Cree Youth, Health (Miyupimaatisiiun), and Engagement in Health Planning

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ABSTRACT

Indigenous communities experience a greater burden of ill health than all other communities in Canada. In the Eeyou Istchee territory of northern Quebec, all nine James Bay Cree communities experience similar health challenges. In 2014, the Cree Board of Health and Social Services for James Bay (CBHSSJB) supported an initiative to stimulate local community prioritization for health change. While many healthcare challenges identified were specific to youth (defined as less than 35 years of age), youth's perspectives in these reports to date have been limited. We hence sought to understand how Cree youth perceived youth health and their engagement in health and health planning across Eeyou Istchee. As part of a CBHSSJB-McGill partnership, this qualitative descriptive study used a community-based participatory research approach. In collaboration with Cree community partners, ten Cree youth were recruited to participate in two focus groups, and five Cree youth coordinators were recruited to participate in key informant interviews. Thematic analysis was conducted; inductive codes were grouped into thematic categories. Cree participants characterized youth engagement in the following levels and capacities: participation in community and recreational activities; membership in youth councils at the local and regional levels; and, in decision-making as planners of health-related initiatives. Cree youth recommended greater use of social media, youth assemblies, and youth planners to further strengthen youth engagement and youth health in the region. Our findings revealed an interconnectedness between youth health and youth engagement; James Bay Cree youth described how they need to be engaged to be healthy, and need to be healthy to be engaged. Cree participants contributed novel and practical insights to engage Indigenous youth in health planning across Canada.

RÉSUMÉ

Les communautés autochtones font face au fardeau des problèmes de santé par rapport aux autres communautés en Canada. Dans le territoire d'Eeyou Istchee au nord du Québec, les neufs communautés cries de la baie James sont ainsi confrontées à des défis semblables. En 2014, le conseil Cri de la santé et des services sociaux de la Baie James (CBHSSJB) a soutenu une initiative visant à encourager les communautés locales pour définir leurs propres objectifs prioritaires en vue d'améliorer leur santé. Bien que de nombreuses priorités identifiées concernent surtout les jeunes (défini comme ayant moins de 35 ans), les perspectives des jeunes dans ces rapports à ce jour on été limités. Nous avons donc cherché à comprendre comment les jeunes Cris percevaient la santé des jeunes et leur engagement dans la santé et la planification de la santé dans la région d'Eeyou Istchee. Dans le cadre de ce CBHSSJB-McGill partenariat, cette étude descriptive et qualitative a utilisé une approche de recherche participative dans la collectivité. En collaboration avec nos partenaires cris, dix jeunes cris ont été recrutés pour participer à deux groups de discussion, et cinq coordonnateurs jeunesse cris ont été recrutés pour participer aux entrevues d'informateurs clés. Une analyse thématique a été menée; les codes inductifs ont été regroupés en catégories thématiques. Les participants cris ont caractérisé l'engagement des jeunes cris dans les niveaux et capacités suivantes : participation dans les activités communautaires et récréatives; l'adhésion aux conseils de la jeunesse locaux et régionaux; et, à la prise de décisions en tant que jeunes planificateurs en soins de santé. Les jeunes participants cris ont recommandé davantage l'utilisations des médias sociaux, des assemblées de jeunes, et des jeunes planificateurs en soins de santé pour renforcer encore l'engagement de la jeunesse. Nos résultats dévoilent une interconnexion entre la santé des jeunes et l'engagement des jeunes; les jeunes Cris de la baie James ont expliqué comment ils doivent être engagés pour être en santé, et comment ils doivent être en santé pour pouvoir s'engager. Les participants cris ont aussi contribué des idées nouvelles et pratiques pour mieux engager les jeunes autochtones à la planification de la santé au Canada.

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LIST OF ABBREVIATIONS

IAMP   Iiyuu Ahtaawin Miyupimaatisiiun Planning

CBHSSJB   Cree Board of Health and Social Services of James Bay

CBPR   Community-Based Participatory Research

STI   Sexually transmitted infection

IRB   Institutional Review Board

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ACKNOWLEDGEMENTS

PREFACE AND CONTRIBUTION OF AUTHORS

This thesis is submitted in the traditional thesis format, and is part of a larger overarching evaluation study entitled "A collaborative evaluation of Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) initiative for Cree health", developed in partnership by McGill researchers Drs. Mary Ellen Macdonald and Susan Law, as well as Cree Board of Health and Social Services of James Bay (CBHSSJB) Directors Dr. Robert Carlin and Jill Torrie.

Drs. Mary Ellen Macdonald and Susan Law developed the original focus group and interview consent forms, which Nickoo Merati adapted for the purposes of this study. Nickoo Merati developed the interview guide, with feedback provided by Drs. Susan Law, Jon Salsberg, and Mary Ellen Macdonald, as well as Martine Levesque and Joey Saganash. Our valued community partners, namely Amy Gallant and Bérengère Ruet, performed youth participant recruitment, and all other recruitment occurred via Nickoo Merati's efforts guided by recommendations from multiple Cree people, namely Joshua Iserhoff and Stella Moar Wapachee. Nickoo Merati co-facilitated all focus groups with Bérengère Ruet, and Nickoo Merati conducted interviews with assistance from Dr. Susan Law. Nickoo Merati coded and performed preliminary analysis of the data with guidance for Drs. Susan Law and Jon Salsberg. Validation of the study results was performed by CBHSSJB partners Dr. Robert Carlin and Jill Torrie, and community partners Joey Saganash and Kaitlynn Hester Moses. Nickoo Merati researched and wrote the thesis manuscript with editorial support from Drs. Susan Law and Jon Salsberg. Joey Saganash provided essential cultural teaching and safety feedback throughout the entire process.

GLOSSARY OF TERMS

For the purposes of this thesis, the following terms are defined as below.

Eeyou Istchee: Eeyou Istchee (in Cree meaning the "Cree Peoples Land"), or the James Bay Cree region, is the territory corresponding to the regional authority of the Cree Nation Government. This region is composed of nine Cree Nation communities, including: Chisasibi, Eastmain, Mistissini, Nemaska, Oujé-Bougoumou, Waskaganish, Waswanipi, Wemindji, and Whapmagoostui.

