

**The Kahnawà:ke Schools' Diabetes Prevention Project: Perspectives on Data Sovereignty
in Indigenous Community-Academic Partnered Health Research**

By

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Abstract

Introduction. Data sovereignty in Indigenous research recognizes the authority of Indigenous peoples over research data and processes. Data sovereignty is an important tool for the self-determination of Indigenous communities, as it fosters the collection of relevant data that aligns with community goals and interests. While guidelines exist to support Indigenous community-academic research partnerships in facilitating community-controlled research and data sovereignty, these guidelines often lack practical clarity, and could benefit from practical examples of successful partnerships. **Purpose.** The purpose of this study is to explore how The Kahnawà:ke Schools' Diabetes Prevention Project (KSDPP), a mature and successful Indigenous community-academic research partnership, operationalizes data sovereignty and facilitates research in a community-controlled manner. **Methods.** Eight individuals having various roles within the KSDPP participated in semi-structured interviews. The interview guide was theory-informed using indicators of data sovereignty extracted from literature on data sovereignty in community-controlled research. The KSDPP Code of Research Ethics and letters of information/consent forms from past KSDPP studies were also reviewed. These data were collected and analyzed using a thematic analysis. **Results.** Seven themes were identified related to research benefits, collaboration and communication, capacity and growth, respectful relationships, data stewardship, defining community control, and growth through adversity. **Discussion.** The community controls the KSDPP research process and accordingly the content, management, and use of data created. The community values the cooperation and roles played by academic partners and defines control as appropriate and beneficial to their culture and context.

Statement of Collaboration

This thesis titled “The Kahnawà:ke Schools’ Diabetes Prevention Project: Perspectives on Data Sovereignty in Indigenous Community-Academic Partnered Health Research” was completed by Andrea Ianni under the supervision of Dr. Lucie Lévesque. The idea for the project was generated by discussions among Andrea Ianni, Lucie Lévesque, and members of the Kahnawà:ke Schools’ Diabetes Prevention Project’s (KSDPP) research team, with input and final approval from the KSDPP Community Advisory Board. Andrea Ianni completed the literature review, collected data by acquiring KSDPP documents and conducting qualitative interviews, prepared and analyzed the data, interpreted results and wrote the entirety of this thesis. Lucie Lévesque reviewed and edited this document and provided ongoing support and guidance throughout the project. Additionally, members of the KSDPP research team and CAB offered guidance, collaborated on finalizing the interview guide, and reviewed results of the analysis. This thesis and the final manuscript has/will be reviewed by select KSDPP CAB members.

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List of Abbreviations

CAB – Community Advisory Board

CANZUS – Canada, Australia, New Zealand, United States of America

CIHR – Canadian Institutes of Health Research

FNIGC – First Nations Information Governance Centre

GREB – Queen’s General Research Ethics Board

KSDPP – Kahnawà:ke Schools’ Diabetes Prevention Project

NAHO – National Aboriginal Health Organization

NSERC – Natural Sciences and Engineering Research Council of Canada

OCAP® - Ownership, Control, Access, and Possession

REB – Research Ethics Board

RT – Research Team

SSHRC – Social Sciences and Humanities Research Council

TCPS2 – Tri-Council Policy Statement 2

UN – United Nations

UNDRIP – United Nations Declaration on the Rights of Indigenous Peoples

UNGA – United Nations General Assembly

Glossary

Academic Researcher	An external or Kahnawà:ke community member who is actively involved in the KSDPP research process holds a position in an academic institution
Community Researcher	A Kahnawà:ke community member who is actively involved in the KSDPP research process
Community Staff	A community member who is employed by the KSDPP
Data Sovereignty	Indigenous data sovereignty recognizes the authority of Indigenous peoples over all data about their people, lands, and lives (Kukutai & Taylor, 2016)
Self Determination	The right of Indigenous peoples to control their destiny by framing their lives and communities in their own norms, laws, and cultures (Dalton, 2005).

Prologue

I am of mixed descent, with my father's family immigrating from Italy, and my mother's traceable family originating on Cornwall Island in Akwesasne Mohawk Territory. Following her time in an Ontario residential school, my maternal grandmother found that she was unable to return to Akwesasne and was brought to Toronto to be raised in a home by Catholic nuns. As a result, I, like my mother, was born and raised off-reserve. So, while I am by blood and government status an Indigenous person of Akwesasne, my connection to the community, land, and culture is lacking. Furthermore, I don't feel I have the same experiences as an Indigenous or Mohawk person who lives on a reserve. Accordingly, I wish to acknowledge that my heritage does not equate to lived experience or secure in-group status. With regards to my research I had to remember the limitations in my understanding and experience of Indigenous and Mohawk life and culture, and do all in my power to learn, grow, and minimize existing presumptions. The people of Kahnawà:ke, with whom I had the opportunity to work and from whom I continuously learn, have helped me understand more about the meaning of my identity. I hope to continue to reflect on and evolve this understanding throughout my life.

I further acknowledge that my past training in research has exclusively been delivered within a colonial institution, and furthermore in an area of research very detached from community-partnered principles. Since starting my Master's, I have trained in and witnessed community-partnered research in action with the Kahnawà:ke Schools' Diabetes Prevention Project. I have developed a strong appreciation for community-partnered and community-empowering approaches that minimize traditional power imbalances between the researcher and the community. This project was an incredible opportunity for me to continue to challenge the

assumptions and understandings of research practice grounded in my colonial education, and experience research as outlined by the community's best practice.

Community Engagement

I first became involved with the Kahnawà:ke Schools' Diabetes Prevention Project (KSDPP) two years ago in the summer before I formally started my Master's degree. My first time visiting Kahnawake was June that year, when I attended the annual research team meeting. This meeting is attended by KSDPP staff, academic partners, and individuals from partnering communities from across Canada. This was a great opportunity to form relationships with the team while experiencing the Kahnawà:ke community and Mohawk culture. It also allowed me to begin making myself useful to the project by assisting in whatever I could throughout the week to start to get an idea of how things worked in the project. This would be the first of several visits to Kahnawà:ke for meetings and events, and gatherings with other First Nations and Métis communities (as part of the KSDPP Community Mobilization training).

These visits to Kahnawà:ke have provided me with opportunities to learn, build relationships, and give back to the project. In addition to tasks like reviewing and contributing to training manuals, preparing participant materials, and assisting at training sessions, I found myself doing things I would have never guessed were related to research. I had Alex McComber of the KSDPP welcome me into his home for dinner several times and offer me his spare room when I was in community. I was able to utilize my Italian heritage to cook lasagna in the Kahnawà:ke Youth Centre kitchen for a community fundraiser. I spent six hours in the sun cheering on community youth and I got more tanned than I have been in years. I drove an elder around town and had lengthy conversations with her that shaped the way I now view the world. I hugged more people in the last two years than I probably have in my whole life. From the

training sessions across provinces, to the team dinners, to the Winnipeg Jets game, these experiences are the most rewarding I have had in my education thus far, and it makes me eternally grateful to everyone in the KSDPP and excited to continue the relationships that have developed.

Chapter 1

Introduction

1.1 Background Information

In the field of Indigenous research, recent decades have featured a clear shift from research done ‘to’ Indigenous peoples to research done ‘with’ and for the benefit of Indigenous peoples (Ball & Janyst, 2008). This generation of research aims to empower Indigenous peoples, employ Indigenous ways of knowing, and eliminate racism and oppression (Rigney, 1999). In doing so, partnering Indigenous communities can build community capacity and control, forward community goals, and create knowledge that is relevant and beneficial to them (Ball & Janyst, 2008; L. T. Smith, 1999). This can be understood as bolstering Indigenous self-determination, the right of Indigenous peoples to control their destiny by framing their lives and communities in their own norms, laws, and cultures (J. E. Dalton, 2005).

Data sovereignty in Indigenous research recognizes the authority of Indigenous peoples over research data (Kukutai & Taylor, 2016). Data sovereignty is a way in which Indigenous communities can assert self-determination over research and restore self-governance (Smith, 2016). Guiding principles of data sovereignty (e.g., OCAP®) and ethical academic-partnered research that supports data sovereignty in Canada (e.g., Tri-Council Policy Statement 2, Chapter 9) outline how academic researchers and partnering Indigenous communities can work together in an ethical manner that is respectful of Indigenous knowledge (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council [SSHRC], 2014; The First Nations Information Governance Centre [FNIGC], 2014). Despite known challenges related to the interpretation and operationalization of these guidelines (Mitchell & Baker, 2005; Moore, 2015;

Stiegman & Castleden, 2015) and challenges with the implementation of participatory approaches, information is lacking about how such challenges can be managed and overcome (Harding et al., 2012; Kendall, Sunderland, Barnett, Nalder, & Matthews, 2011).

1.2 Purpose of Study and Research Question

The purpose of this study is to address calls for practical examples of how existing Indigenous community-academic research partnerships operate in ways that respect and honour the sovereignty of Indigenous communities. The Kahnawà:ke Schools' Diabetes Prevention Project constitutes an ideal example to investigate how this research partnership practices data sovereignty and upholds the ideals of participatory research. The research seeks to answer the question, *how does the KSDPP operationalize data sovereignty and facilitate research in a community-controlled manner?*

1.3 Research Context

Kahnawà:ke is a Kanien'kehá:ka (Mohawk) community of approximately 8000 people in what is now called southern Québec. In the 1980s, consistent with health discrepancies between Indigenous peoples and the general Canadian population (Harris et al., 1997), the community was battling a disproportionately high prevalence of type 2 diabetes (Montour & Macaulay, 1985) and complications from diabetes (Macaulay, Montour, & Adelson, 1988). Following the sharing of this information with the community, stakeholders from across the community mobilised and expressed interest in preventing diabetes among future generations (Montour & Macaulay, 1988). This led to the creation of the Kahnawà:ke Schools' Diabetes Prevention Project, which received initial funding in 1994 (Macaulay et al., 1997). The purpose of the project was to implement and evaluate culturally-informed programming for the children of

Kahnawà:ke to reduce obesity, enhance physical activity, and improve healthy eating (Macaulay et al., 1997). The project has continued to operate beyond the initial research funding and for the last 25 years has run community programming and driven academic-partnered research. The project has been recognized as a best practice by the Public Health Agency of Canada (Public Health Agency of Canada, 2016), called “a shining example of researcher-community collaboration and community partnership” by CIHR (CIHR, 2015), and has had their Code of Research Ethics acknowledged in the TCPS2 (CIHR, NSERC, & SSHRC, 2014). This is a well-established and mature community-academic research partnerships that will serve a strong model for how community-driven research can operationalize data sovereignty.

At the beginning of my graduate studies in 2017, I was introduced into the KSDPP through the pre-existing relationship and longstanding membership of my supervisor, Dr. Lucie Lévesque. Over the two years of my master’s research, it was important for me to be present in and to establish a relationship with community members and researchers within the KSDPP. While I was able to join the project through an existing relationship, for me to participate in strong community-driven research, it was important that I formed my own relationships based in mutual trust (Castleden, Sloan Morgan, & Lamb, 2012). I became involved in events in the community and in projects within the KSDPP that allowed me to grow my relationship with several researchers, staff members, and CAB members. Toward the end of this time, the idea for this project emerged out of initial discussions about the current state of the KSDPP Code of Research Ethics and interest by project team members in reviewing literature for potential updated best practices and operational norms that could inform a revision of the document. As it became clear that my project would be focused within the KSDPP, it gave me the opportunity to

rely on my now two-year strong relationships and to work with project members who trusted that I would be respectful and do good work for the KSDPP.

1.4 Anticipated Implications

Findings from this study will supplement existing literature by offering a practical gaze at how data sovereignty has been operationalized within community-driven research by a successful First Nation community-academic research partnership. In doing so, First Nation communities (and perhaps other Indigenous communities) and academic allied researchers may glean strategies for implementing data sovereignty within their own partnered research. For KSDPP, findings from this research will serve to inform and refine project operations.

1.5 Thesis Organization

This thesis was completed as outlined by the Queen’s University School of Kinesiology and Health Studies’ requirements for a manuscript format thesis. No significant changes from the approved thesis proposal occurred (Appendix A). Chapter two will overview the United Nations Declaration on the Rights of Indigenous Peoples as it relates to data sovereignty and the Canadian post-colonial climate, and will review the history of unethical research on Indigenous peoples in Canada. Next, it will highlight the value of data sovereignty, introduce prominent guidelines for the conduct of ethical research with Indigenous peoples, and discuss issues with current practices related to data sovereignty and recommended guidelines. Chapter two will end justify the selection of the KSDPP as a model project and the project purpose and rationale. Chapter three is a manuscript in preparation titled “The Kahnawà:ke Schools’ Diabetes Prevention Project: Perspectives on Data Sovereignty in Indigenous Community-Academic Partnered Health Research” which outlines the study rationale, purpose and method and presents

and discusses results of how the KSDPP operates, as informed by project documents and members. Chapter four provides a brief general discussion of the findings, their significance and implications for guiding future partnerships; it also mentions the strengths and limitations of the research.

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Chapter 2

Literature Review

2.1 The UNDRIP and the Canadian ‘Post-Colonial’ Climate

On September 13th 2007, the United Nations General Assembly (UNGA) gathered to vote on the United Nations’ Declaration on the Rights of Indigenous Peoples (UNDRIP). The successful adoption of the Declaration provided Indigenous peoples around the world with an international human rights tool that acknowledged their distinct cultural rights (Davis, 2008). The UNDRIP is worthy of discussion here as it has been valued in outlining and benchmarking the growing call for Indigenous data sovereignty (Davis, 2016). The final draft of the UNDRIP outlines 43 articles on Indigenous rights and interaction ideals with surrounding nation-states (UNGA, 2007). The scope of these articles is vast, including prohibition of discrimination, rights to cultural practice, access to services, self-governance, control of lands, and redress for past violation of rights (Gover, 2015). An overarching assertion of the UNDRIP, and perhaps the one of most contention during drafting (Davis, 2008; Gover, 2015), was the right of Indigenous peoples to self-determination (Kukutai & Taylor, 2016). The UNDRIP demand for self-determination (See: Article 3 and Article 4; UNAG, 2007) reinforces Indigenous peoples’ claims to data sovereignty, and has bolstered the presence of data sovereignty considerations in modern ethical discussions (Kukutai & Taylor, 2016). The Canadian government’s reaction to UNDRIP, and the difficulty related to its drafting and ratification are representative of the colonial paternalism that persists in Canada and similar nations in the relationships and arrangements with people indigenous to these lands.

