standpoint theory: An acceptable academic research process for Indigenous academics. *International Journal of the Humanities*, 3(8), 25-36. DOI:10.18848/1447-9508/CGP/v03i08/41775

Gibson, G. (2017). *Culture and rights impact assessment: A survey of the field*. The Firelight Group for Mikisew Cree First Nation. Retrieved from <u>https://liveworkwell.ca/sites/default/files/pageuploads/Culture%20and%20Rights%20Im</u> <u>pact%20Assessment.pdf</u>

Godin, K., Stapleton, J., Kirkpatrick, S. I., Hanning, R. M., and Leatherdale, S. T. (2015).
 Applying systematic review search methods to the grey literature: a case study examining guidelines for school-based breakfast programs in Canada. *Systematic Reviews*, 4(1), 138–138. <u>https://doi.org/10.1186/s13643-015-0125-0</u>

- Indigenous Services Canada. (2020, November 3). Annual Report to Parliament 2020. Government of Canada. Retrieved November 21, 2022, from <u>https://www.sac-isc.gc.ca/eng/1602010609492/1602010631711</u>
- Jones, J., Cunsolo, A., Harper, S.L. (2018, May 24). Who is research serving? A systematic realist review of circumpolar environment-related Indigenous health literature. *PLoS ONE*, 13(5):e0196090. https://doi.org/10.1371/journal.pone.0196090
- Koster, R., Baccar, K., and Lemelin, R. H. (2012). Moving from research on, to research with and for indigenous communities: a critical reflection on community-based participatory research. *The Canadian Geographer / Le Géographe Canadien 56*(2), 195–210. <u>https://doi.org/10.1111/j.1541-0064.2012.00428.x</u>
- Kovach, M. (2017). Doing Indigenous methodologies. In N. K. Denzin and Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 214-234). Sage Publications.
- Marinova, D., and Raven, M. (2006). Indigenous knowledge and intellectual property: A sustainability agenda. *Journal of Economic Surveys*, 20(4), 587-605. <u>https://doi.org/10.1111/j.1467-6419.2006.00260.x</u>
- Métis National Council. (2002). *Citizenship*. Retrieved from <u>https://www.metisnation.ca/about/citizenship#:~:text=The%20M%C3%A9tis%20Nation</u> <u>al%20Council%20General,accepted%20by%20the%20M%C3%A9tis%20Nation.%E2%</u> <u>80%9D</u>
- Oneha, M. F., Dodgson, J. E., DeCambra, M. H., Titcomb, C., Enos, R., and Morimoto-Ching, S. (2016). Connecting culturally and spiritually to healthy eating: A community assessment with Native Hawaiians. *Asian Pacific Island Nursing*, *1*(3), 116-126.
- *Ontario Population 2022.* World Population Review. (2022). Retrieved November 21, 2022, from https://worldpopulationreview.com/canadian-provinces/ontario-population
- Paronen, O., and Oja, P. (1998). How to understand a community Community assessment for the promotion of health-related physical activity. *Patient Education and Counseling*, 33, S25-S28.
- Richardson, J., Ramuscak, N., Davis, S., and Ho, T. (2018). *Identifying community assessment* practices for public health. Region of Peel. <u>https://coherent-</u> commons.s3.amazonaws.com/artifacts/file/file/3ddea50c-a79b-42fd-b772-<u>6efcc9badd67.pdf?X-Amz-Algorithm=AWS4-HMAC-SHA256andX-Amz-</u> <u>Credential=AKIA23B6R4NTCRHS5NZ3%2F20230606%2Fus-east-</u> 2%2Fs3%2Faws4\_requestandX-Amz-Date=20230606T154905ZandX-Amz-<u>Expires=3600andX-Amz-SignedHeaders=hostandX-Amz-</u> <u>Signature=a8adc8363a62eba713b038b1e09591cedfc640bcc792973d2bf0f13fd67b0966</u>
- Simon Fraser University. (2022). *Grey literature: What it is and how to find it.* <u>https://www.lib.sfu.ca/help/research-assistance/format-type/grey-literature</u>

- Sharpe, P. A., Greaney, M. L., Lee, P. R., and Royce, S. W. (2000). Assets-oriented community assessment. *Public Health Reports*, 115(2-3), 205-211. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1308712/</u>
- Snilstveit, B., Oliver, S., and Vojtkova, M. (2012). Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. *Journal of Development Effectiveness*, 4(3), 409-429. <u>https://doi.org/10.1080/19439342.2012.710641</u>
- Statistics Canada. (2022, September 28). *Population Estimates, quarterly*. Population estimates, quarterly. Retrieved November 21, 2022, from https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000901
- The Truth and Reconciliation Commission of Canada. (2015). *Honouring the Truth, Reconciling* for the Future: Summary of the Final Report of the Truth and Reconciliation Commission of Canada. Retrieved from <u>https://ehprnh2mwo3.exactdn.com/wp-</u> <u>content/uploads/2021/01/Executive\_Summary\_English\_Web.pdf</u>
- Wang C, Burris MA. Photovoice: concept, methodology, and use for participatory needs assessment. Health Educ Behav. 1997 Jun;24(3):369-87. doi: 10.1177/109019819702400309. PMID: 9158980.
- West, R., Stewart, L., Foster, K., and Usher, K. (2012). Through a critical lens: Indigenist research and the Dadirri method. *Qualitative Health Research*, 22(11), 1582-1590. https://doi.org/10.1177/1049732312457596
- Ylitalo, K. R., Meyer, R. U., Stone, K., Doyle, E. I., and Curtis, R. (2016). Using the Community Assessment for Public Health Emergency Response (CASPER) to assess barriers to healthy eating and active living in a low-income community. *Evaluation and Program Planning*, 59, 41-46. <u>http://dx.doi.org/10.1016/j.evalprogplan.2016.08.003</u>