Grand Council of the Crees: Governmental entity that represents the Crees across Eeyou Istchee. The Grand Council of the Crees was created by the Deputy Registrar General of Canada in 1974, and negotiated for and recognized in the signing of the James Bay and Northern Quebec Agreement in November 1975 between the Cree Nation and the Quebec and Canadian governments. This council is the highest political body representing the Cree. The current Grand Council of the Crees Grand Chief is Abel Bosum, with Deputy-Grand Chief Mandy Gull, elected at large by the Cree people.[1]

Cree Nation Government: Represents the administrative arm of the Grand Council of the Crees. It is responsible towards environmental protection, the hunting, fishing and trapping regime, economic and community development, the Board of Compensation, and other matters. The Board of Directors is composed of: Chairman and Grand Council of the Crees Grand Chief Abel Bosum, Vice-Chairman and Deputy-Grand Chief Mandy Gull, as well as the Chiefs of each of the nine Cree Communities, and one other person from each community delegated by the community. The Cree Board of Health and Social Services of James Bay and the Cree School Board, independent entities created through the James Bay and Northern Quebec Agreement, sit as observers, especially when issues related to their mandates are discussed.[2]

Cree Board of Health and Social Services of James Bay (CBHSSJB) or Cree Health Board: Entity responsible for the administration of health and social services for all persons residing either permanently or temporarily in Region 18, the administrative region of the Ministry of Health and Social Services of Quebec corresponding to the Cree territory of James Bay. In partnership with the Government of Québec, the CBHSSJB provides health and social services to the nine communities of the Cree Nation in Eeyou Istchee.[3]

Miyupimaatisiiun: An all-encompassing Cree word for a global concept of health that can be loosely translated as "being alive well". Miyupimaatisiiun encompasses physical, mental,

emotional and spiritual wellness: it implies a way of living that allows one to care for their family, enjoy life and participate in their community, and be sufficiently strong to be able to hunt in the frigid conditions of the North.[4]

Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) Team: In the Cree language, 'Iiyuu Ahtaawin' means 'Cree community' and Miyupimaatisiiun is defined as above. The IAMP initiative is a community-based and –driven wellness planning process involving Eeyou Istchee's local and regional entities and groups.[5] The IAMP Team as defined in this paper is the team of individuals responsible for the evaluation of the IAMP initiative, composed of seven CBHSSJB members (both Cree and non-Cree) and four McGill researchers (non-Cree).

Youth Fusion: A national organization and charity that seeks to affect youth perseverance, employability and civic engagement by implementing innovative experiential learning projects that create ongoing links between school systems and the community. Their mission is to increase student retention by organizing fun and active extracurricular activities by creating school partnerships across the country, including a partnership with Nemaska's Luke Mettaweskum School.[6]

Youth: A self-identified label, but also corresponding to the ages of 13 to 34 as defined by the Cree Nation Youth Council.[7] This age range differs from the CBHSSJB definition of youth, which is 10 to 29 years of age.

Youth coordinator: A Cree person who is actively involved in leading and planning youth activities and engagement opportunities, either locally in their community, or regionally across Eeyou Istchee. Youth coordinator may not be this individual's formal position or sole role in the community, but they serve as key informants regarding the structures that exist for youth to engage across Eeyou Istchee.

Youth council member: A Cree youth member who sits on either a local or regional youth council, and represents the youth and youth needs in their corresponding community or communities.

CHAPTER 1: INTRODUCTION

The research for this thesis explored how Cree youth engage in health planning in their communities across Eeyou Istchee, and described the structures that exist in order for them to do so. I worked in partnership with Cree colleagues and youth members from the Nemaska community in Eeyou Istchee, Quebec, as well as colleagues from the Cree Board of Health and Social Services of James Bay. Ways in which youth could better engage in their health and health planning were also discussed with the youth in this study.

1.1 Introduction to Health and Health Planning Challenge

Indigenous communities experience a greater burden of ill health than all other communities in Canada.[8] Peoples in Northern and remote areas face particular challenges with mental health, obesity, diabetes, substance abuse, and maternal or child health issues.[9] Indigenous communities also report poorer health outcomes according to national studies,[10] and are often restricted from access to healthcare resources.[11,12]

In the Eeyou Istchee territory of Northern Quebec, all nine Cree communities experience similar health challenges.[13] While the Cree communities report longer life expectancies and lower infant mortality rates than other Indigenous populations, the Cree are currently overrepresented in diabetes, heart disease and sexually transmitted infections (STIs).[13] Moreover, the Cree conceptualization of health is distinguished from a Western biomedical definition; the Cree define health through the Miyupimaatisiiun, best interpreted as "being alive well". Miyupimaatisiiun encompasses physical, mental, emotional and spiritual wellness: it implies a way of living that allows one to care for their family, enjoy life and participate in their community, and be sufficiently strong to be able to hunt in the frigid conditions of the North.[4] For the Cree, health implies much more than merely the absence of disease.

Despite having the resources to meet health needs, the Cree Board of Health and Social Services for James Bay (CBHSSJB) recognized a misalignment between Miyupimaatisiiun and service provision. As such, the CBHSSJB supported a major community-based planning initiative – the Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) – for all nine Cree communities of the Cree Nation. Funded in part by Health Canada, the IAMP initiative is driven by the need to improve planning and outcomes across CBHSSJB, by encouraging communities to take control of their health planning and create their own detailed plans for Miyupimaatisiiun.

IAMP then partnered with a team of McGill researchers to create the IAMP evaluation research project; using a community-based participatory research approach, the goal of the IAMP evaluation project is to evaluate the ongoing process and progress of the IAMP initiative.