These social and political environments surrounding Indigenous peoples in Canada are also important to consider when examining the need for data sovereignty. Canada is a member of the Canada, Australia, New Zealand and the USA (CANZUS) grouping. These nations are all affluent democracies settled during the 19th century British colonial expansion and are similarly influenced in legal constitutions by English common law (McHugh, 2004). Although Indigenous nations within each of these countries constitute a culturally and, at times, territorially distinct minority facing socio-economic marginalisation within their territories, “eerie parallels” can be drawn between these nation groups (Gover, 2015). While the CANZUS grouping predates the UNGA in 2007 (earliest published reference I came across being Muller & Cleaver, 2000), it remains effective in describing the only four UN nations who, in addition to raising the most objections to the UNDRIP articles during drafting (Davis, 2008), voted against the adoption of the UNDRIP (Kukutai & Taylor, 2016). Gover (2015) points out that the objections of these nations concern articles pertaining to Indigenous rights to self-determination, self-governance, and property. Certain articles could pose threats to the political arrangements these colonial states have utilized to manipulate Indigenous consent to settler-governance (Gover, 2015). CANZUS states further object to the notion of giving Indigenous peoples preferential treatment over their non-Indigenous populations to achieve equity among nation groups. In the eventual statements of support following the UN’s adoption of the UNDRIP, Canadian and other CANZUS governments similarly reiterated their antagonistic position and emphasized the non-legally binding nature of the document and its lack of influence on changing national law (Gover, 2015). Canada reported “We are now confident that Canada can interpret the principles expressed in the Declaration in a manner that is consistent with our Constitution and legal framework” (Indigenous and Northern Affairs Canada, 2010).

The perceived dishonesty and actions of the CANZUS nations throughout the negotiation of the UNDRIP had left Indigenous leaders and peoples frustrated (Davis, 2008). In 2016, the Canadian government dropped its objector status, and declared they are “full supporters of the declaration, without qualification” (Fontaine, 2016). However, many are critical of the meaningfulness of this support, as it has resulted in little action (Morin, 2017). Bill C-262 was first read by Parliament in 2016, with a purpose of ensuring that Canadian laws are harmonious with the UNDRIP (Parliament of Canada, 2016). After three readings over two years, the bill was finally passed through the House of Commons without any supporting Conservative voters in 2018. Then facing the Senate, the bill continued to face opposition and ongoing delay by Conservative Senators who employed “procedural maneuvers” to prevent the bill from being passed before Parliament entered summer recess (Galloway, 2019). In doing so, the bill lost the progress it made and must be reintroduced following the 2019 fall federal election (Galloway, 2019). The delays and resistance from a prevalent opposition mirror the difficulty observed in the drafting and voting of the UNDRIP that occurred over decades. Accordingly, while Canada is now a “full supporter” of the UNDRIP and Indigenous rights, it is difficult to see that much has changed.

This summary of the position held by Canada and other CANZUS nations regarding the UNDRIP portrays the difficulty faced by Indigenous peoples living in these countries to achieve recognition as sovereign peoples. The difficulty of actualizing self-determination as a minority of 4.9% of the Canadian population (Statistics Canada, 2017) is clear when 53% of the broader Canadian population feel that Indigenous people would be better off integrating with the broader Canadian culture (Angus Reid Institute, 2018). This report showed that 66% of Canadians believe Indigenous people should not have independence and control over their own affairs. The

actions and beliefs of the Canadian government and the general population emphasize the prevailing colonial culture that is resistant to the decolonisation of Indigenous peoples and their self-determination.

Following their review of this thesis, a member of the KSDPP CAB shared some helpful information about the right to self-determination, and a newer concept called the right to development. I would like to reflect that information here for consideration throughout the thesis as well as moving forward in how we understand self-determination in Indigenous community-based research. Indigenous rights to self-determination and development are two related concepts, but with an important distinction.

Self-determination is an older right for which Indigenous peoples have fought, predating the struggles surrounding the UNDRIP. By the time of the UNDRIP drafting, the newer concept of right to development had emerged. This right is reflected in Article 23 of the UNDRIP, which outlines Indigenous peoples' right to be active in developing and determining health and other social and economic programs through their own institutes where possible (UNGA, 2007). Above, I reported that self-determination was a feature of articles to which CANZUS nations most opposed during drafting of the UNDRIP (Gover, 2015). However, CAB brought to my attention that a Kahnawà:ke community member, who had been involved in drafting discussions for decades, reported that it was in fact the right to development that was most difficult for Canada and other nations to accept. The important distinction between self-determination and development is that self-determination allows Indigenous people to control federal institutes and systems, while development allows them to overhaul and create their own.

The Canadian colonial context is the setting in which 'bottom-up' approaches to research by Indigenous peoples and allies are emerging. Allied researchers look to collaborate where

possible to support Indigenous peoples who are working to achieve self-determination within the community, rather than waiting for ‘top-down’ political and systemic changes to promote or permit self-governance and sovereignty. This is congruent with the growing discourse of data sovereignty and community-controlled research, which is reflected in the efforts of community-academic research partnerships to ensure that meaningful data are collected and governed by the Indigenous community.

Smith (2016) contends that Indigenous systems of authority and knowledge have been eroded due to the imposed Western governance models. The path toward re-establishing these systems and self-determination is aligned with what has been called “data self-determination” (Walter & Suina, 2018). Data self-determination can be understood as data sovereignty in action, the act of Indigenous peoples reasserting control over existing data and collecting new data to inform their action and reach their goals (Smith, 2016). It is important to acknowledge, however, that despite the undisputable ideals of data sovereignty principles, it can be extremely challenging to implement data sovereignty.

Historic colonization, oppression, and the resulting intergenerational trauma have left a disproportionate number of Indigenous peoples and communities in Canada in poor health and with inadequate socioeconomic standing (McCaslin & Boyer, 2009), demoralised and afflicted with issues of mental ill-health (Kirmayer, Simpson, & Cargo, 2003), and with a lack of confidence in their ability to manage their own environment (Lee, 1992). In response to these inequities and injustices, Indigenous-led grassroots movements that focus on rebuilding Indigenous nation sovereignty, such as IdleNoMore, have emerged in Canada (Raynauld, Richez, & Morris, 2018). These efforts demonstrate the ambition of many Indigenous communities looking to re-establish themselves as a strong independent people, and it is these

internally-motivated community developmental goals that research with Indigenous peoples must support (Ball & Janyst, 2008). Accordingly, many allies within academic institutions are looking to support communities by providing institutional resources for research that aim to reduce disparities. These partnerships require trust between the community and academic researchers, which can be difficult to achieve given the history of abuse and manipulation, as described in the next section.

2.2 Unethical Research History

Many Indigenous peoples have a deep-rooted distrust of external research given the history of unethical and abusive Indigenous research in Canada. In addition to a complete disregard for the most basic ethical principles of human dignity and informed consent, much of this historic research on Indigenous peoples in Canada was directly antagonistic to data sovereignty considerations. For example, in the 1940s and 1950s the Department of Indian Affairs of Canada led nutrition experiments using malnourished Indigenous children within the residential school system (Mosby, 2013). This government department purposefully withheld nutrients from Indigenous children in the name of research. To evaluate the effects of malnourishment and the lack of various supplements, children were denied nutrients to the point of severe malnourishment and even death (Mosby, 2013). Participants were not only deprived of basic nutrition, but they were also deprived of their human rights; they were not provided with information about the research nor asked to consent. Moreover, the data collected did not reflect the needs of the community nor improve the quality of life of Indigenous peoples. This unethical research satisfied the interests of non-Indigenous academic researchers for the benefit of the general Canadian population (MacDonald, Stanwick, & Lynk, 2014).

The nutrition trials were unfortunately not the precedent for unethical research in Indigenous communities. In the 1930s, infants of the Qu'Apelle reserves in Saskatchewan were subjected to tuberculosis vaccination trials (Lux, 1998). Lux mentions that as this was a time where Indigenous peoples in Canada were beginning to use political organization to voice their concerns and oppose oppression. Dr. Ferguson, who conducted the trials, reported that he considered it inadvisable to force the community into participation; he had to first “gain the confidence of these Indians”. While collaborating with community members to agree on participation is seemingly congruent with modern ethical standards (e.g. TCPS2; (Canadian Institutes of Health Research et al., 2014), a review of this study from purpose to results exposes this cooperation as nothing more than the result of coercion to permit manipulation. Lux (1998) reveals that the study was framed as a demonstration that the vaccine was effective enough to combat tuberculosis even in the Indigenous infants who were “less evolved” or “primitive” due to their low percentage of “white blood”. Although the vaccine was deemed efficacious, more than 17% of the 609 infants and children involved in the study died from non-tuberculosis causes (Lux, 1998). This finding was downplayed, effectively distracting attention from the upstream source of the high tuberculosis rates, grotesque child mortality rates, and the impoverished conditions of the Qu'Apelle people (Lux, 1998).

Perhaps one of the most infamous and recent examples of unethical research, which sparked fierce discourse about Indigenous data ownership, is the Nuuchahnulth blood studies. In the early 1980s, Dr. Ward at the University of British Columbia collected blood from the Nuuchahnulth people who consented to his genetic research on the high arthritis rates in the community (R. Dalton, 2002). The Nuuchahnulth people welcomed this external researcher into their community with the understanding that their interests would be respected, and that they

would see improvement in their lives. However, without consulting the community, Ward used the blood to his benefit, and shared the data, which led to hundreds of published reports on topics for which participant consent had not been obtained, including reports supporting the Bering Strait migration theory, which is contested by Nuu-chah-nulth people (Wiwchar, 2004). This betrayal exemplifies the classic and often prevailing notion in academic culture that a researcher and/or their institution own all collected data and resulting knowledge. These are only a few examples that demonstrate an abusive history that has left many Indigenous peoples negative toward the idea of research and Western-influenced data approaches (Pool, 2016).

2.3 Indigenous Self-Determination, Data Sovereignty, and Ethical Research with Indigenous Peoples

The subjugation of Indigenous peoples to unethical and abusive research practices highlights the ethical imperative for academic institutional researchers to support Indigenous self-determination and data sovereignty in research. Indigenous self-determination has been defined as the right of Indigenous peoples to control their destiny by framing their lives and communities in their own norms, laws, and cultures (Dalton, 2005). Self-determination is a common term in Indigenous research discourse as Indigenous peoples strive for more control over their research experience (Smith, 1999).

Data sovereignty for Indigenous peoples is intertwined with Indigenous self-determination through research. Data sovereignty is often understood as the management of information according to laws of the nation holding it, a concept made popular by the removal of geographical access barriers in the digital age (Snipp, 2016). This, however, is a predominately western conceptualization. For Indigenous peoples striving for recognition as sovereign nations,

data sovereignty transcends data location and ownership of data to include considerations of cultural relevance and usefulness (Smith, 2016).

Indigenous data sovereignty recognizes the authority of Indigenous peoples over all data about their people, lands, and lives (Kukutai & Taylor, 2016). In contrast with state-controlled data collection or institutionally driven research, an Indigenous community empowered in their own data collection can be strategic in determining a role for data, responsive in developing projects to address needs, and culturally authoritative by controlling what is measured and how it is measured (Schultz & Raine, 2014). Accordingly, if research is to be carried out in ways that are conducive to Indigenous self-determination, the Indigenous group or community engaged ought to determine the potential meaningfulness of the data prior to collection and govern how the data are to be accessed and used (Schnarch, 2004; Snipp 2016). The reciprocal nature of data collection for bolstering self-governance and exercising self-governance over data collection is outlined by Smith (2016), who identifies these “twin capabilities” as fundamental to Indigenous self-determination in practice. The restoration of eroded indigenous governance systems aligns with the need for Indigenous peoples’ control over and interpretation of archival colonial data and the creation of new data to serve modern purposes (Smith, 2016).

As an ongoing process, data sovereignty can guide Indigenous communities toward improved health and healthcare (Walker, Lovett, Kukutai, Jones, & Henry, 2017). Recently, ethical and operational guidelines have emerged and continue to be revised in order to foster protections for Indigenous peoples involved in research (CIHR et al., 2014; The First Nations Information Governance Centre [FNIGC], 2014) . These guidelines are congruent with contemporary goals of community empowerment and self-determination.

Recent discussions about Indigenous data sovereignty with First Nations in Canada have been guided by the principles of ownership, control, access, and possession (OCAP®; FNIGC, 2014). The OCAP® principles outline that the collection, protection, and use of data from First Nations peoples in Canada ought to be controlled by those First Nations peoples. The First Nations Information Governance Centre (FNIGC) trademarked the term in 2014 to prevent its misuse and misinterpretation, however, the term was present in the literature more than a decade prior (see Espey, 2002; Schnarch, 2004). The first iteration of OCAP®, which did not acknowledge possession (OCA), originated from a meeting of the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey (reformed as the FNIGC; FNIGC, 2014). The OCAP® principles, which emerged as “a political response to colonialism and the role of knowledge production in reproducing colonial relations” (Espey, 2002, p. 6), have become familiar in First Nations community research across Canada. The FNIGC (2014) acknowledges that the OCAP® principles are not conceptually novel and had been discussed or sought out by Indigenous communities well before they were modelled as an ethical guideline. A certification process is being established to offer training on OCAP® to Indigenous peoples and researchers to promote accurate implementation of the framework (FNIGC, 2016). Presently, a preliminary “Fundamentals of OCAP®” course is available online. A foundational goal of OCAP® is to operationalize self-determination in research by ensuring Indigenous communities have control over the creation, access, and use of their own data (Schnarch, 2004).

While intended primarily for First Nations peoples, the OCAP® principles may serve as a foundation to support all Indigenous peoples worldwide in self-determination through data sovereignty (FNIGC, 2016a). Similar Inuit and Métis specific guidelines exist. Inuit benefit from the work of the Inuit Nipingit (the National Inuit Committee on Ethics and Research) who

outlined practices and produced reference materials for research involving Inuit (Nickels & Knotsch, 2011), while the Métis Centre at the former National Aboriginal Health Organization (NAHO) organized a gathering of researchers, students, and Métis organizations to discuss and generate ethical principles of research with Métis peoples (Métis Centre at National Aboriginal Health Organization, 2011).