Notably, many health challenges that the James Bay Cree leadership have prioritized primarily affect youth (13 to 34 years of age, as defined by the Cree Nation Youth Council). For example, one in five Cree youth gets involved with Cree Youth Protection Services each year, and many of these visits are youth coming in for mental health crises, behavioural disorders associated with alcohol and drugs, or suicide attempts.[14] In addition, increases in chronic diseases among youth, and the rate of diabetes and sedentary lifestyles of youth, are identified as healthcare and social issues important to the Cree Nation, and thus need to be addressed.[13]

While many health priorities for change are specific to the youth sector, the IAMP evaluation thus far has not yet formally involved youth to ask them how they have been engaged or how they need to be engaged in health planning. This further corroborates current evidence stressing the absence of youth voice and participation in health care planning and research on a global scale.[15] This is furthermore an important area to address, considering that half of the James Bay Cree population is under 25 years of age, and about 1 in 5 babies is born to a mother under the age of 20[16]; these population trends are predicted to continue in the coming years.[13,17] Therefore to place the end-users' (youth's) priorities in research, young Cree people should be heard in all steps of the evaluation research and future health planning efforts. This investigation aims to better understand how youth perceive health or Miyupimaatisiiun, as well as their past, present and future engagement in health initiatives in the community.

1.2 Research Questions

Defined in collaboration with our Cree partners, our questions are driven by a community need to understand Cree youth's perspectives on their engagement in health and health planning; accordingly, the three interconnected questions that guide this project are the following:

1. **How are James Bay Cree youth engaged in health-related activities in their communities?**

2. **How would James Bay Cree youth like to be engaged in youth health planning in Eeyou Istchee?**

3. **How do James Bay Cree youth view their health in relation to their engagement in health and health planning?**

1.3 Researcher's Position

Recognizing the importance of reflexivity in Indigenous research,[18] I would like to situate my location in this work as the lead researcher of this project, and acknowledge my personal motivations in this study. I am a second-generation immigrant from Iran, and I lived in Ottawa, Ontario for most of my life before moving to Montréal, Quebec in 2012.

As a non-Cree person, I was motivated to develop this study because I stand in many positions that connect to this research. As an ethnic minority, I am a strong advocate for marginalized populations' rights and appreciating differing ways of knowing. As a Canadian citizen, I believe in our shared social justice imperative to better educate ourselves about those who have come before us, and to listen to Indigenous histories and realities in an effort towards greater trust and reconciliation for Indigenous peoples. As a student in health research, I believe in differing conceptualizations of health and wellness. As a spiritual person, I connect with many Indigenous teachings, stories and worldviews. As a young person, I recognize the shortcomings of adult-centric research and the value of youth as true end-users of youth-related research. Taken together, all my positions have fuelled my passion to learn more about Cree youth, and use my researcher platform to support the James Bay Cree people's value to encourage and support their youth and youth voices as a priority in health planning.

All that said, I emphasize that I have conducted this research and written this manuscript as a non-Cree person looking to understand, and that my external position to the community and culture limits my ability to fully understand the cultural components of this study. For this reason, I am incredibly indebted to the Cree partners who have helped me along this journey to learn and better understand the context of this research. In addition, the more opportunities I receive to speak to Cree youth and youth leaders and hear their stories, the more I believe in the power of collaboration between all peoples as described by CIHR's recent action plan, which highlights the importance of strengthening a relationship of mutual trust and respect to improve the health of First Nations, Inuit and Métis. I feel very privileged to have connected with my partners in Nemaska, and I thank them for joining me on this learning journey that is meaningful first to them, and second to myself.

CHAPTER 2: LITERATURE REVIEW

2.1 Review Introduction

Youth involvement in health planning and research

Youth involvement in health research and planning has been approached with many differing frameworks. A classic typology for describing youth involvement is Hart's Ladder of Youth Participation.[19] Hart describes a ladder of youth involvement as a spectrum from low to high engagement: for example, the lowest level describes a form of youth participation where "adults use young people to support causes and pretend the causes are inspired by young people"; the highest level describes how youth are "initiating projects or programs and decision-making is shared between young people and adults".[20] In more recent years, researchers have moved away from Hart's more linear approach. Wong and colleagues, for example, propose a typology wherein five main types of adult-youth participation categories exist on a continuum of youth participation. Wong et al. also acknowledge that a purely egalitarian view between adult and youth participants is not always productive or appropriate.[19]

While youth involvement has been previously characterized,[9] the inclusion of young people's contributions in health research and planning still remains the exception rather than the rule. Much of the literature in adolescent journals could still be described as "adult-centric", and often overlooks young people's viewpoints.[21] There has been, however, a shift from youth viewed as problems to youth viewed as resources for solving problems.[19] Young people's involvement in health research and planning has also been gaining recognition as not only enhancing the planning process, but also as a way to empower youth.[22]

Literature is now emerging discussing how youth benefit from being engaged in health-related planning.[23] Youth engagement can be defined as meaningful and sustained involvement of a young person in an activity focusing outside the self; full youth engagement consists of a cognitive, affective, and behavioural component.[24] Youth engagement in important decisions (such as health) has also been found to support youth empowerment[25]; empowerment is defined as a process through which youth develop skills and become problem solvers and decision makers.[26] Finally, youth engagement corresponds with important developmental skills; according to Erikson's stages of development, the period between 13-19 years of age in an adolescent's life is when social identity develops. Moreover, the development of social identity requires skills in

relationship building, in building social roles, and in contributing as a member of society.[27] Giving adolescents the opportunity to partake in health research and planning fosters developmental needs such as problem-solving, strategizing, critical reflection and sharing recommendations.[28]

Why youth voice matters in health planning and research

While there are clear benefits of planning involvement for young people, there are also benefits for the planning process itself. As integral members of their community, young people have unique experiences that adults may not be able to relate to. As such, youth are placed in optimal positions to determine the relevance of the efforts geared towards health challenges that affect them,[19] and their experiences need to be heard. It should be noted that, specific to Eeyou Istchee, we found a few initiatives documenting Cree youth health-related perspectives and experiences, including: Hayes on cultural change as expressed by youth in an eastern James Bay Cree community[29]; Lessard on the aspirations of Mistissini youth[30]; Radu's model of decolonized Miyupimaatisiiun in Chisasibi that included youth people's participation[31]; DyckFehderau documenting stories by Cree people from all Eeyou Istchee communities regarding their experiences with diabetes (including young people's stories)[32]; and Caron and Dehghani's community consultations with youth from five Cree communities about Cree youth-friendly health services.[33]

In line with the CBPR approach, issues raised by young people in the community are fundamentally community-lived experiences, and hence should be fully included in a community-driven framework – especially when the health challenges directly impact youth.

In fact, without full community involvement, formed policies on health risk becoming superficial and ineffective.[34] Non-meaningful youth involvement can lead to a superficial understanding of health challenges, and can legitimize a health plan or policy in which a large part of the affected community have not been involved – potentially leading to outright failure of the policy.[35] Especially in Indigenous populations, given the history of harm experienced through research, such a mistake compounds the distrust that Indigenous communities may have and signifies a substantial ethical consequence and concern.[36]

Furthermore, Indigenous communities in Canada share a history of colonial oppression that colours everyday Indigenous life[37]; in James Bay particularly, the hydroelectric conflict of the 1970s threatened the Cree's rights to their land, and their traditional hunting and gathering

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ways of life.[38] Therefore, Cree youth are keen to forge a new future for their communities.[39] In addition, youth engagement has been identified as a path for Indigenous youth towards Miyupimaatisiiun.[40]

2.2 Review Questions

Considering this project's goals as outlined in the previous section, it is critical to first make sense of the existing literature that includes Indigenous youth perspectives on their health and engagement in health, in order to most effectively plan for better health and health services.[4] Driven by a need to understand the concepts and systems of Indigenous youth health and engagement in health planning, from the perspectives of youth themselves, the review questions guiding our qualitative literature review were the following:

1) How do Indigenous youth in Canada conceptualize their health and health care?

2) How are Indigenous youth engaged in health research and planning?

2.3 Review Methods

Eligibility criteria

Given the resources and time available for this review, the following inclusion and exclusion criteria were utilized:

a. Inclusion criteria:
- Must include **Indigenous** context explicitly
- Must include youth defined as between **14 to 30 years of age**
- Must include empirical **qualitative** data
- Must be in Canada
- Must capture **youth's perspectives** about health and wellbeing and/or planning
- Must capture **youth's own voices** (in other words, not solely the adults' or researchers' opinions)

b. Exclusion criteria:
- Excluded studies outside **Canada** (Indigenous populations outside of North America have experienced different histories and lived contexts,[41,42] including being situated in different healthcare systems where opportunities for engagement may present differently)
- Excluded papers not published in **English**

- Excluded papers where **age range of participant reporting the opinion was unclear** (for example, for studies including a broad age range, the extract must clearly come from a youth between the ages of 14 to 30 years)
- Excluded papers that were not explicitly covering **health research** topics

Sources of information

Qualitative research, especially Indigenous qualitative research, is difficult to find.[43] It was not sufficient to simply look through electronic databases, and much time was spent to search in the grey literature, forward track articles that seemed relevant from those obtained, asking senior researchers in the field, and look especially through graduate student theses manually in order to obtain relevant information.

While there is much remaining debate on whether the quality of qualitative research should or can be assessed, we chose to trust the sources of differing types of knowledge as is appropriate in the Indigenous context of the extracts used, and we did not formally assess quality.

The bibliographic databases searched for the purposes of this review were MEDLINE (as accessed through PubMed), SCOPUS, and iPortal Indigenous Studies Portal Research Tool. PubMed has been shown to produce the most extensive coverage of literature relevant to the topic "aboriginal".[44] Additionally, through personal experience as well as that of the librarian, much of the literature directly relevant to the review question is un-indexed; un-indexed literature is accessible via a keyword search through PubMed. The reference management software EndNote was used to maintain the search records and full bibliographic information of relevant studies.

Identification of studies

The search strategy was developed in collaboration with Genevieve Gore, the Liaison Librarian for the Department of Family Medicine at McGill University. To address our review question we used 4 core concepts: *Qualitative, Adolescent, Indigenous Canada*, and *Health Planning*. These concepts were captured with appropriate subject headings (MeSH Terms) and keywords; please see the Appendix A for the full search strategy matrix.

As mentioned in the section above, much of the literature relevant to the review question is not indexed; hence, an appropriate combination of subject headings and keywords was used to thoroughly reach articles of interest.

In order to capture the youth age of interest (defined in our study as 14 to 30 years old), we added *Youth* as a concept instead of an age limit to the search. Again, since much of the relevant Indigenous literature in Pubmed is not indexed, an age limit would have excluded un-indexed papers. Therefore, the *Youth* concept was defined through the MeSH terms Adolescent (defined by PubMed as 13 to 18 years old), and Young Adult (defined by PubMed as 19 to 25 years old), as well as the keywords illustrated in the search strategy matrix.

Selection of studies

The search was conducted in the aforementioned bibliographic databases from April to November 2017. All studies yielded from the initial search strategy were extracted to the bibliographic software EndNote. The primary reviewer then reviewed titles and abstracts of extracted articles; studies were excluded based on a lack of relevance to the research question, or the unavailability of the full text version of the article. This process reduced the number of papers; however, the majority of the studies were not directly relevant to the research question.

Upon closer inspection of the full texts, we realized that some of the papers included information on but not from Indigenous youth. In addition, we noticed that many of the papers stated that they included youth as part of their larger study, yet the opinions included were unclear as to if they pertained to youth voices or adults and/or children from the wider included age range. Hence, we adjusted our inclusion criteria to ensure that we only included articles that clearly captured perspectives of the youth themselves and identified the voices appropriately.

Following an iterative review of the full texts based on our finalized exclusion/inclusion criteria, we retained a pile of 19 studies eligible for synthesis. The overall search process, including the number of records identified, included, and excluded, is depicted in Appendix B. The characteristics of the included studies can be found in the Appendix C.

An evaluation of the quality of each individual study was beyond the scope of this work, and was found ethically challenging to undertake in this review[45]; the primary author found that appraising the quality of insight and validity of Indigenous perspectives recorded in the eligible studies may go against the overall participatory research framework and approach to this

knowledge venture, and that any and all Indigenous youth experiences and voices should be recognized and valued as expertise in this already-limited arena.

Extraction

The eligible studies' full texts were thoroughly scanned to identify health concepts as perceived by, as well as engagement in health-related planning and research identified by Indigenous youth. Data was defined as all text found within the Abstract, Introduction and Results sections of included papers. Much of the data was extracted in the form of youth quotes and manuscript text excerpts. The primary reviewer performed data extraction and coding via the NVivo 11 software, by carefully reading each line of text in order to extract any information relevant to the review questions.