In response to criticism that the existing federal research guidelines (the first Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans published in 1998) lacked Indigenous voices, perspectives, and focus throughout their drafting (Castleden et al., 2012), the Canadian Institutes of Health Research (CIHR) released a document for the ethical conduct of research with Indigenous peoples in Canada (CIHR, 2007). The CIHR Guidelines for Health Research Involving Aboriginal People was drafted with input from Indigenous communities and organizations, as well as academic researchers, and was designed to promote mutually beneficial and culturally competent research partnerships (CIHR, 2007). This document informed Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada of the TCPS2 (CIHR, NSERC, & SSHRC, 2010), which is the current guiding document for Tri-Council funded research in Canada (CIHR et al., 2014). This chapter aims to guide academic research ethics boards (REBs) in evaluating proposed research and ensuring that research reflects the Tri-Council's key principles (respect, concern for welfare, and justice for Indigenous peoples) (CIHR et al., 2014). Chapter 9 has a clear focus on respectful community-academic relationships and promoting community engagement and collaboration throughout the research design, consistent with popular participatory research approaches (Brant Castellano & Reading, 2010; Castleden et al., 2012). While having less direct focus on data sovereignty or governance than the OCAP® principles, several of the participatory practices promoted by Chapter 9 align with

efforts to ensure community control over research and data. Furthermore, Chapter 9 acknowledges and recommends discussion and consideration of OCAP® (CIHR et al., 2014).

These are two prominent examples of guiding ethical principles and documents among the several published by organizations and individual authors. The diverse landscape of guidelines for ethical research with Indigenous peoples is unquestionably a positive improvement over past research practices. However, ethical guidelines are not without their own issues and criticisms, and ought to be reviewed and applied critically. Indigenous peoples in Canada have a diverse range of cultures and community contexts, and accordingly it can be difficult to be served by one ‘all-purpose’ guideline. Further, instances where guidelines make strong recommendations may be challenging to put into action. Accordingly, despite the existence of such guidelines, many Indigenous peoples continue to be affected negatively by research and have had their distrust further validated (Taniguchi, Taulii, & Maddock, 2012). Such difficulties in operationalizing data sovereignty within the context of Indigenous research and criticisms of existing guidelines are explored further in the next section.

2.4 Challenges in the Operationalization of Data Sovereignty and Ethical Guidelines

Indigenous peoples participating in a UN expert group meeting generated questions and concerns about Indigenous data collection and data sovereignty, including “how do we collect data?”, “who should control information?”, and “what are the data for?” (Davis, 2016). OCAP® and similar data sovereignty literature posit that the establishment of nation or community governance structures that outline rules, standards, roles, responsibilities, and establish data infrastructures for use in community can address many such questions and concerns (FNIGC, 2014; Smith 2016). The TCPS2 Chapter 9 is congruent with this approach by calling for the

creation of research agreements between communities and academic partners to address such topics (CIHR et al., 2014).

Outlining and implementing research agreements can be a lengthy and difficult process, potentially requiring more capacity and resources than are available in some communities (Snipp, 2016). For example, a lack of capacity to create community information governance structures may put communities in a precarious situation whereby they might be compelled to relinquish data to other parties. In these situations, Indigenous data sovereignty is difficult to achieve (FNIGC, 2014). Even when a nation or community can establish or access a data governance system, expertise in research ethics, and the collection, analysis, and management of data may be required of users of the system (Snipp, 2016). Further ethical concerns are raised, for example, when community members may be expected to collect and store sensitive data from other members of their own community, requiring careful balance between collective community and individual rights (Riddell, Salamanca, Pepler, Cardinal, & McIvor, 2017).

Community-academic partnered or participatory research presents as one solution to many of these concerns as it makes institutional research and data management capacity available to communities in a community-driven manner (Wallerstein & Duran, 2006). One mechanism through which participatory research partnerships operate in a manner congruent to data sovereignty principles and guidelines is with the establishment and operation of a community advisory board (CAB). A CAB is a core feature of effective participatory research styles such as community-based participatory research (CBPR; Israel et al., 2005). A research CAB is consistent with many data sovereignty guidelines such as OCAP®; it can operate as a community governance structure with decision making authority that generates and enforces information, research, and data policies/protocol (FNIGC, 2014; Smith, 2016). Participatory

research is additionally a theme underpinning much of Chapter 9 of the TCPS2 (CIHR et al., 2014). Institutional REBs, even when equipped with federal ethical guidelines, cannot determine if the research proposed will be meaningful, suitable, or truly ethical within the community (Brunger & Wall, 2016; Snipp, 2016). Accordingly, in addition to governing and protecting data, a CAB can also address data sovereignty concerns related to the community-relevance and community-usefulness of data (Schnarch, 2004) by moderating what and how research is conducted.

Approaches like CBPR can foster community capacity building and promote respectful collaborations (Tobias, Richmond, & Luginaah, 2013), however, additional barriers and challenges intrinsic to the institutional research culture may emerge (Harding et al., 2012; Marley, 2018). First, principles of CBPR are often interpreted and applied differently among academic researchers, and the practice of these principles often diverges from the optimal theoretical action (Castleden et al., 2012). The participatory approach does not align well with typical institutional models of research. A lack of accommodation from the academy creates issues regarding timelines, funding, and empowerment of the community with true control and ownership over research, as their role may often be reduced to tokenistic consultation (Kendall, Sunderland, Barnett, Nalder, & Matthews, 2011). Further, any data housed within the academy may be viewed as belonging to the researchers or as available for secondary analysis without further community consultation or permission (Harding et al., 2012). This, and similar concerns originating from a colonial academic culture, research assumptions, and a lack of understanding emphasize the need for a CAB to govern community data and information (Snipp, 2016).

CABs can require a vast amount of time and resources, which communities may not be able or be willing to invest (Brunger & Wall, 2016). Additionally, the process of community

review and thorough community engagement in research can be exhausting for these populations that already suffer from a history of over-research (Brunger & Wall, 2016). Moreover, there remains a concern, especially in smaller communities, that individuals may be identified from even de-identified (often qualitative) data held by community organizations; the identification of individuals who shared minority opinions can lead to stigmatization or social turmoil (Wilson, Kenny, & Dickson-Swift, 2018). Brunger and Wall (2016) concluded that participatory research and implementation of ethical guidelines ought to be done critically, with a focus on adhering to actual ethical research in the community rather than to applying general and all-encompassing ethical guidelines.

Beyond the challenges in operationalizing guidelines through participatory approaches, criticisms mounting against the guidelines themselves further illustrate the challenges of upholding data sovereignty through community-academic partnerships. A prominent criticism is that much of the existing framework or guidelines are vague or lacking pragmatic instruction. Moore (2015) reported a theme emerging from interviews with researchers and REB representatives is the TCPS2 Chapter 9 was vague and unclear, often giving researchers little certainty about how to proceed. Similarly, Mitchel and Baker (2005) reported issues with OCAP® lacking clear practical guidance. The highly interpretable or generally vague nature of these guidelines creates an environment of uncertainty and variable application by researchers and REBs (Kendall et al., 2011; Stiegman & Castleden, 2015). Regarding both OCAP® and Chapter 9 of the TCPS2, authors have advised further efforts from researchers and/or organizations to supplement the existing guidelines with practical examples of how researchers and community partners have operationalized them (Mitchell & Baker, 2005; Moore, 2015).

Finally, in addition to challenges with participatory research and ethical guidelines, further impedances to data sovereignty have been identified that are beyond the control of the partnership. For example, limitations of federal laws regarding ownership of federal data (e.g. census and demographic data being subject to Canada's Access to Information Act; FNIGC, 2014), data being subject to foreign federal access due to storage server locations (e.g. USA PATRIOT Act; Raab, 2006), and rigid institutional policies, forms, and expectations that do not align with data sovereignty principles and community engaged research have been identified (FNIGC 2016; Wilson et al., 2018). In such instances, where a partnership cannot resolve or avoid an issue, ways of mitigating the impact of the issue must be considered at the start of the project development.

Following this review of difficulties operationalizing data sovereignty and ethical Indigenous research with participatory approaches, criticisms of the guidelines themselves, and some wider systemic barriers, it is clear that achieving data sovereignty in Indigenous community-academic partnerships is no easy feat. In line with the recommendations referenced above, it is critical to investigate how challenges related to data sovereignty in community research are dealt with on the ground, and report examples to serve as practical supplements to the theoretical guidelines. Many authors have outlined issues with operationalizing data sovereignty and ethical guidelines in Indigenous community research, and in some instances include examples of how some problems emerged and were managed (e.g., Kendall et al., 2011; Mitchell & Baker, 2005). My review of this literature yielded incomplete information about how such partnerships operate and how ethical principles are applied in practice. In some instances, inconsistencies may exist between OCAP® and community values and laws (Mitchell & Baker, 2005). For example, from their work with the Aboriginal Women's Cancer Care Project,

Mitchell and Baker (2005) acknowledge that OCAP® principles lack clear articulation in practice, and call for supplementation of these guidelines with practical examples and lessons from the field. It is thus critical to investigate how challenges related to data sovereignty are dealt with on the ground.

2.5 Kahnawà:ke and the Kahnawà:ke Schools' Diabetes Prevention Project

Kahnawà:ke is a community with a population over 8000 people; the territory is located only 15 KM south of Montreal. The community traditionally practised agriculture, gathered foods, fished, and hunted. Both from the shifting norm toward employment in the structural steel industry as 'ironworkers' (in the late 19th century through the mid-20th century), and the government's ongoing appropriation of community land, Kahnawà:ke had largely become detached from agriculture, fishing, and gathering activities (Macaulay et al., 2003; Phillips, 2000).

Perhaps one of the most prominent land expropriations by the Canadian government through the Indian Act was the approximately 1300 acres of land (more than 10% of the community's current size) taken in 1955-1956 for the construction of The St. Lawrence Seaway (Holmes, 1999). The construction of the Seaway cut off the community's access to the Saint Lawrence River and the Lachine Rapids, for which the community is named (Kahnawà:ke in Kanien'kehá means "on the rapids"). It is a significant historical event that fostered changes to the community's environment from the loss of shoreline land and associated activities (Phillips, 2000). Before the Seaway construction, the river was a source of travel and economic opportunity through trade and employment, it provided the community with fresh fish to eat, the riverside was an abundant source of natural berries for preserves and other foods, access to the river offered important social activities and entertainment, and the river was a vital water source

for the community which had no sewer system and few people with running water (Phillips, 2000).

In spite of hardships from lost land, Kahnawà:ke remains a strong community. The community features a strong traditional government through the longhouse system, and decentralized power and control over services beyond the federally recognized Mohawk Council of Kahnawà:ke, such as education services, health services, youth recreation, social and community services (including their own police force), and local economic development services (Macaulay et al., 2003). Kahnawà:ke utilizes a Community Decision Making Process that aligns with the 1979 Community Mandate to rebuild Traditional Government and involves the community in decisions about the community and laws enacted (Kahnawà:ke Legislative Coordinating Commission [KLCC], n.d.). This participatory democratic approach sustains and meets the traditional principles of the Haudenosaunee (Iroquois) Confederacy with modern practices. This culturally based decision-making approach is reflected in the governance of the KSDPP (Cargo et al., 2003). However, consistent with the community-controlled and owned foundation of the project, community voices in the partnership exert more influence on decisions (Cargo et al., 2008).

The Kahnawà:ke Schools' Diabetes Prevention Project (KSDPP) is a diabetes prevention initiative founded in 1994 in response to rising rates of type 2 diabetes in the community. A patient chart study by Montour and Macaulay (1985) revealed that 12% of adults aged between 45-64 years in the community of Kahnawà:ke had diabetes, a rate more than double that of the general Canadian population. These findings were shared with community members who mobilised to address the issue. In 1994, the KSDPP was founded as a response to the

community's wishes to protect future generations from type 2 diabetes and to promote wholistic healthy living.

One of the first activities of the KSDPP was to establish a Community Advisory Board (CAB; Macaulay et al., 1998). CAB membership is based on an open-door policy, with ongoing recruitment of members. The KSDPP CAB typically consists of approximately 15 to 20 volunteer members representing several sectors of the community (health, social, political, spiritual, recreational, and private sectors) as well as interested community members (Cargo et al., 2003). From this diverse community representation, the CAB is equipped with cultural and community knowledge and a range of diverse expertise that can be applied to decision-making within the KSDPP. In addition to involvement in the formation of the project vision, the CAB monitors, develops, implements, and reviews all project activities during monthly meetings where members discuss and vote on decisions about KSDPP interventions and research (Potvin, Cargo, McComber, Delormier, & Macaulay, 2003). The CAB are also tasked as “ambassadors of wellness” who act as role models of health living within their roles in the community (Potvin et al., 2003).

Early on, the KSDPP CAB and the research team developed the KSDPP Code of Research Ethics, which was touted as an “innovative” document at the time (Macaulay et al., 1998). It has since been acknowledged in the TCPS2 as an example of community protocol expressing Kahnawà:ke's right to self-governance (CIHR, et al., 2014). The KSDPP Code of Research Ethics promotes shared leadership in partnered research and community data sovereignty by ensuring community ownership and control of data.

From the start, the KSDPP had strong community reach, implementing over 60 unique interventions in the baseline years and yielding an 87% consent rate to participate in the

intervention and evaluation within the schools; physical activity and healthy eating among school children improved (Macaulay et al., 1997). Although improvements in diabetes risk factors in children during the first few years of the KSDPP intervention were not maintained (Paradis et al., 2005), it is important to acknowledge that a focus on measurable health outcomes as an indication of program success is simplistic and risks the oversight of important program impacts (Nutbeam, 1998).

Many additional indicators should be considered in gauging the positive impact of the KSDPP, which is a recognized best practice by the Public Health Agency of Canada (PHAC, 2016) and has been deemed “a shining example of researcher-community collaboration and community partnership” by the Canadian Institutes of Health Research (CIHR, 2015). The success of the KSDPP can be inferred by the sustained implementation of culturally relevant health curriculum generated for community schools, by changes in teacher attitudes toward extracurricular activities, by an increased understanding among community members regarding the importance of healthy lifestyles and disease management, by built capacity and experience in the community for supporting and evaluating healthy lifestyle initiatives, by new recreation paths and programs supportive of physical activity, and by the ongoing implementation of healthy nutrition policies in schools (Macaulay et al., 2003). Finally, the most recent data on type 2 diabetes in the community indicates a prevalence of 12.8% in adults aged between 45-64 years, and that the standardized incidence rate (new cases/1000 people 18 years and older; 8.7 in 1986) has decreased to 5.9 (Horn et al., 2007). Although these rates are higher than those reported in the general adult Canadian population, the stabilization in the incidence of type 2 diabetes in Kahnawà:ke, relative to increases recorded in other First Nations communities during this time

period, suggests that the KSDPP may be one of the influences that has contributed to this positive trend (Horn et al., 2007).

The KSDPP continues to operate 25 years since it was established, under the governance of the CAB and an updated KSDPP Code of Research Ethics (Kahnawà:ke Schools' Diabetes Prevention Project, 2007). I thus posit that KSDPP accordingly qualifies as a successful community-academic partnership, where academy resources continue to be employed under the direction of the community to complete meaningful and community-driven research. Given the maturity and continuity of this partnership, it constitutes an invaluable example from which to learn about how ethical research can be implemented and how community data sovereignty can be achieved.