Synthesis

We conducted a qualitative thematic analysis as outlined by Thomas and Harden (2008)[43] in order to elicit common themes regarding the benefits of Indigenous youth health research engagement from their own perspectives. The thematic synthesis process was conducted in three stages, where the level of abstraction increased with each subsequent synthesis stage.

In the first stage, free line-by-line coding was performed to inductively create a bank of 'codes' that remained close to the surface of the youth perspectives. In the second stage, the degree of abstraction increased as we grouped codes into appropriate 'descriptive themes', which represent an overarching concept perceived by youth that still remains close to the findings of the included studies. Each study was coded for multiple descriptive themes. In the third and final stage, the reviewer created 'analytical themes' by grouping of descriptive themes, and increasing the level of abstraction one step further.

The entirety of this process was recursive and iterative in order to yield satisfactory final syntheses. In this review, the three levels of synthesis abstraction (codes, descriptive themes and analytical themes) were sufficient to answer our review question on the definitions and mechanisms of health and engagement from the point of view of Indigenous youth.

2.4 Review Results

With the review objectives in mind, this literature review presents what is known in the Canadian context about (A) Indigenous youth health and conceptualizations; (B) Indigenous youth engagement; and (C) Strategies to better engage youth in health.

2.4A) Indigenous youth health conceptualizations

While concepts of health and wellbeing have been described variably, historically and today, the Western medical system often responds using a biomedical approach; this is in contrast to the more holistic and interconnected approaches to health that are often described in Indigenous narratives and communities.[46] In general, almost all included studies pointed to the fact that Indigenous youth view health as a holistic and interconnected state, consisting of wellness in the physical, mental, spiritual and emotional components of the medicine wheel.[47,48]

While many dimensions of youth health were discussed, this review will focus on the cultural components of youth health as described by the Indigenous youth participants themselves, and how their culture plays a role in their concepts of health and wellbeing.

In all included studies that discussed youth health, culture was part of the narrative. Youth expressed how connecting to their Indigenous traditions and heritage was an important aspect of their wellbeing,[49] allowing them to better understand their identity,[50] to heal and forgive themselves based on their past hardships,[51] and to feel connected, like they belonged, and not lost.[48,50-52] Radu highlighted youth's agency toward their cultural continuity and identity as part of their wellbeing. Youth described cultural activities (such as dancing and pow wows) as: a state of wellness and a coping mechanism[48,51-53]; creating a sense of community and family[48]; and, a space that promotes resilience and positive sense of self[51] – even when the cultural activities and ceremonies they partook in were relatively Pan-Indigenous and not necessarily their own.[29] Genuis et al. also reported how youth felt towards their traditional foods as part of their cultural identity, and how they believed returning to traditional foods was an important part of their cultural health.[54]

Greater cultural education in schools was also discussed as a way to increase youth's knowledge and pride in who they are.[53] Youth identified different methods to connect to their cultural teachings, including bush excursions and wearing cultural dressings[29] as well as tribal canoe journeys and activities.[53] While some youth acknowledged a loss of their cultural identity associated with modernity,[48,50,52] and some youth acknowledged a loss of their cultural identity associated with denial and suppression from people in their communities as well as the non-Indigenous education system,[31] youth still valued and respected traditional ways of life, expressing that they "*never want to lose it*".[50] Youth described the direct and indirect impacts of colonization, and how this affected their own battles with depression and low self-esteem[48] –

underscoring the need for better education on the repercussions of injustice histories and residential schools as key to bettering their health.[51,52] The importance of connecting to their Elders to better learn their culture and feel supported in challenging times was highlighted,[53] despite generational gaps between Elders and youth[47] that were also discussed. Hayes pointed to a conflict between youths' and Elders' perceptions of tradition; youth in this study described how they rejected Elders defending Anglican Church rules as 'authentic' tradition, while they looked instead for "*Native spiritual guidance*".[29] This conflict of traditional values was also suggested by Hatala and colleagues.[51] That being said, the importance of learning their Indigenous language in specific was a point of divergence amongst included studies. While some youth described learning the language as culturally important,[50,54] some felt language was not as important or furthermore embarrassing.[50]

Finally, youth expressed a sense of responsibility to pass down traditional teachings[51] and spread cultural education and connectedness[48] for the next generation, as an ultimate method to honour their ancestors.[55]

2.4B) Indigenous youth engagement

Indigenous youth engagement was described in many capacities and to varied degrees amongst included studies. While these studies do offer youth engagement examples, a few stressed that this was not enough; Radu emphasize how Indigenous youth are often portrayed as struggling, but their personal stories and perspectives are rarely heard or sought; Beatty et al. reported that youth generally had lower participation and engagement in Indigenous communities; and, in Caron and Dehghani's report, youth report feeling forgotten. With this in mind, the next section synthesizes what was discussed surrounding all levels of youth involvement and engagement in their communities, health, research and governance.

Youth engagement in leadership

The importance of youth's positive leadership and role modeling was described.

In Monchalin and colleagues' study, youth described leadership as starting small and within families, where youth try to be good role models for their family members, and youth expressed that they sometimes felt pressure to uphold a strong leader image for other youth. Youth described how it was important for them to work on themselves first to be able to work outside for others second. Youth also highlighted the importance of patience, dedication and resilience when trying to make positive change. They spoke to their larger purpose of getting an

education and graduating for themselves, for their families, for their communities and for all Indigenous peoples. The importance of older youth leading by example for younger youth was also elicited through Woodland's study and Genuis et al.'s study.

Crooks et al. spoke to the sustainability of Indigenous youth leadership, noting that once youth became involved in peer-to-peer leadership and mentorship, they were likely to continue. The youth in Crooks et al.'s study emphasized the importance of not being shy when leading other younger youth, to make the most out of that leadership and mentorship opportunity. Stewart and colleagues described how youth being given leadership opportunities further helped youth recognize their own strengths and abilities to influence their communities in positive ways.

Specifically regarding youth's leadership and engagement in politics, Beatty et al. reported youth's feelings as varied. Youth described barriers to their political participation as including: close affiliation to candidates and associated conflicts of interest; drama that characterized their local political parties; feeling like they were too young or did not know enough about politics; perception of election unfairness and bias towards nepotism; dissatisfaction with a lack of financial support, communication and action from the Band (governing) council; and, feeling tired due to a lack of change. Some youth in this study expressed that they did want to vote to make a difference, and thought voting to be important in principle; however, Beatty et al. did report a declining Indigenous youth voter turnout in this region.

Youth engagement in health decision-making
A few papers included in this review explored youth engagement as genuine decision-makers and planners.

Youth engagement in health research decision-making: The most studied form of youth engagement in decision-making was youth's engagement in youth-related research in a co-researcher capacity. For the purposes of this chapter, youth co-researchers are defined as youth who are involved in all stages of the research process, from the identification of the research problem to the data collection to the interpretation and dissemination of findings.

The research from Genuis et al., Clark et al. and Crook et al. described how youth believed that when they lead the research project, they felt they could best connect to youth participants through mutual lived experiences and understandings, and best access the participating youth's knowledge. Monchalin and colleagues also highlighted how youth felt they

were in the best position to really listen to other youth. Stewart's team moreover described how youth engagement and creation in a research project allowed youth to have control over their own narrative from research with Indigenous peoples. Fletcher and Mullett further described how engagement in research led youth to better understand and appreciate research as a whole. Genuis et al. discussed how, over the course of the research process, university researchers became the learners and the youth co-researchers increasingly assumed the roles of experts and agents for positive change.

Additionally, many included studies discussed the positive and personal growth impacts of youth engaged as co-researchers. Included studies from Fletcher and Mullett, Clark et al., Genuis et al. and Stewart et al. all reported youth capacity building and technical skill development associated to their engagement. Fletcher and Mullet described how research engagement encouraged youth to be more inquisitive and better access and understand community knowledge. They also highlighted how youth's research engagement led to youth job opportunities, where youth could use their learned videography and facilitation skills in their future careers. Similarly, Clark et al. reported that youth were proud of the research skill development and abilities, and that conducting data collection helped with their overall work ethic. One youth in Stewart et al.'s project described how their engagement as a Photovoice co-researcher gave them the opportunity to have and use a camera to express their voice, which was an experience they otherwise would not have the money to afford. Finally, Clark et al. reported that youth engagement in research helps foster youth self-confidence, and pride as an Indigenous person. Clark's and Stewart's teams suggested how research engagement led youth to develop a concept of research as helping others.

Lastly, a few studies spoke to the longevity and sustainability of research endeavours when youth are engaged in decision-making as co-researchers. For example, McClymont Peace and Myers highlighted how youth co-researcher's climate change research and ultimate awareness projects were to later be used as education and advocacy tools and to encourage other youth to better understand and engage. Stewart and colleagues' paper also included youth who described how they gained a sense of responsibility towards their peers and community through the co-researcher process. Genuis et al. described how having youth on the research team was important for youth to tell their stories in their own ways, and deliver these messages to those "who are in a position to bring about community change". Indeed, they also described how

engagement in research helped develop trust and openness among the research team, and cultivated a sense of community and relational investment in the future community.

Engagement in political health decision-making: There were a few studies that described youth's meaningful engagement in decision-making Indigenous government bodies and entities. Radu's study highlighted how, according to some youth, genuine decision-making engagement was lacking in their region; youth felt their voices at the decision-making table were not taken seriously, were left unheard, or were devalued. Youth in Monchalin et al.'s study also expressed upset when their leaders utilized 'youth' as the reason behind their health initiatives, but failed to include youth in making these decisions. That being said, Blanchett-Cohen et al.'s study reported how youth felt valued only when they were meaningfully engaged, and when they saw tangible action on their recommendations.

2.4C) Strategies to better engage Indigenous youth in health

Youth's motivations to engage in health

A few included studies explored the reasons behind youth's motivation to be more engaged in their health and health planning specifically. One youth in Blanchett-Cohen et al.'s study reported their reason as being driven by frustration: *"I am sick of seeing my friends dying of addictions, I am actually going to do something… It is frustration that motivates me to create unity…"*. Another youth in this study described the importance of youth feeling ownership over the program or service in order to feel motivated and accountable to the program. Youth said they were motivated to lead to better health change since, ironically, their current and older leaders were "*fighting against each other. We youth work together… we need to control the agenda"*. One youth also emphasized that youth should be involved in all, and not just youth-specific, community health issues.

In Fletcher and Mullett's study, youth wanted to feel that they belonged and that they had a voice. Youth in the Clark and colleagues' study suggested that they have long been advocates for youth voices, and sitting at council tables where decisions were made related to youth health was essential to them. Monchalin and colleagues highlighted how youth felt bad about the health challenges that youth faced in their communities, and felt the need to mobilize actors towards change – youth in Radu's study furthered this notion by feeling the need to create demonstrations in solidarity with the health and wellbeing changes they believed their people needed.

Successful strategies to better engage youth

To better engage youth in health planning, a few strategies and facilitators were reported in some of this review's included studies.

Firstly, many highlighted the effectiveness of arts-based youth engagement methods, specifically youth engagement in health-related planning: Blanchett-Cohen et al. described how comic strips featuring Indigenous characters and culturally relevant humour and facts could facilitate discussions around healthy living, how youth viewed hip hop and dance as one of the best ways they felt they could express their messages, and how theatre and pretending could be a mechanism for youth to safely explore and engage in health discussions; Radu described film as a medium for Indigenous youth to express their identity, as well as rap as a medium to express identity and engage in social discourse; and, Hayes expanded music written for youth by youth as a method for youth to share their sorrows and lessons with other youth, and feel empowered.

Using social media as an advertisement and engagement platform for Indigenous youth was also widely discussed. Beatty and colleagues highlighted the ubiquity of Facebook and texting amongst Indigenous youth, and Blanchett-Cohen and colleagues underscored the importance of using social media as a youth communication tool. Furthermore, youth in Blanchett-Cohen et al.'s study highlighted the importance of having a communication strategy to reach out to the youth through social media, instead of using posters that may have negative connotations since "*a poster… it looks really bureaucratic, and they have already participated in tons of things [through posters] that have not seen follow through*". Youth in Beatty et al.'s study described how social media was an essential tool for youth to engage in online political discussions, polls, and campaigning.