2.6 Purpose and Rationale

Data sovereignty in Indigenous communities continues to grow as a focus for supporting self-determination for Indigenous peoples around the world. The purpose of this investigation is to provide insight into the establishment and detailed operation of a mature and successful Indigenous community-academic research partnership that operationalizes data sovereignty. This responds to calls in the literature for practical examples to be generated for use in conjunction with existing theoretical guidelines and principles. Accordingly, the research question that will be addressed is as follows,

How does the KSDPP operationalize data sovereignty and facilitate research in a community-controlled manner?

The findings from this study are expected to inform data sovereignty efforts and ethical research guidelines in informing academic researchers and Indigenous communities looking for

guidance in forming new or evolving current research partnerships. Additionally, the research process will provide an opportunity for KSDPP team members to review how they operate and to discuss any challenges they might face related to data sovereignty.

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Chapter 3

The Kahnawà:ke Schools' Diabetes Prevention Project: Perspectives on Data Sovereignty in Indigenous Community-Academic Partnered Health Research

Keywords: KSDPP, Ethics, Governance, CBPR

Abstract

Introduction. Data sovereignty in Indigenous research recognizes the authority of Indigenous peoples over research data and processes, and is an important tool for the self-determination of Indigenous communities. It can foster the collection of data relevant to community interests and responsive to community needs. Existing data sovereignty and community-controlled research guidelines often lack clarity, and could benefit from practical examples drawn from established partnerships. **Purpose.** The purpose of this study is to explore how The Kahnawà:ke Schools' Diabetes Prevention Project (KSDPP) operationalizes data sovereignty and facilitates research in a community-controlled manner. **Methods.** Eight individuals with different member-roles within the KSDPP participated in semi-structured interviews. Additionally, a document review was completed using the KSDPP Code of Research Ethics and letters of information/consent forms from past KSDPP studies. These data were collected, indexed, and analyzed using a thematic analysis. **Results.** Seven themes were identified related to beneficial research, collaboration and communication, capacity and growth, respectful relationships, data stewardship, definitions of community control, and responding to challenges. **Discussion.** By controlling the overall research process through decision-making authority, the community controls the creation, management, and use of data. However, the community values the cooperation and roles played by academic partners and accordingly defines control as appropriate and beneficial to their culture and context.

3.1 Background

Data sovereignty for Indigenous peoples recognizes the authority of Indigenous communities over data about their people, land, and lives (Kukutai & Taylor, 2016). Data sovereignty aligns with the right of Indigenous peoples to self-determination as outlined in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP; Davis, 2016). Smith (2016) outlines the importance of communities generating relevant data to serve modern purposes in restoring Indigenous models of self-governance and knowledge. Further, ongoing data sovereignty can be a valuable guide for Indigenous communities striving for improved health (Walker, Lovett, Kukutai, Jones, & Henry, 2017).

The Canadian government's reluctance to endorse true self-determination by Indigenous peoples is reflected in its opposition during the drafting of and continued resistance against the full implementation of the UNDRIP (Galloway, 2019; Gover, 2015). Accordingly, grassroots Indigenous-led efforts such as the IdleNoMore movement push for rebuilding Indigenous nation sovereignty (Raynauld, Richez, & Boudreau Morris, 2018), rather than idly waiting for top-down systemic and political changes to evoke and permit self-governance. Such approaches are congruent with the growing discourse around data sovereignty in Indigenous community-controlled research, whereby community-academic partners partner in the collection of meaningful data that is governed by the community. Through community-controlled research and data collection, Indigenous peoples can be strategic in determining a role for data, responsive in developing projects to address needs, and culturally authoritative by controlling what is measured and how it is measured (Schultz & Raine, 2014).

Research ethics' guidelines that focus on guiding academic researchers and their community partners in facilitating community-driven research and supporting data sovereignty have been

released and revised in Canada (Canadian Institutes of Health Research [CIHR], Natural Sciences and Engineering Research Council of Canada [NSERC], & Social Sciences and Humanities Research Council [SSHRC], 2014; The First Nations Information Governance Centre [FNIGC], 2014). The principles of ownership, control, access, and possession (OCAP®; FNIGC, 2014) have become a staple in recent discussions about data sovereignty for First Nations in Canada. OCAP®, which was trademarked by the FNIGC to protect its misinterpretation and misuse, was created as an ethical guideline to operationalize self-determination in research by ensuring that First Nations (and by extension other Indigenous) communities have control over the creation, access, and use of their own data (Schnarch, 2004).

The Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans (TCPS2) Chapter 9, is titled Research Involving the First Nations, Inuit and Métis Peoples of Canada (CIHR et al., 2014). Chapter 9, which was informed by the previous CIHR Guidelines for Health Research Involving Aboriginal People (CIHR, 2007), promotes respectful community-academic relationships and community engagement, consistent with popular participatory research approaches (Brant Castellano & Reading, 2010; Castleden, Sloan Morgan, & Lamb, 2012). The TCPS2 Chapter 9 is less tailored to the focus of data sovereignty than OCAP®, though in addition to recommending consideration of the OCAP® principles (CIHR et al., 2014), several of the participatory principles align with efforts to ensure community-controlled research and data.

Data sovereignty guidelines and literature stipulate that the establishment of community governance structures can be an important step in operationalizing data sovereignty to outline data rules, standards, roles, responsibilities, and to establish data infrastructure for use in community (FNIGC, 2014, Smith, 2016). However, expertise in research ethics and in the

collection, analysis, and management of data can be required of community members, which might require more capacity and resources than are available in some communities (Snipp, 2016). Further, ethical concerns exist regarding the collection and management of sensitive data by fellow community members, especially in smaller communities where people may be identified from even anonymized qualitative data and face social turmoil from potential minority opinions (Wilson, Kenny, & Dickson-Swift, 2018).

Community-academic partnered or participatory research presents as one solution to many of the above concerns (Wallerstein & Duran, 2006). Typical participatory approaches, such as community-based participatory research (CBPR), often utilize a community advisory board (CAB) to govern the partnered research (Israel et al., 2005). CABs can be congruent with governance structures outlined in Indigenous data sovereignty literature, although they can require more time and resources to establish and manage than a community may have available and can be extremely taxing for community members (Brunger & Wall, 2016). Additionally, colonial academic culture and expectations, such as timelines and ideas of ownership, can conflict with Indigenous sovereign ideals, and create issues within community-academic partnerships (Harding et al., 2012; Marley, 2018).

Criticisms of community-controlled research and data sovereignty guidelines further highlight the challenges in the operationalization of these approaches. Both the OCAP® principles and the TCPS2 Chapter 9 have been criticized for being vague and lacking clear pragmatic guidance on their implementation (Mitchell & Baker, 2005; Moore, 2015). The highly interpretable nature of such guidelines creates an environment of uncertainty and variable application by researchers and institutional research ethics boards (REBs; Kendall, Sunderland, Barnett, Nalder, & Matthews, 2011; Stiegman & Castleden, 2015). Considering these practical challenges in

implementing community-academic partnered research and in using established guidelines, it is clear that the operationalization of community-controlled research that fosters data sovereignty is not easy to accomplish. Accordingly, authors have paired their criticisms of ethical guidelines with calls for examples of how successful partnerships practically operationalize data sovereignty, information that could be a valuable supplement to the ethical guidelines (e.g. Mitchell & Baker, 2005).

The purpose of this study was to document one such example of a mature and successful Indigenous community-academic research partnership that operationalizes community-controlled research in a way that facilitates data sovereignty. The partnership of focus is the Kahnawà:ke Schools' Diabetes Prevention Project (KSDPP), a 25-year old project established in the Kanien'kehá:ka (Mohawk) territory of Kahnawà:ke, QC. In addition to being recognized as a best practice by the Public Health Agency of Canada (Public Health Agency of Canada, 2016), the KSDPP's unique Code of Research Ethics has been regarded as an "innovative" document (Macaulay et al., 1998) and referenced in the TCPS2 as an ideal community model of research governance (CIHR et al., 2014). Given its success and maturity, the KSDPP constitutes an invaluable example of how community-academic partners can facilitate ethical community-controlled research and data sovereignty.

3.2 Method

3.2.1 Overview of Methodology and Data Collection

This project was facilitated as a qualitative and descriptive case study (Yin, 2014) to explore the phenomenon of operationalized data sovereignty in a community-academic partnered research. The subject or case of focus is the KSDPP. The case study is based on a constructivist

paradigm that emphasizes subjective understandings of how things work according to each research participant or data source (Baxter & Jack, 2008). This approach was selected because it fostered story sharing from each of the participants who offered their unique perspectives of the KSDPP and data sovereignty.

In my investigation, I explored multiple sources to ensure that various facets of the phenomenon could be uncovered (Baxter & Jack, 2008). A conceptual framework was used to guide data collection from two main data sources. Information was gathered from project documents (KSDPP Code of Research Ethics and past letters of information/consent forms) and from diverse KSDPP team members (community staff, CAB members, and researchers) ensuring various perspectives. Both data sources were supplemented by my experience and observations working with the project for the past two years.

3.2.2 Institutional and Community Ethics

This project received clearance from the Queen's University General Ethics Review Board (GREB; TRAQ # 6026710, clearance letter is in Appendix B). Additionally, as per the KSDPP Code of Research Ethics, the project was discussed with KSDPP research team members before being presented to, discussed with, and approved by the KSDPP Community Advisory Board (Certificate of Approval in Appendix C). Furthermore, the interview guide was developed in collaboration with CAB members, CAB reviewed and approved the project findings and interpretation, and all data from this project are owned, controlled and possessed the KSDPP.

3.2.3 Conceptual Framework of Data Sovereignty in Partnered Research

A conceptual framework of features indicating operationalized data sovereignty in Indigenous community-academic research partnerships was generated by reviewing several prominent works

addressing Indigenous data sovereignty or data sovereignty in Indigenous partnered research (Harding et al., 2012; Schnarch, 2004; Snipp, 2016). Table 1 features indicators of data sovereignty and the published source of the indicator. This framework was used to inform the interview guide questions along with CAB input and approval. It was also used to inform the indexing of all data for the thematic analysis.

Table 1. Data sovereignty indicators and published source.

Published Source	Data sovereignty indicator
Snarch, 2004	Community relevance and community usefulness are used to determine the worth of a study
	A community developed code of ethical research, which may differ from federal or partnering institutional research guidelines
	Community has a right to seek control in all aspects of the research and information management processes that impact them.
	A sense of community collectively owned information
	Community may have direct possession of data to assert ownership
	Group or institution may be caretaker or steward of community data and is accountable to the community
	Community has access to information and data about themselves regardless of where they are currently held
	Community manages and makes decisions regarding access to their collective information which may be enforced through formal protocols
Harding, et al., 2012	There are channels and timelines for communication between community and partners
	Community determines acceptable data sources, e.g. information heard in conversations, informal discussions, or social gatherings
	Community has outlined protocols for the transport, storage, security, and retention of data
	Community controls permissions regarding, and ownership of, formal and informal data throughout the research process
	Community can set conditions for data analyses, including scope of research, privacy issues, and intellectual property rights
	Community and partners agree on principles of co-authorship and a transparent review process for publications, presentations, all forms of information dissemination
Snipp, 2016	Community collects data for internally motivated purposes and goals
	Data collected reflects the interests, values and priorities of the community
	Reliance on outsiders with existing resources is managed, and compromises of community data control and sovereignty are minimized
	Expertise in the production and management of data of all types is present in the community
	Information is managed in a way that is consistent with the laws, practices and customs of the community
	The community controls data content – meaning what is collected, for what purpose, and how it is used.
	Community determines who belongs among them and who should be excluded for data collection
	Community has the power to determine who has access to these data
Privacy and confidentiality promoted according to community laws and regulations.	

3.2.4 Data Collection

KSDPP Document Review

A review of the KSDPP Code of Research Ethics and 10 letters of information-combined consent forms (LOIs) from recent KSDPP research projects were completed (including my own LOI). The Code of Research Ethics was downloaded from the KSDPP website. I searched filing cabinets and computer storage at the KSDPP office for project LOIs; none were obtained from the filing cabinets, and two were obtained from the office computers. I then searched KSDPP research team meeting minutes from the previous nine years to compile a list of recent research projects and the researchers involved. I then reviewed copies of the biannual reports that KSDPP had submitted to the Kahnawà:ke Onkwa'takaritahtshera Health and Social Services agency dated as far back as 2011 to cross-check the list of projects generated from meeting minutes. From this list, I then contacted each researcher to request LOIs directly from them; an additional seven LOIs were thus obtained.

Qualitative Interviews

Participants. Interview participants were all individuals within the KSDPP with extensive experience and knowledge about the overall operation of KSDPP. Participants were academic and community researchers, community project staff, and/or CAB members. Participants had been involved with the KSDPP from 11 years to 25 years, with some members having subsequently or concurrently played varying roles (e.g., community project staff and community researcher).

Sampling and Recruitment. Purposeful sampling was used to identify potential participants. Specifically, criterion purposeful sampling was used to recruit members who would

meet the criteria of having extensive experience and knowledge about the operation of the KSDPP and a longstanding membership (Palinkas et al., 2015). Potential participants were identified from a discussion between my supervisor Dr. Lucie Lévesque and me, with input from Dr. Alex McComber of the KSDPP, with saturation of perspectives in mind. LL and AM have extensive experience within the KSDPP and identified past and present project members who would have the experience to speak to the operationalization of data sovereignty within the project. Eight (n=8) participants were invited to participate and all eight consented to be interviewed.

Interview Guide. The indicators in Table 1 were used to generate questions and follow-up prompts for a semi-structured interview guide. The semi-structured approach provides the same starting point for discussion of the topics across participants while allowing for flexibility to follow-up on emerging commentary (Roulston, 2010). I met with a sub-committee of three CAB members to thoroughly review and finalize the interview guide (see Appendix D). This resulted in a revised list of questions and probes, with refinement of the language of most questions.

Interviews and Transcripts. Five interviews were completed in person and three interviews were conducted with Zoom video conferencing software. Of those completed in person, four were completed in Kahnawà:ke (three at the KSDPP office, and one at the participant's home); one was completed in a university office. The three completed over Zoom because one participant was out of the country and the two others were unavailable to meet in person. All participants consented to having the interview recorded. The recordings were transcribed verbatim and sent back to participants to review and offer clarifications, interpretations, or to redact passages. Following the interviews, half of the participants offered

clarifications on transcripts or participated in brief follow-up conversations to clarify or share ideas.

3.2.5 Data Analysis: Thematic Analysis

Interview transcripts, the KSDPP Code of Research Ethics, and letters of information were used as data sources and combined for the thematic analysis. After having transcribed the interview recordings and reviewed all of the transcripts and documents, I was thoroughly familiarized with the content. I first used indexing to manage the data. Indexing involves sorting excerpts from the data (i.e., transcripts and documents) into appropriate indexes that are labelled based on the topic of the excerpt (Ritchie, Lewis, Lewis, Nicholls, & Ormston, 2013). By referring back to the data sovereignty indicators (Table 1) as I read through the data, I was using the framework to inform the indexes (e.g., “Community control of data access”). Additionally, I paid attention to recurrent topics that were not anticipated by the framework (i.e. “Funding”) and created indexes representing them as needed. Indexing made it clear where data fit into different topics as informed by the framework or that had emerged (Bloor & Wood, 2006). I continued to create, refine, and combine indexes in response to the data, and often assigned each excerpt to several indexes as appropriate to maximize inclusion of data across the indexed topics and reflect nuances in the data (Bloor & Wood, 2006). Having sorted the data into these indexes, I then coded within each index. The analysis from this point aligned more closely with the Braun & Clarke (2006) six-step process. Indexing before coding allowed me not only to see how data fit into the theoretical framework (Ritchie et al., 2013), but also addressed existing criticism of traditional coding by ensuring that the context of the passages is maintained and considered when generating codes (Bryman, 2001). Braun and Clark’s first step (familiarization) had already occurred, as this was done to inform indexing. Following the remaining steps in Braun

and Clark (2006), codes were generated from data within each index while paying attention to the topic that index represented. Once the coding was completed within each index, the codes were pooled together across indexes, with any redundant codes being combined. Codes continued to be reviewed, combined, and grouped into subthemes and themes, which were reviewed further and eventually finalized and defined (Braun & Clarke, 2006).

3.2.6 Qualitative Rigour

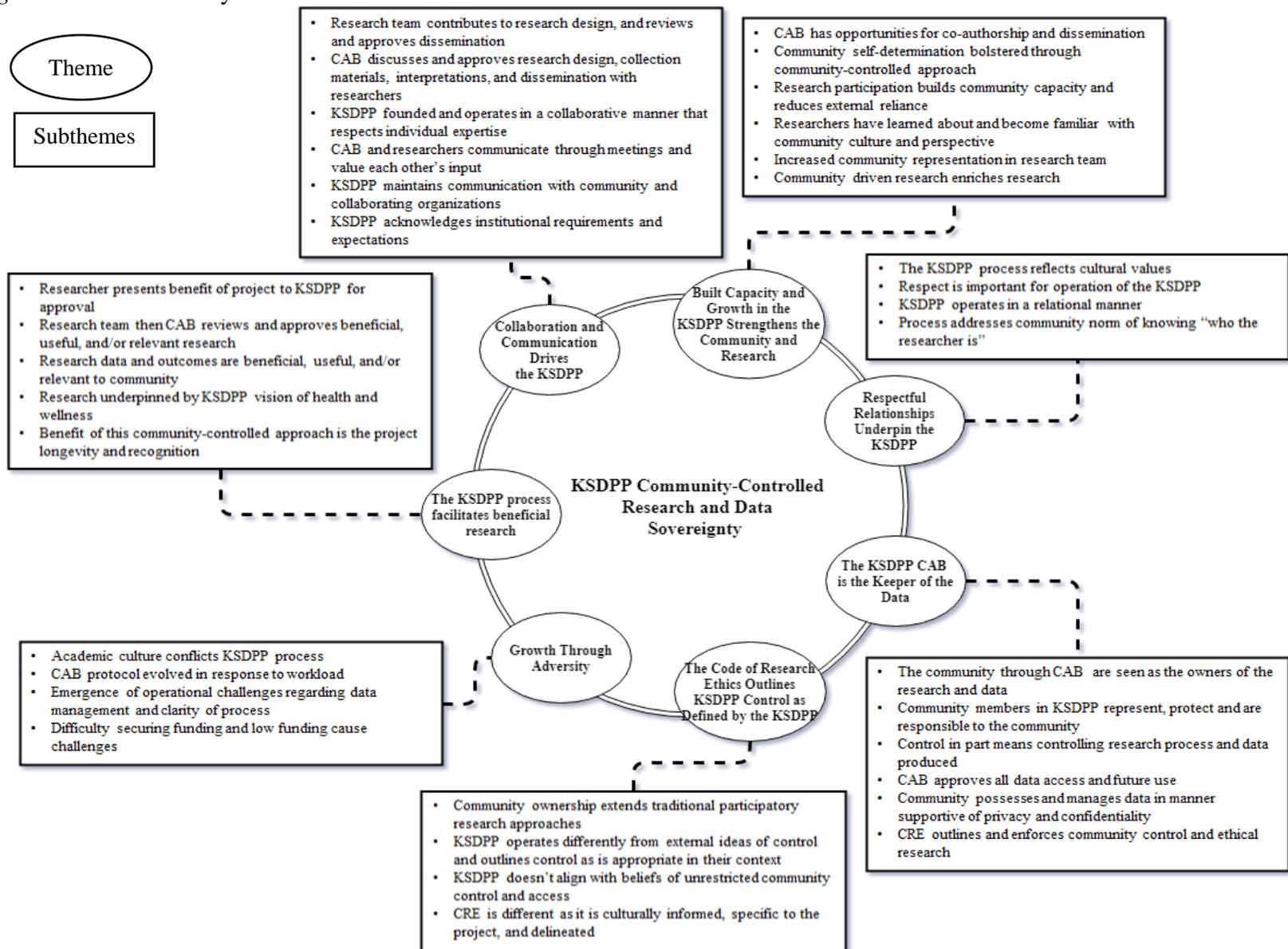
To promote the transferability of a qualitative study, it is important to verify the rigour of the data collected. The verification of my data was completed using two commonly discussed methods, triangulation and member validation (Ritchie et al., 2013). For triangulation, the KSDPP Code of Research Ethics was analysed with LOIs and interview transcripts. This provided an opportunity for a comparative look across these sources, and verification of data content, and strengthened conclusions drawn (Patton, 2002). Member validation was accomplished by returning transcripts to interviewees and inviting ongoing conversation about the transcripts to share any clarifications or interpretations (Lewis-Beck, Bryman, & Liao, 2004). As mentioned prior, several participants offered brief clarifications, and a few further continued the conversation to emphasize their key interpretation or add ideas at a later date. I also presented themes and subthemes back to a KSDPP community member (who was interviewed) for review of content and wording. His feedback was incorporated directly into the final themes, subthemes, and the way in which they were described. Ritchie et al. (2013) further identify that if the design allows for all perspectives to be captured, transferability of the findings is further increased. This was ensured by recruiting from a diversity of member-roles within the KSDPP, including community and external members.

Beyond the methodological design, I had further opportunities to strengthen the rigour of my project. Participant observation is the process by which researchers observe and participate in the activities of the case being studied to better understand those activities (Kawulich, 2005). As a member of the KSDPP for two years, I observed and participated in the KSDPP research process, adhering to the KSDPP Code of Research Ethics in the present study. This has given me firsthand experience with which to understand the information provided by interviewees and the information extracted from the documents. Finally, to further strengthen my analysis and to account for bias, a ‘critical friend’ who was becoming familiar with the KSDPP, but had not been exposed to the data collection phase of this study, was used as a sounding board for decisions made during the analysis (Foulger, 2010). The critical friend assisted in coding a share of the indexes, reviewed and discussed the pooled codes, and contributed to the generation of codes into subthemes and themes.

3.3 Presentation and Discussion of Results

Seven themes emerged from the qualitative analysis. These themes relate to research benefits, collaboration and communication, capacity and growth, respectful relationships, data stewardship, self-determination, and growth through adversity. These themes and their subthemes are illustrated in Figure 1. The following discussion elaborates each theme further and situates it within the literature. Table 2 outlines practical recommendations and information about project operations related to each theme learned from the KSDPP. For further pragmatic detail, I recommend review of the KSDPP Code of Research Ethics, which can be retrieved online (https://www.ksdpp.org/media/ksdpp_code_of_research_ethics2007.pdf).

Figure 1. Thematic analysis themes and subthemes.



Theme 1: The KSDPP Process Facilitates Beneficial Research. The KSDPP approves research that aligns with the project vision of a healthy Kahnawà:ke. This research yields outcomes that are beneficial, useful, and/or relevant to the community and the project. This theme outlined the process by which the KSDPP is designed to filter research and ultimately the creation of data that will be relevant to the community.

“...the Community Advisory Board makes a judgement on whether projects are suitable in relation to that [KSDPP] vision, but also the community has a very good idea of what its own needs and priorities are. So, if a researcher came along, and the project that is proposed doesn't meet the community's needs or priorities, they won't approve it” –

Academic Researcher

This quote echoed what all individuals I interviewed shared regarding the approval process for a proposed research project within the KSDPP. Some individuals further mentioned that ideas are usually first presented to or originate within the research team. One community researcher shared that the research team additionally reviews an idea for academic relevance:

“It will distill down to a possible set of research questions that we'll talk about at the research team. Because that's where essentially the role of the research team is to ensure it's a feasible research question, you know, that it makes sense from a literature standpoint, that it's innovative, and that it fits of course with KSDPP overall, like what we just talked about – our values and our mission” –

Community/Academic Researcher,
Former CAB

This process of community review is crucial to the practice of data sovereignty as it ensures that the community is motivated by their own goals in the collection of data that will reflect

Kahnawà:ke and KSDPP priorities, values, and interests (Snipp, 2016). Schnarch (2004) maintains that traditional academic measures of quality are subordinate to considerations of the community usefulness and relevance of a study. As articulated in the quote above, rather than treating traditional academic quality criteria as subordinate or discounting academic considerations entirely, these are considered separately by the research team (RT) in addition to evaluations of community usefulness and relevance that occur both at the RT and at the CAB levels.

“Some of the elders approached us and... asked us if we would do something to prevent this disease [type 2 diabetes] and would we please focus on the young, would we please focus on children, because they were adults, they knew they were very set in their ways, they had leg amputations, they had their heart attacks and their strokes, and they felt focusing on the youth was high priority.” – Academic Researcher, Co-Founder

Research facilitated within the KSDPP benefits all partners with a primary motivation that aligns with the project vision of a healthy Kahnawà:ke. Speaking to the initial motivation for the formation of the KSDPP, the above quote articulated the importance of community values and goals motivating research (Snipp, 2016), as the community knows what projects will respond to community needs (Schultz & Raine, 2014). It was this community knowledge and motivation that directed the inception of the project.

Theme 2: Collaboration and Communication Drives the KSDPP. Since the beginning of the project, the KSDPP has utilized researcher and CAB collaboration and ongoing communication within and beyond the project, acknowledging everyone’s expertise and needs,

and keeping the community informed. This theme articulates the dynamic within the KSDPP team. While RT and CAB are separate groups within the project, they collaborate throughout the research process and maintain communication through regular monthly meetings.

“The partners will work cooperatively and collaboratively throughout the research process” –
KSDPP Code of Research Ethics

“I’m realizing the impact of the governance structure that we have is that, you know, we bring, we all agree that we are part of this endeavour together. And, within that we collaborate, we discuss, we disagree, we agree, we work together, and that’s been sustained, you know, it’s been sustained for all this time” – Community/Academic
Researcher, Former CAB

Interviewees shared that the collaboration and discussion within and between the researchers and CAB is ongoing. Throughout all aspects of the research process, from project purpose to dissemination, RT reports to CAB to discuss, incorporate feedback, and address community concerns. This continual cooperation is congruent with an important principle of community-controlled research, which is establishing communication channels and timelines among stakeholders within the project (Harding et al., 2012). The monthly RT and CAB meetings provide a regular opportunity for cooperation across the team. The Kahnawà:ke community at large and other organizations are also stakeholders in the project, and appropriately, communication is maintained with the community beyond the KSDPP.

“KSDPP also has all sorts of activities that they partner with other organizations for... there’s been constant communication with the Youth Centre... in the years where the

project was really intensely running, there was constant communication with the local radio station, with the local newspaper, etc” – Academic Researcher

“Being from the community, we pretty much know who’s who, you know, and we keep them informed... Our basic way of getting information out to the community is just by making posters and posting it in all convenience stores and areas where a lot of people will see it” – Community Staff, CAB

The collaborative process is also very important to data sovereignty. Schnarch (2004) outlines past issues within partnered research that set the stage for OCAP®, including instances in which researchers designed and secured funding for projects without any community input, and instances where researchers treated community researchers as informants rather than colleagues. Harding (2012) argues that without meaningful communication and collaboration with community, outside researchers might apply reductionist approaches that ignore community knowledge and levels of acceptable risk for community members. The KSDPP was founded on this model of collaboration and communication between researchers and the community. One interviewee told the story of how the KSDPP mission, vision, and Code of Research Ethics were created collaboratively within the team over many months. She shared that the opportunity for the researchers and community to come together and articulate their needs and expectations from the project relative to the research data and processes was crucial for building trust as a new team and set a strong foundation for the functioning of the KSDPP.

Theme 3: Built Capacity and Growth Strengthen the Community and Research. The KSDPP has fostered built research capacity through opportunities for community members to gain experience working in research project design, collecting and managing data, the interpretation and analysis of data, and dissemination opportunities. This built capacity has

increased community participation in the research team and research process over years of the KSDPP. In turn, researchers involved with the project have gained experience working with the community, learned about community cultural practices, and learned about conducting culturally safe research. This type of knowledge exchange can bolster community input and community control of the research, which promotes community self-determination and has the potential to result in richer research. Many of the interviewees referenced the reciprocal capacity built by the KSDPP, and further how it has evolved the project.

“I think when we started the research team meeting, it tended to be more the researchers, but as the research became more tightly integrated with the program, we started to have [community staff members] at the meetings, and [CAB member] at the meetings. And so, there was more of an open conversation and more of that direct input into the shaping of the research” – Academic Researcher

“The outsiders who were involved all this time are evolved themselves... I mean everyone was sympathetic from the beginning... but we’re much more knowledgeable, we’re much more, you know, just we feel much more, like we understand the thinking of the community. Still never will perfectly obviously, or even close to it, but better than 20 years ago, you know? So, everyone is evolved.” – Academic Researcher

The opportunity for direct shaping of the research by the community is crucial for data sovereignty, as discussed in Theme 2. The inclusion of community voices throughout the research process addresses criticisms of community members being used by researchers for mere consultation (Kendall et al., 2011). Over the 25 years of the KSDPP, the transition from a predominantly non-Indigenous led research team to one in which Indigenous researchers are the main KSDPP research leads is also crucial to community-controlled research and data

sovereignty. This built research capacity aligns with Snipp (2016) who states that an essential mechanism of data sovereignty is community expertise in the production and management of data. Congruently, Schnarch (2004) outlines the importance of capacity building within a community-controlled project, positing that the capacity to access resources, complete research, and disseminate results makes community control possible.