Youth from different studies also underscored the importance of taking a community-based approach to engagement strategies with youth. In Blanchett-Cohen's study, community-driven and -owned approaches were described as more effectiveness and respectful for youth. Youth in this study did note, however, that those youth who had become disconnected from their original communities were still able to connect with other Indigenous communities.

The effectiveness of peer-to-peer strategies for youth engagement was highlighted, specifically how peer-to-peer strategies: facilitate more comfortable and clear communication amongst peers[52,56]; capitalize on common youth lived experiences[52]; empower youth and make them feel more comfortable to attend youth health activities or services[33]; and, avoid the

hierarchal dynamics involved when someone older talks down to them about their health behaviours.[47] An example of a successful youth-led, peer-to-peer health awareness project as documented in Blanchett-Cohen et al.'s study is the Making Aboriginal Kids Walk Away initiative, where Indigenous youth leaders in Thunder Bay teach their peers about traditional tobacco uses and raise awareness on health-related issues.

Holding physical spaces for youth to gather and connect to their Indigenous cultures was also highlighted as a strategy for better youth engagement. Indigenous youth in Blanchett-Cohen et al.'s study who lived in urban contexts described how youth centres could be an effective place to offer health services alongside traditional remedies. Radu also underscored the importance of holding deliberate spaces for youth to feel comfortable to share their wellbeing approaches.

Another strategy that youth in Blanchett-Cohen et al.'s study suggested to increase youth engagement was to only talk to and consult with the youth during planning, but also to involve those specific youth who were consulted with in the implementation of that health plan. They also suggested creative incentives could increase youth engagement, such as recognition and rewards for their participation. Finally, they highlighted the importance of health planners making it clear to the youth why the youth's attendance and engagement matters and is valuable; furthermore, youth in Beatty et al.'s research stated that youth were only interested in engaging if they perceived their engagement as helpful, fun and useful to produce visible change within their communities.

Areas for improvement to better engage youth
There were a few direct recommendations made by the youth to better their engagement in their health and health planning overall.

Youth in the Blanchett-Cohen study highlighted disrespect and labelling experienced from healthcare professionals as a reason why they did not want to be involved or engaged in healthcare. They also described how, when youth did plan or organize health-related activities, their positive contributions were not appreciated and showcased enough. One felt that youth voices were always last on the decision-makers' agenda, if they were even on the agenda. A primary concern and area for future action raised by these youth was the desire to be involved in the design and delivery of health programs and services.

Youth in Beatty et al.'s study expressed how they did not feel involved nor that their concerns were being addressed, and expressed a dissatisfaction with the lack of requested changes being made. They also mentioned the lack of organization in political Band Council-organized events as a barrier to their involvement in the political decision-making overall. Another concern raised was the need for more sports leagues and facilities for youth to participate in.

Finally, Caron and Dehghani's study described how some youth did not understand certain health problems and therefore they did not care enough to engage in health planning.

2.5 Review Conclusions

In brief, Indigenous youth across Canada described the cultural components of their wellbeing as essential to their overall wellbeing, including fostering their cultural identity, healing and connection. Youth engagement was described as a component of their wellbeing. Youth also highlighted the importance traditional foods and ceremonies, greater cultural education in schools, greater connection to Elders, and a responsibility to pass down traditional teachings to the next generation in order to foster Indigenous youth health and wellbeing overall.

Indigenous youth engagement across studies was varied. Youth engagement in leadership was associated with youth's personal growth, ensuring the program is sustainable, and making a difference through political engagement. Youth engagement in health decision-making, in a co-researcher context, was associated with benefits for the health research process itself, personal growth and future career opportunities, a greater appreciation for research, and the sustainability of the health project for the future of their communities and peoples. Youth engagement in political health decision-making was described as lacking, but essential to youth feeling valued in their communities.

Strategies to better engage youth in health decision-making were discussed. Youth's motivations to engage in health decision-making were described. Youth discussed successful strategies to increase youth engagement, and recommended areas to improve.

The results of this review will be expanded upon and related to this study's novel findings in Chapter 5.

CHAPTER 3: STUDY DESIGN AND METHODS

3.1 Context

A brief history of Nemaska

Nemaska, one of the nine Cree communities in Eeyou Istchee, is a small inland community currently located on the shores of Lake Champion with a total population of approximately 851 in 2017.[57] Nemaska, similar to all communities in Eeyou Istchee, has experienced a history of marked interference from government institutions and forced relocation. Nemaska was originally located on the shores of Nemaska Lake, now nostalgically referred to as Old Nemaska. In 1968, the James Bay Hydro-Quebec project was in full effect, and representatives from the Government of Canada and the project were sent to inform the Nemaska Cree people that they had to relocate and that their community would be flooded as a result of the project's operations. By 1970, the Nemaska Cree were forced to displace from their ancestral homes, and break their long-established harmonies and relationships with the land and the Lake, to the neighbouring communities of Mistissini and Waskaganish. During this time, the Nemaska Cree were also subject to institutionalized education in the form of residential schools. In 1997, after seven years of exile, the Nemaska Cree gathered at Champion Lake (or Nemeskaau sakheekin in Cree) to discuss their situation. In accordance with their traditional decision-making processes, and after much discussion, community consultation, and guidance from Nemaska Elders, they made a decision to rebuild a new life on the shores of the Champion Lake.[50] Old Nemaska is still very important to Nemaska Cree; they have rebuilt and reconstructed the Old Nemaska site in efforts to reconstruct it the way it was in 1960s before they were forced to leave, and many community members view Old Nemaska as a second home. Nemaska youth, families and community members still return annually for a summer gathering, to socialize, fish, play traditional and non-traditional games, and remember – as one former resident put it, "It's like paradise… you'll wonder why we ever left".[50] Despite adversity, the Nemaska Cree have persevered, rebuilt their community, and maintained their cultural pride and traditional way of life. And their story is still being written.[58]