The KSDPP Code of Research Ethics requires that researchers implement capacity building opportunities when possible, a notion reiterated by most of the individuals interviewed. These capacity building opportunities represent a way to reduce reliance on external parties and accordingly minimize compromises to data sovereignty (Snipp, 2016). In addition to hiring community research assistants for data collection and management, interviewees spoke to the larger scale capacity that has been built within research team and CAB.

“Now there’s been so much capacity built, you know, not just more research assistants or employees are from the community, but faculty members are from the community. You know? Or, now the scientific director is from the community. And, it makes a huge difference” – Academic Researcher

“CAB members reviewing theses was not part of the original KSDPP. That came later... I think when community, you know, the capacity development within community, and community members feeling confidence and secure in reviewing theses” – Academic Researcher, Co-Founder

Some respondents spoke to the effect of researchers’ experience working in the community context and a learned appreciation for the community perspective. With experience, the researchers have a better understanding of what the community wants, which supports the

community-driven approach as it means research decisions have more opportunity to be informed by community perspective.

“The [research] team is also experienced in working with the community and around Indigenous methods etcetera long enough that, that’s the first filter. And research team can, I don’t wanna say... it’s not about predict or read the minds of CAB, but knows the community... to the point where the ally researcher can say “Mmm, you know what, I don’t think the community’s going to go for that because dot, dot, dot”” – CAB, Community Researcher

This high level of community control and capacity in creating and managing meaningful data is supportive of community self-determination, a larger goal to which data sovereignty is ancillary (Schnarch, 2004). An additional benefit, as mentioned by several interviewees, is that community input throughout the research process, and review and involvement as authors on manuscripts, always makes the research outputs much richer.

Theme 4: Respectful Relationships Underpin the KSDPP. Respect among project members and the formation of relationships is important and beneficial within the KSDPP, as it reflects community cultural values and norms. This theme is related to Theme 2, with the added specification that the cooperation across the KSDPP team is underpinned by mutual respect and a relational approach to research.

“Again, in our identified values, respectful relationships, you know? And working together in good ways to find solutions not problems, to take down barriers not put them up. Those are things that make... I think that have given strength to the project and to the

community, and that relationship between research and community” – CAB, Community Researcher

“We kind of have like a family structure, you know, like a clan structure. It is a family structure, but, there’s like a strong affiliation that happens because I think people agree to be a part of this relationship that acknowledges everybody’s equal contribution, but also the differences that are just there because people are doing research for different reasons... but that we can agree to do things in a way that respects everyone’s needs” – Community/Academic Researcher, Former CAB

Community-research relationships founded in trust are critical to the successful operation of participatory research, and often evolve out of collaboration (Castleden et al., 2012). This is demonstrated in the KSDPP approach. The KSDPP Code of Research Ethics outlines the requirement for the researcher to visit the community; this is typically the starting point of forming relationships within the community. Researchers interviewed often shared that they respected and valued the community knowledge and expertise provided by KSDPP community partners; this is considered to be essential to form strong, trusting relationships (Castleden et al., 2012). From the community perspective, the relational approach is also reflective of cultural values and community norms.

“I think that that’s customary – like how we do things, we just welcome people, carefully, listen and not to dismiss them and consider what people are saying you know – as part of our decision making model, as part of our international relations that we have” – Community/Academic Researcher, Former CAB

“Back in the 1700s... where they had to meet up with other... Indigenous communities, and you kind of had to go to the wood’s edge, and you... had to introduce yourself and you have to state what you are coming there for” – Elder, CAB

The cultural value of international relationships (as defined by the formation of relationships between traditional sovereign Indigenous and other contacted nations or peoples) is communicated in the above passages. Additionally, respondents mentioned the history of harmful research in Indigenous communities as a source of a community norm of hesitation and wanting to know about the researchers who come into the community. Accordingly, the process to ‘enter’ KSDPP, and the stipulations related to the collection and management of data, are reflective of the norms and values of the community (Snipp, 2016). The use of culture-based frameworks and approaches is a valuable strategy employed by First Nations organizations striving for sovereignty (Schnarch, 2004).

Theme 5: The KSDPP Community Advisory Board is the Keeper of the Data. The community owns the research, controls the collection of data, restricts data access, and possesses the data through the decision-making authority held by the KSDPP CAB, who represents and is accountable to the Kahnawà:ke community. This theme stipulates that the community, through the KSDPP CAB, owns the data by being in charge of the research. This approach counters historical problems about data control and decision-making related to data sovereignty as highlighted by Schnarch (2004). Contrary to traditional academic controlled research, the KSDPP has successfully instilled a research and data governance structure that, while benefitting from collaboration, is ultimately controlled by the CAB.

“[Control is] around making decisions. So, it’s community decision making on what data are collected, why it’s collected, how it’s collected, and who is going to collect it and

how it's going to be analysed and translated and stored. So, it very much is underpinned by collective decision making and having community and program staff driving that decision-making process rather than researchers” – Academic Researcher

Individuals shared that the CAB is ultimately in control of the data, as all decisions about research (including purposes, data collection materials, current and future data access and use, data storage, and dissemination) must be reviewed and approved by the CAB. This is congruent with the general sentiment across Indigenous data sovereignty literature that calls for community control of data (Harding et al., 2012; Schnarch, 2004; Snipp, 2016). Tied closely to the concept of control is the perception of ownership. The KSDPP CAB, as representatives of the community of Kahnawà:ke, were similarly described as the owners of the project and data. This is reflected in past research that studied perceived project ownership of the KSDPP and found that the community is consistently considered the owners of the KSDPP (Cargo et al., 2008; Cargo, Delormier, Lévesque, McComber, & Macaulay, 2011; Cargo et al., 2003).

“It's always been Kahnawà:ke's project. And so, they're deeply invested, and that is why in the times when the resources were scarce, that somehow things kept going... it was owned by the community. It was always their baby, right? And it wasn't, if it had been the researchers' baby, then it would have ended a long time ago.” – Academic Researcher

As outlined in Schnarch (2004), OCAP® presents ownership as a pillar of data sovereignty whereby the community collectively owns information the same way an individual would own their information. Schnarch (2004) further outlines another model of community ownership could be that a caretaker or data steward can be chosen to be in charge of the data on the community's behalf; this person or entity ought to be accountable to the community. This notion was supported in several interviews where the CAB and other community members within the

KSDPP were considered to be accountable to the community and responsible for protecting the community from harm. Appropriately, the KSDPP Code of Research Ethics, most of the LOIs reviewed, and all of the individuals interviewed consistently reported that data is possessed by the community and stored in Kahnawà:ke, either physically or digitally.

Theme 6: The Code of Research Ethics Outlines KSDPP Control as Defined by the KSDPP. The KSDPP Code of Research Ethics is a unique document that carefully leveraged accepted participatory principles (Minkler & Wallerstein, 2011) with the KSDPP’s definition of what community control means, while still valuing the role of academic partners. This theme mainly reflects emergent discussion about how the KSDPP operates in a community-controlled manner according to its own model of what control ought to look like. Some participants shared concerns they had with existing guidelines or research protocols for Indigenous community-academic research partnerships.

“When I read some of the documentation, and the words that are used, and the approach that’s used, it’s much like, you know, we’re going to control you... the collaborative part is less evident in the documents” – Community/Academic Researcher, Former CAB

This interviewee also shared that a perspective she has observed in the community and some community-partnered research is the idea that the community should have full control over everything in the research, essentially acted out as having power over the researcher and making them “jump through hoops”. She explained that this is an idea “that we don’t share at KSDPP, in the same way”. Other respondents similarly shared that the KSDPP approach is that the community (through CAB) does have control over the research, but the project still collaborates with researchers as partners, values the role they play, and considers their input and perspectives on decisions around the creation, management, and use of data.

“I think CAB enjoys the relationship too. They enjoy that they feel safe, and that they are the only ones with the vote, but they enjoy the discussion... If it stopped benefitting them, they would be the adults in the room who would say “this isn’t doing anything for us, we can have all the decision-making power without having you here” ... So, it’s not just that “we have control”, they, you know, “we’re enjoying this relationship, but on our own terms”. I think that’s the important part. So, it is collaborative, and they do have control.” – Academic Researcher,

The important distinction here is that the KSDPP has defined control as controlling the research by having decision-making authority, while working with – rather than controlling – the researcher. This contrasts the norms or attitudes some interviewees had observed elsewhere in and beyond the community. Similarly, a community staff member interviewee shared that another attitude that she has observed in the community is the belief that anyone in Kahnawà:ke should be able to access data, a belief to which the KSDPP doesn’t subscribe. This raises the question about what norms or customs the KSDPP ought to be following in the way they manage and control the data (Snipp, 2016). It is important to acknowledge that we cannot assume communities will have one harmonized opinion regarding issues, and we ought to focus on the core values that transcend narrow interest (Snipp, 2016). Accordingly, the way KSDPP defines and enacts control ought to ultimately reflect core community values. The KSDPP’s use of collaboration and reliance on trusting relationships within their definition of control aligns with cultural values and community norms, as discussed in relation to the above themes.

The KSDPP has designed a Code of Research Ethics that outlines community control in a way that is beneficial to the project and the community. This point articulates the importance of building agreements and partnerships that are specific to the community context and culture,

rather than trying to apply general all-encompassing guidelines. This idea has been presented previously by authors who outline ways in which unadjusted guidelines have not been appropriate to community partnerships (e.g. Brunger & Wall, 2016; Mitchell & Baker, 2005). Several discussions I had with the study respondents reiterated this idea through examples in which a community might be ill-equipped or unwilling to take on the responsibility of controlling certain aspects of the research. One interviewee explained how this can occur while remaining congruent with community-control and data sovereignty ideals and guidelines.

“Whatever model you take is going to work for that partnership, and if it’s about ownership, it is ultimately going to have the community as the biggest stakeholder because they have the most at stake in that literal sense of deciding how it’s going to play out. But, the details of it will be different... the community, you know, can defer control of certain aspects of it, but at their own decision and for their own benefit.” – Academic Researcher

The tailored way in which the KSDPP Code of Research Ethics outlines the KSDPP process is of no surprise, given that it was made specifically “for the people, by the people” (Academic Researcher). As expected by Schnarch (2004), the KSDPP Code is different from other funding agency produced or general ethical guidelines. For one, several interviewees reported that the KSDPP Code of Research Ethics is delineated and clear in outlining obligations and processes for community and partners. This is in direct contrast to the highly interpretable and vague nature of existing guidelines (Mitchell & Baker, 2005; Moore, 2015; Stiegman & Castleden, 2015). The largest difference however, as reported in most interviews, is that the KSDPP Code of Research Ethics is informed by Kahnawà:ke cultural principles. This supports the notion that the KSDPP research process is culture-based, as KSDPP Code of Research Ethics was formed in

collaboration with the community and incorporates the community world view. In her interview, an elder compared the process outlined in the KSDPP Code of Research Ethics to when visitors come to dinner at the kitchen table, and people are uncertain about where they can sit. Some people might be very particular in where they like to sit, and some people are more flexible. The KSDPP process is one where the community invites everyone to the table to figure out if they can sit together and resolve any issues and conflicts in opinion or perspective.

“Everybody’s in their own, you know, mind frame... but it works and those are the things that you need to discuss, you know? We’re going to have visitors here so everybody, you know, everybody move down [the table]” – Elder, CAB

This conversation was very insightful, as it articulated the international and collaborative approach outlined in the KSDPP Code of Research Ethics, while framing it in a community practice and perspective that highlighted the cultural roots of the KSDPP.

Theme 7: Growth Through Adversity. Challenges can and have emerged in the community-controlled research process, but the KSDPP has always addressed these challenges and managed to move forward. Challenges have promoted growth at times to overcome issues such as CAB exhaustion due to high research related demands, and stubborn academic culture. Most of the challenges shared were consistent with prevalent challenges outlined in participatory, community-controlled, or data sovereignty literature. For example, respondents identified that there can be issues when working with researchers trained in a colonial academic culture, stemming from their expectations about how research should work (Harding et al., 2012; Marley, 2018).

“You have to be very clear and... put your foot down, and say “no” ... if it’s just clearly to benefit the researcher or that department, then, you know, you just want a bunch of guinea pigs to experiment on...” – Community Staff, CAB

“We had two researchers on the initial team who actually left... participatory research wasn’t for them, they felt things were moving too slowly, and decisions, you know, took too long to happen... they just didn’t like the sharing of power that participatory research requires” – Academic Researcher, Co-Founder

The KSDPP Code of Research Ethics was referenced as a solution to and/or way to avoid these challenges. Several respondents presented the KSDPP Code of Research Ethics as a “filter” through which all research requests must pass. Harding et al. (2012) further outline issues of authorship within academic culture, and states that principles of co-authorship should be established. In a revision of the Code of Research Ethics, the KSDPP outlined authorship guidelines that acknowledge the opportunity for community members and knowledge holders to be co-authors. The guidelines require that a potential author be active in the writing process and significantly contribute. One interviewee explained the importance of this rule, revealing that the motivation for the stipulation largely resulted from past issues with an academic norm.

“...certainly, from the university side of things... I know that in the early days of KSDPP it happened, it doesn’t happen anymore. But, because people in somebody’s department or by association, maybe they’re an expert on a particular topic that the paper’s about, but they weren’t involved in it, or maybe one of the contributing authors consulted with that person on the side, and they would get put in as an author. That doesn’t work. No. you have to have your face at the table” – CAB, Community Researcher

This is one example of how the KSDPP has evolved in response to emerging challenges. Another instance was in response to the heavy workload of CAB members. CAB members are often volunteers with other jobs and personal responsibilities, and can face exhaustion from a high volume of research (Brunger & Wall, 2016). A few interviewees outlined how the CAB protocol changed over time to assign a sub-committee to individual projects, rather than have all members be responsible for all projects.

“It was becoming very burdensome for all of the Community Advisory Board members to become involved with all of the research projects, so... researchers have been assigned, or no, they have gathered their own, you know, individual committee, like two or three people... I think it’s helped promote capacity building for community members as well. Because they have a chance to get in-depth knowledge of one project rather than trying to keep track of all of it. Because, community members were becoming exhausted. I mean, it’s a huge commitment.” – Academic Researcher, Co-Founder

A separate category of challenges that emerged was funding. Respondents shared that the research process can become challenging with a lack of funding, as there is no resource to hire community research assistants and staff who are important to the community-control of the project. Previous reports have acknowledged the ineffectiveness of guidelines for ethical research with Indigenous peoples when funding is not attached (Aboriginal and Torres Strait Islander Commission, 1991). Difficulties can emerge in acquiring research funding for Indigenous community-academic partnerships, such as uncertainty about how funding should/can be acquired before conversations about the research occur within the community (Castleden et al., 2012). One researcher addressed this challenge by outlining the process through which researchers meet with CAB and discuss an idea for a research grant. CAB can then grant

an “approval of principle”. Following this, a sub-committee of research team members will write the grant proposal and if successful, return to CAB to build the elaborate protocol in collaboration with the community.

A few more challenges were mentioned regarding the management of large amounts of data, and new team members. However, these were often related to challenges discussed above, as solutions could be related to funding or ensuring incoming members were familiar with and would abide by the Code of Research Ethics. The general impression was that logistical challenges will always emerge and need to be dealt with however possible by the partnership.

“I think that KSDPP has always done the best that KSDPP can do, and I would say that that best can vary based on the resources available” – Academic Researcher

“We know it’s not impossible, and we’re just going to do it and... our academic partners were always supportive of that as much as possible, to support community direction. And then you know, if it just wasn’t feasible, we find a feasible solution, and it didn’t matter if it was in, had to be in a university solution” – Community/Academic Researcher, Former CAB

Table 2. Practical recommendations for implementing data sovereignty within Indigenous community-academic partnered research

Theme	Practical Recommendations
Theme 1: Beneficial research facilitated	<ul style="list-style-type: none"> - Establish a community governance structure that enables the community to review and approve research that will benefit the community - Clarify distinct roles of research team and CAB members: A separate research team and CAB allows main responsibilities to be spread out, with the research team having more focus on building the initial research proposal, and the CAB giving feedback and considering community relevance and benefits before voting and issuing a certificate of approval - Have research ideas vetted by the research team before they are brought to the CAB to reduce CAB burden - Collaboratively create a project vision and/or mission statement to make it clear what the interests and goals of the project and community are, so individuals can ensure research questions and data collection purposes will align with those
Theme 2: Collaboration and communication	<ul style="list-style-type: none"> - Provide regular opportunities for collaboration and cooperation between researchers and CAB - Ensure all team members acknowledge the expertise and contribution of other team members, and have an open dialogue about needs and expectations - Hold regular (e.g., monthly) Research Team meetings to have ongoing discussions and provide collective guidance about research occurring, new ideas, dissemination opportunities, challenges, etc. - Hold regular (e.g., monthly) CAB meetings (ideally one week after Research Team meetings) to have discussions and make collective decisions about project activities - Provide CAB with regular research updates and opportunities to ask questions in between meetings. - Identify and train a community administrator to organize CAB meetings and maintain communication between the meetings - Establish ongoing communication to the community at large to sharing updates, findings, and opportunities via flyers in high traffic areas/community centers, local newspaper and radio stations, focus groups, booths at community events/fairs, social media, etc. - Designate a community ombudsperson to mediate community concerns related to the project - Form partnerships and maintain communication with other community establishments, groups, and stakeholders (that align with the project mission and vision, e.g. health center, school council, etc.) in order to work together, share resources and opportunities, and have a wider reach in the community

Theme 3: Built capacity and growth	<ul style="list-style-type: none"> - Create opportunities for community members to be involved in the research process - Pair student trainees with community members where appropriate - Train community members to develop research skills (e.g., data collection and analysis) - Provide training opportunities for Indigenous students – especially for students from the community- and foster opportunities for community research certification and graduate degrees - Facilitate partnerships with academic institutions and support community member involvement in the academy - Support outside-community researchers in learning about the community culture and context and promote thinking through the community perspective to enhance community-relevant thinking by outside researchers - Create opportunities for CAB members and other community members to be involved with dissemination (presentations, papers, etc.) - Formally recognize CAB members and other community members for their contributions
Theme 4: Respectful relationships	<ul style="list-style-type: none"> - Establish expectations and obligations at the start of the relationship so everyone can have a mutual understanding of each other’s position and respect each other’s needs - Foster trust and respect of all team members’ expertise, perspectives, needs, and expectations - Attend meetings in person as much as possible (‘show your face at the table’) - Designate project members who live in community to liaise outside researchers with community members during community data collection - Ground the project and its practices in cultural and community values (e.g. in KSDPP: welcoming and forming international relations, a duty to share knowledge with others, collective decision making, etc.)
Theme 5: The CAB is the keeper of the data	<ul style="list-style-type: none"> - Establish a CAB that is representative of the community (reflecting diverse sectors and accordingly interests), and accountable to the community - Establish CAB subcommittees to reduce burden on individual CAB members - Ensure that the community - through the CAB - has the final decision-making authority on all matters related to the research and research data - Where possible and desirable, have the community maintain possession of the data (physical and digital), and keep it in a secure fashion (i.e. locked in a safe, password-protected, anonymized, etc.) - Monitor researcher possession of data (e.g., during data collection and analysis) and ensure return of data to the community

	<ul style="list-style-type: none"> - Determine the protocol for data access - Inform research participants, community members and academic institutions about the data possession and access protocols - Assign and train a community data keeper or guardian (can overlap with coordinator position) – ensure that this position does not put the person in a conflict of interest or vulnerable position - Develop a protocol for the turnover of this position - Have the CAB review and approve all data collection ideas and materials before they are used to ensure it will be beneficial and not cause harm - Ensure that requests for secondary data analysis be treated as new research - Ensure that all dissemination opportunities are reviewed and approved by CAB members to ensure the community is well-represented and data are appropriately used
Theme 6: Code of Research Ethics defining community control	<ul style="list-style-type: none"> - At the beginning of the project, bring researchers and community members together for strategic planning and to develop a Code of Research Ethics (or terms of reference); note that this process can take many months - Ensure the Code of Research Ethics is clear and delineated regarding how the project should operate (how research/data collection are proposed and approved, how communication and collaboration are maintained, how data are disseminated, managed and protected, etc.) - Ensure the Code of Research Ethics outlines authorship opportunities for community members - Ensure the Code of Research Ethics outlines the clear obligations and responsibilities of all partners (both individually and collectively; see KSDPP Code of Research Ethics for examples) - Ensure the Code of Research Ethics reflects cultural and community values and perspectives/worldviews in the project protocol (e.g. Haudenosaunee teachings and decision-making process in KSDPP Code of Research Ethics) - Establish what community control and ownership will look like and reflect this in the Code of Research Ethics - Confirm member commitment to follow the Code of Research Ethics - When using community control and data sovereignty guidelines or existing models, use discretion and collectively (led by the community) build your own model of community control and data governance that is feasible, culturally and contextually appropriate, and will benefit the community; other models ought not to be thought as prescriptions
Theme 7: Growth through adversity	<ul style="list-style-type: none"> - Maintain strong self-esteem and confidence; challenges will arise, but they can be managed - Have the partnership (community and academic researchers) work together to address issues in whatever way the community deems the best way forward

-
- Clarify that reliance on the academy for certain solutions doesn't mean failure or a loss of self-governance
 - Revise protocols/Code of Research ethics as needed to changing environments and lessons learned from past challenges
 - Ensure that any changes to protocols/Code of Research ethics are endorsed by all team members and approved by the CAB
-

3.4 Future Directions and Limitations

Results from this study have the opportunity to benefit Indigenous communities and academic allied researchers who may be active in, or entering, a community-academic research partnership. This investigation of how the KSDPP, a successful and mature partnership, facilitates community-controlled research and operationalizes data sovereignty can supplement often vague ethical guidelines with this practical example. Other communities and ally researchers may value the insight into the governance structure of the KSDPP, the suggested underpinnings of their success and longevity, their perspective of community control, and/or their experience with emerging challenges.

Further research ought to provide more examples of how other projects have built community-controlled research partnerships and operationalized data sovereignty. Having diverse perspectives and experiences would be valuable as these would permit a range of different projects to which a community context might best relate. Additionally, further exploration of themes within the KSDPP case would equip KSDPP with a better understanding of the importance or impact of different aspects of their approach. This information could guide future efforts in the KSDPP to further develop or prioritize different features of the project.

One limitation of this study was the extent to which member verification was completed. It would have been ideal to send not only transcripts, but also a brief report of my interpretations or themes to each participant for further discussion. While there was generally strong congruence across my interviews, by only having one interviewee directly review resultant themes, it reduced the opportunity for potential varying perspectives on these final interpretations. An additional limitation arises in the positionality of myself relative to my interviewees. First, as I and all respondents are internal to the KSDPP, the perspectives that informed the project data and conclusions are limited to those of insiders. The project might have benefitted further by having external perspectives such as Kahnawà:ke community members who are not involved in the KSDPP, especially with regards to the outcomes of the KSDPP operation and research. Furthermore, due to the length and nature of my interviewees' involvement in the KSDPP, it is reasonable to assume that they hold positive attitudes toward the project. Accordingly, when sharing information about the KSDPP, responses could be oriented toward a positive presentation. This is not to suggest that respondents at any point were untruthful or deceptive, but rather a limitation to consider where again, an external voice with a more neutral relationship to the project may have been valuable.

3.5 Conclusion

This study was a great opportunity to explore the operation of an exemplary Indigenous community-academic partnership. Having been successful in creating a community-controlled partnership that fosters data sovereignty, themes around the KSDPP process may provide insight into effective strategies. Emerging themes outlined the KSDPP governance structure which consists of a research team and Community Advisory Board, both of which communicate and collaborate throughout the research process. Final decision-making authority rests with CAB,

who represent and are accountable to the community. CAB however values collaboration from researchers, and the cooperation across the KSDPP team is rooted in trustful relationships. The Code of Research Ethics clearly outlines the KSDPP process and is uniquely tailored to the project and Kahnawà:ke culture. Challenges have emerged over the years, but they promoted project growth and were managed to the best of the partners' abilities. These findings may be a valuable supplement to existing ethical and data sovereignty guidelines, and provide guidance of what constitutes true community self-determination of research.

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Chapter 4

General Discussion

4.1 Summary of Key Findings

This project was successful in uncovering themes that outline features of how the Kahnawà:ke Schools' Diabetes Prevention Project (KSDPP) facilitates community-driven research and operationalizes data sovereignty. Over the last 25 years, the KSDPP has successfully operated in a community-controlled and owned fashion, and this thesis gave me the opportunity to go behind the curtain and investigate what was valuable in making this happen within the Kahnawà:ke context. All of the data sovereignty indicators from Harding et al., 2012; Schnarch, 2004; Snipp, 2016 collected in Table 1 were reflected in the data, and sub-themes and themes that emerged. This suggests that overall, the KSDPP has and continues to operate in a way congruent with guidelines and academic literature of community-controlled research and data sovereignty.

An overarching purpose of data sovereignty in Indigenous research is to forward the self-determination of Indigenous peoples (Schnarch, 2004), thereby aligning research and data with the community's internally-motivated goals (Ball & Janyst, 2008). A key feature in accomplishing this is that research and data collected are relevant and useful to the community (Snipp, 2016), and allow the community to be strategic and responsive to emerging needs (Schultz & Raine, 2014). Theme 1 addresses this purpose as it presented the KSDPP research team (RT) and Community Advisory Board (CAB) as the governance structure that ensures the community relevance and value of project research. This study further outlined themes around the dynamic of how these divisions of the KSDPP team operate, highlighting the ongoing collaborative and communicative approach, which is underpinned by mutually respectful

relationships. These features of the KSDPP process were often presented as essential to the success of the project and ensuring the community relevance of the research. Ongoing cooperation and respectful relationship building is congruent with existing understandings of crucial features in research partnerships (Castleden, Sloan Morgan, & Lamb, 2012; Harding et al., 2012). Furthermore, these components of the KSDPP approach were also grounded in the cultural values and community norms of Kahnawà:ke, supporting the idea that culturally-based and community specific frameworks or approaches to data collection and management are important features of data sovereignty (Schnarch, 2004; Snipp, 2016). Finally, growth of the KSDPP governance structure was reflected in a theme that outlined how built capacity in the community created more community participation, and accordingly control, among the research team and in the research process. Capacity building is a key principle of participatory research (Israel, Schulz, Parker, & Becker, 1998), and essential in Indigenous research partnerships that implement data sovereignty (Schnarch, 2004). This study connected these understandings, demonstrating the impact of capacity built through participation on the community control and ownership of a project.

One of the most important findings from this study, in my opinion, is the manner in which the KSDPP defined community control. In some interviews, project members shared their experiences about how community control can often be presented or implemented, with an emphasis on total control over the research and researchers. These conversations highlighted how the KSDPP values collaboration with academic partners. While final decision-making authority regarding research and data rests with CAB, researcher perspectives and contributions are respected and incorporated. Additionally, a few community members reported that they do not view reliance on academic partners as a failure or as compromising to their control and

sovereignty, as could be interpreted from some data sovereignty guidelines and literature (e.g. Snipp, 2016). Consistent with assertions from Brunger & Wall (2016), the core ideal within this theme was that community control cannot be prescribed by external definitions or guidelines, and that the community ought to define what control means to them by implementing features as is feasible, relevant and beneficial. This finding is valuable in addressing the research question as it reflects a general mentality that is applicable to any community context, rather than a specific strategy which saw success in Kahnawà:ke.

4.2 Project Strengths

The major strength of this project stems from the maturity and experience of the KSDPP and its members. The opportunity to work alongside and hear the perspectives and stories of KSDPP members was incredibly valuable. The members I interviewed have been in the KSDPP for 12 to 25 years, with many at the upper end of that range. These team members have experienced community-controlled research throughout the evolution of the KSDPP over recent decades, predating the establishment of the TCPS2 Chapter 9 and OCAP®. The perspectives and insight they have gained and shared from this longstanding involvement are refined by experience and can be valuable to communities and researchers new to the field.

Additionally, this project was strengthened by the KSDPP process. The original idea was presented to, refined by, and approved by the research team and the Community Advisory Board. Further, interview questions were reviewed and refined with CAB member input, as were the final themes and sub-themes. This thesis is also being reviewed by CAB before it's finalization and will benefit from their feedback. Moreover, I was fortunate to have the opportunity to form relationships with several project members in the previous years, as this became crucial in the interviews. This established rapport added a richness and openness to our conversations, and

promoted trust in my management and presentation of the knowledge they shared. Beyond allowing me to form trusting relationships, my two years in the KSDPP equipped me with insider experience that allowed me to better understand the project and the data that I collected, and ultimately strengthened my analysis.

4.3 Project Limitations

The first limitation of this project was that only one interviewee, a community member within the KSDPP, reviewed the themes and sub-themes and informed their organization, naming, and description. I had utilized member validation in the sense that all interviewees received copies of their transcripts with an invitation to converse further and provide any clarifications and ideas or interpretations. Furthermore, I had several participants offer brief corrections, and a few engage in further conversation emphasizing a key point or sharing another idea. However, it would have been further beneficial to have all eight participants receive a copy of the output from the thematic analysis, and incorporate their feedback into the themes, sub-themes, and descriptions of them.

The next limitations result from my and the interviewees' positionality. As members of the KSDPP, our perspective toward the project's operation and outcome can only be that of someone internal to the project. While this is beneficial on topics that require an insider perspective and knowledge, such as the inner workings of the project governance, it can be limiting on topics that may benefit from external perspectives. For example, when discussing the community benefits of the project, the interviewees can only share how they view the benefits as a member of the KSDPP, and I can only understand and interpret this information likewise. The project could benefit further from having external voices as well, for example non-KSDPP affiliated community members, to allow for more varied perspectives where feasible.

Furthermore, my respondents all had longstanding relationships with the KSDPP, and could be expected to have positive attitudes toward the project. Accordingly, this would possibly situate information shared within a positive perspective of the KSDPP. While there is no reason to believe participants were untruthful in their interviews, an opportunity to collect information from individuals with a neutral attitude toward the KSDPP (again perhaps project outsiders) may have been valuable in capturing varied perspectives.

4.4 Contributions to Indigenous Research

As per the purpose of this study, the information from this thesis project will supplement Indigenous community-driven and data sovereignty literature with a practical example of how a mature and successful community-academic partnership operates. This can be used in combination with existing ethical and operational guidelines that are often criticized for their vague and ungrounded nature. Findings have the benefit to offer guidance and to foster conversation between Indigenous communities and academic researchers entering into research partnerships. Additionally, this project can motivate and guide future project evolution within the KSDPP as it provided an opportunity for members to reflect on the current operation of the project. The data collected and team member discussions constituted an opportunity for rich inward reflection, and features ideas for future directions in the project that can drive further discussion and growth among the team. Finally, conversation within this project surrounding the definition of community control (and ownership) and the application of existing guidelines raises opportunities for further discussion around the suitability of OCAP® and other guidelines, and potential changes that may need to occur in academic institutional and funding agency policies.

4.5 Future Directions

The primary direction of future research ought to be replicating projects like this to examine established community-academic partnerships from diverse Indigenous communities and contexts. By populating the literature with numerous practical examples of how diverse partnerships conduct community-controlled research and operationalize data sovereignty, we can create a rich environment from which communities have more opportunities to review strategies and draw guidance for a project within a relatable context. It could also allow review and meta-analytic approaches to scan and connect diverse experiences, perhaps uncovering commonalities and key underlying principles that may have value in all contexts. Additionally, there may be further research opportunity within the KSDPP to explore themes more deeply in order to inform progress and further practice.

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Appendix A: Thesis Change Statement

No significant changes from the approved thesis proposal occurred

Date of thesis proposal: May/2019

Appendix B: Queen's Ethical Clearance and Letter of Information/Consent Form



May 30, 2019

Mr. Andrea Ianni
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GREB Ref #: GSKHS-317-19; TRAQ # 6026710

Title: "GSKHS-317-19 Data Sovereignty in Indigenous Community-Academic Partnered Health Research: A Kahnawake Schools' Diabetes Prevention Project Case Study"

Dear Mr. Ianni:

The General Research Ethics Board (GREB), by means of a delegated board review, has cleared your proposal **entitled "GSKHS-317-19 Data Sovereignty in Indigenous Community-Academic Partnered Health Research: A Kahnawake Schools' Diabetes Prevention Project Case Study"** for ethical compliance with the Tri-Council Guidelines (TCPS 2 (2014)) and Queen's ethics policies. In accordance with the Tri-Council Guidelines (Article 6.14) and Standard Operating Procedures (405.001), your project has been cleared for one year. You are reminded of your obligation to submit an annual renewal form prior to the annual renewal due date (access this form at <http://www.queensu.ca/traq/signon.html>; click on "Events;" under "Create New Event" click on "General Research Ethics Board Annual Renewal/Closure Form for Cleared Studies"). Please note that when your research project is completed, you need to submit an Annual Renewal/Closure Form in Romeo/traq indicating that the project is 'completed' so that the file can be closed. This should be submitted at the time of completion; there is no need to wait until the annual renewal due date.

You are reminded of your obligation to advise the GREB of any adverse event(s) that occur during this one-year period (access this form at <http://www.queensu.ca/traq/signon.html>; click on "Events;" under "Create New Event" click on "General Research Ethics Board Adverse Event Form"). An adverse event includes, but is not limited to, a complaint, a change or unexpected event that alters the level of risk for the researcher or participants or situation that requires a substantial change in approach to a participant(s). You are also advised that all adverse events must be reported to the GREB within 48 hours.

You are also reminded that all changes that might affect human participants must be cleared by the GREB. For example, you must report changes to the level of risk, applicant characteristics, and implementation of new procedures. To submit an amendment form, access the application by at <http://www.queensu.ca/traq/signon.html>; click on "Events;" under "Create New Event" click on "General Research Ethics Board Request for the Amendment of Approved Studies." Once submitted, these changes will automatically be sent to the Ethics Coordinator, Ms. Gail Irving, at University Research Services for further review and clearance by the GREB or Chair, GREB.

On behalf of the General Research Ethics Board, I wish you continued success in your research.

Sincerely,

A handwritten signature in blue ink, appearing to read "Dean A. Tripp".

Chair, General Research Ethics Board (GREB)
Professor Dean A. Tripp, PhD
Departments of Psychology, Anesthesiology & Urology Queen's University

c: Dr. Lucie Lévesque, Supervisor
Ms. Donna Ivimey, Co-investigator
Dr. Elaine Power, Chair, Unit REB
Ms. Josie Birchall, Dept. Admin.

Letter of Information and Consent Form

Study Title: Data Sovereignty in Indigenous Community-Academic Partnered Health Research: A Kahnawake Schools' Diabetes Prevention Project Case Study

Student Researcher:

Andrea Ianni, Master's student, School of Kinesiology and Health Studies, Queen's University, Kingston, ON, Canada.

Supervisor:

Dr. Lucie Lévesque, Professor, School of Kinesiology and Health Studies, Queen's University, Kingston, ON, Canada

You are invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You can ask me questions at any time if there is anything that is not clear or if you would like more information

My name is Andrea Ianni, and I am a student enrolled in a Master's degree program at Queen's University. I am inviting project staff, Community Advisory Board (CAB) members, and researchers involved with the Kahnawake Schools Diabetes Prevention Project to participate in a study on data sovereignty. The study will examine how data sovereignty considerations and principles are implemented in the Kahnawake Schools Diabetes Prevention Project (KSDPP) as an established community-research partnership. Data sovereignty has to do with the ownership and control over the collection and use of data.

If you agree to take part, I will interview you. The interview will take up to an hour and can take place at a mutually agreed-upon location, or over video conferencing software (Zoom) if preferred or necessary. During the interview, please let me know if you want something kept off the record so that I will know not to record it. There is no known risk should you choose to participate. While there is no direct benefit to you as a participant, study results may be a resource for helping new and developing institutional-community Indigenous research partnerships effectively incorporate data sovereignty and strengthen a culture of ethical Indigenous community-driven research.

You will also be given an opportunity to review your interview transcript before it is analysed and to remove any piece of information that you do not want to share. I will then analyse data from all of the interviews and compile a report. Members of the KSDPP research team and CAB will then be given the opportunity to review the draft report.

Your participation is voluntary. You don't have to answer any questions you don't want to. You can stop participating at any time without penalty. You may withdraw completely or identify transcript concerns until two weeks from the day you receive your transcript copy (with the next day being day 1), by contacting me at andrea.ianni@queensu.ca. If you choose to withdraw in this timeframe, your data will be deleted and destroyed.

The signed consent forms will be held securely in a safe at Queen's University. Digital data (recordings and transcripts) will be kept on a secure and encrypted computer and password-protected drive stored in a safe. Following this project, the data will be returned to KSDPP for secure and indefinite storage in Kahnawake. Due to the size of Kahnawake, it is possible something you share could identify yourself indirectly if quoted in presentations or publications. I will make every attempt to keep any information that identifies you confidential. Unless you wish otherwise, I will de-identify the transcripts, meaning that I will replace your name with a participant code in data and when presenting the research findings in presentations and publications. The participant code key linking your name with participant codes will be stored separately and securely from the de-identified data. Upon completion of this project, this participant code list will be deleted. As the recordings are also returned to KSDPP, there is the possibility that a project member with access to the data may identify you by your voice. Data will be kept in a way consistent with CAB's wishes and the KSDPP Code of Research Ethics. Only my supervisor, Dr. Lévesque, her research coordinator Donna Ivimey, and I will have access to any information that can directly identify you by name.

I hope to publish the results of this study in academic journals and present them at conferences. I may include quotes from some of the interviews when presenting my findings. However, you will not be identified by name in any reports, publications or presentations resulting from this study.

If you have any ethics concerns, please contact the General Research Ethics Board (GREB) at 1-844-535-2988 (Toll free in North America) or chair.GREB@queensu.ca. If you have any questions about the research, please contact me at andrea.ianni@queensu.ca, or my supervisor Dr. Lévesque at levesqul@queensu.ca.

This LOI provides you with the details to help you make an informed choice. All your questions should be answered to your satisfaction before you decide whether or not to participate in this research study. Keep one copy of the Letter of Information for your records and return one copy to me. You have not waived any legal rights by consenting to participate in this study.

By signing below, you are verifying that you have read the Letter of Information and that all of your questions have been answered. Please indicate your preferences by checking the boxes that apply.

The Queen's General Research Ethics Board (GREB) may request to access study data to ensure that the researcher(s) have or are meeting their ethical obligations in conducting the research. If such a request is made, Queen's GREB will provide a justification that will be reviewed by the KSDPP Community Advisory Board.

- Yes, I agree to be interviewed.
- Yes, I agree to have my interview audio-recorded.
- Yes, I give my permission to use audio-recording/direct quotes

Signature of Participant PRINTED NAME Date

Signature of Person Conducting
Consent Discussion PRINTED NAME Date

Appendix C: KSDPP Certificate of Approval from CAB

KAHNAWAKE SCHOOLS DIABETES PREVENTION PROJECT
Center for Research & Training in Diabetes Prevention
P.O. Box 989, Kahnawake Mohawk Territory
Quebec, Canada J0L 1B0
Phone: 450-635-4374
Fax: 450-635-7279



Daily physical activity, healthy eating habits & a positive attitude can prevent diabetes

Review and Approval Process for Ethically Responsible Research Certificate of Approval

The Community Advisory Board of the Kahnawá:ke Schools Diabetes Prevention Project has granted approval:

For the Research Proposal Project entitled:

The Kahnawá:ke Schools' Diabetes Prevention Project: Perspectives on Data

Sovereignty in Indigenous Community-Academic Partnered Health Research

Proposed by:

Name of Researcher: Andrea Ianni, MSc Student

Academic Supervisor: Dr. Lucie Lévesque

Department: School of Kinesiology and Health Studies

Institution: Queen's University, Kingston, Ontario

Month and Date of CAB Approval: December 18th, 2018

Confirmed by the CAB Executive Committee:

Signature: *Eva Johnson*

Name: Eva Johnson, Chairperson, KSDPP Community Advisory Board

Date: *December 19, 2018*

Appendix D: Semi-Structured Interview Guide

Data Sovereignty in KSDPP Interview Guide

Welcome. The purpose of this interview is to discuss the implementation of data sovereignty in the Kahnawake Schools Diabetes Prevention Project. Data sovereignty for Indigenous peoples supports the idea that Indigenous communities should oversee the data collected and information generated about themselves, often emphasizing data ownership, control, access, and possession. As a successful community-academic partnership, the KSDPP can provide insight on how data sovereignty has been implemented, and accordingly serve as an example of what data sovereignty looks like in action. Please do not feel pressured to answer any questions which you do not feel comfortable doing so.

In addition to recording our conversation, I may find it helpful to take some brief notes to help me later when I look back at our talk, is this OK with you? Do you have any questions or concerns before we start? Do you mind starting by sharing the nature and length of your affiliation with the KSDPP (*if needed probe: researcher, CAB member, staff*)?

Questions regarding KSDPP and its operation in general:

- 1. What goals or values does KSDPP have that motivate data collection or research?**
- 2. How does KSDPP assess if a potential project is useful and/or relevant to the community?**
- 3. How does KSDPP minimize reliance on others for data collection and management?**
 - How can data creation and management skills be learned by community members involved in the project?
 - o i.e. What type of training is available and by whom is it offered (*if applicable*)?
- 4. How is communication maintained with stakeholders within KSDPP and Kahnawake?**
 - How is communication maintained with stakeholders beyond the community?
- 5. How might the KSDPP Code of Research Ethics be different than other institutional or federal ethical guidelines?**

Questions regarding what data is collected and how it is managed:

- 6. Do you know of any customs regarding data or information in Kahnawake?**
 - If yes, what are they?
 - How are these reflected in KSDPP's management of data? (*if applicable*)

7. What does “control” over data mean to you?

- How might KSDPP have this control when it comes to data collection?
- How does control over data help KSDPP ensure the data collected supports the interests, values, or priorities of the community?
- Can you think of anything that has or can make it harder for KSDPP to control data and data collection?

8. How does KSDPP decide what can be collected as data?

9. How and where are KSDPP data typically stored?

- How long are data retained?
- What are the protocols and responsibilities for outsiders who might be in possession of KSDPP data?
- How were these protocols established?

10. How does KSDPP determine who is granted access to the data?

Questions regarding community role in data dissemination:

11. How is KSDPP involved in data analysis within projects?

- Information dissemination is the delivery of information to users of that knowledge. How is KSDPP involved in the dissemination of information gathered in research projects?
- How can community or KSDPP members raise any concerns they may have regarding what data is being collected, and how it is being used or presented?

12. How is authorship of presentations/publications decided in partnered research?

Questions regarding outcome

13. How has data sovereignty (control of data creation, management, and dissemination) empowered the KSDPP to reach their goals and vision with data?

14. How does KSDPP promote confidentiality and privacy?

15. How has the data sovereignty policy of KSDPP been beneficial when working with academic partners?

16. How might KSDPP have contributed to the practice of data sovereignty in Indigenous partnered research?

17. Is there anything more you would like to add?