Population composition of Nemaska

This section reviews the data provided by the CBHSSJB from the 2016-2017 Annual Report. The purpose of this section is to provide an illustration of the relatively young population in this community. Ushiniichisuuch or youth, defined by the CBHSSJB as ages 10 to 29, make up over one third of the total population of Nemaska:
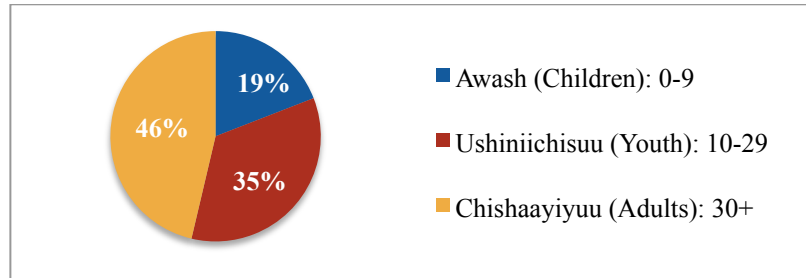
Figure 1. Population pie chart of Nemaska

In addition, according to the Cree Nation Youth Council, a further breakdown of this youth category reveals that the vast majority of the youth population falls between the ages of 13-24.[7] It should be noted that the youth age range used by the CBHSSJB (10-29) is different than the youth age range used by the Cree Nation Youth Council (14-35); the latter, as defined in our Glossary section, was used to recruit participants in this project.

3.2 Research Approach

Community-based participatory research (CBPR) falls under the umbrella of participatory research as it involves all members of the project in all aspects of the research process, including (1) the identification of the research topic, (2) the interpretation of the results, and (3) the diffusion and dissemination of the results.[59]

Key characteristics of CBPR, and how they align with the aims of this research, are outlined in Table 1 below:

Table 1. Characteristics of community-based participatory research for this project	
Study context	**Alignment with CBPR characteristics**
Indigenous context	• CBPR techniques have been shown to be particularly positive in historically disenfranchised communities[60] • CBPR can address the negative impacts of prior research by ensuring community consultation, participation, and centrality of

	Indigenous ways of knowing[61] that are imperative to this project's epistemology • While CBPR does not guarantee cultural safety, it reminds us of the importance of ongoing reflection in order to minimize any assault on participants' cultural identity[62]
Youth as end-users of this research	• Participatory research has roots in the self-determination and sovereignty movements of Canada's First Nations, united to "create scientific knowledge with those who are most affected by the issue being studied"[63] • Continued transparency of the research process with the youth participants can facilitate enhanced trust between the researchers and communities[9]
Power relationships and imbalances	• CBPR as a framework takes into account the power imbalances that have resulted from a long history of colonialism and forced assimilation[64] for Indigenous peoples and populations • Further power relations exist for Indigenous youth; current and historical power relationships were continuously reflected upon, and were discussed with participants
Overarching purpose to inform CBHSSJB and IAMP teams' decision-making about healthier communities	• CBPR approaches aim to incorporate and honour community members' priorities, ensuring the equitable inclusion of youth voices in the development of policy and planning for healthier communities[65]

As outlined above, the CBPR framework is ideal and essential for this community-based youth project. This project aims to promote a shared responsibility of strategic planning towards optimal health outcomes in the James Bay Cree region, and builds upon a broader goal to fully involve the community in order to identify community needs. Through a CBPR approach with a focus on youth involvement, we hope to identify young people's priorities and ultimately improve health outcomes.

Partnership

This project builds upon an existing partnership between McGill researchers and the CBHSSJB, stemming from a joint initiative and featuring a genuine participatory collaboration for health planning across the Eeyou Istchee region. In order to further develop and maintain this partnership through the youth component, the following techniques were undertaken in accordance with Salsberg et al.'s strategies for a successful PR process[66]:

1) Memorandum of Understanding (<u>Appendix K</u>): The pre-existing memorandum with the CBHSSJB was followed and respected. As part of this agreement, it should be noted that this thesis work is under joint ownership of the CBHSSJB and McGill.

2) Use formal and informal group facilitation techniques: The focus group sessions were co-facilitated by the graduate research and a community partner who works at the Luke Mettaweskum school, providing valuable contextual knowledge of local conditions for the Nemaska youth.[67] Informal techniques, such as opening the discussion based on hobby sharing, and frequent activity participation prior to the discussions, were used as advised by our community partners.

3) Frequent communication: Communication was maintained via frequent email, social media, and text message exchange, as well as physical trips between Montreal and Nemaska.

Stakeholders

A summary of the stakeholders implicated in this study, along with a table to justify the importance of each stakeholder's representation, is attached as <u>Appendix D</u>.

3.3 Methodology

We used a qualitative descriptive study design as described by Sandelowski (2000) to gain an in-depth understanding of youths' and youth leaders' perspectives,[68] and to access the emotional and motivational components of their lived experiences.[69] Qualitative descriptive designs stay close to the surface of the data and are ideal when full descriptions of phenomena are desired.[68]

Methods

Ethics: The youth component was originally identified as a priority under the overarching IAMP evaluation project ethics submitted to both the McGill Faculty of Medicine Institutional Review Board (IRB), and parallel CBHSSJB review where an IAMP Memorandum of Understanding with the CBHSSJB was already operating that includes this project. An

amendment to the previous McGill IRB ethics board was submitted and approval was obtained in September 2017 (A01-E01-16A). The additional process of obtaining the Chief's approval for Nemaska community entry was also completed verbally and in writing. It is worthy to highlight that the respect for Cree culture, historical trauma, Cree ownership of data and confidentiality was followed strictly according to the pre-existing Memorandum of Understanding with the CBHSSJB (Appendix K).

Site of collection: Nemaska was primarily chosen as the data collection site since the local Community Miyupimaatisiiun Centre supervisor expressed a desire for greater youth involvement in their wellness coordination and planning processes; this community-identified priority is congruent with our CBPR approach.

All focus groups were conducted on site at the Luke Mettaweskum School, in partnership with the school principal, vice-principal, and a youth leader. Key informant interviews were held either in person at the Nemaska Community Miyupimaatisiiun Centre, or via Skype or telephone.

Recruitment: Participant recruitment for the youth focus groups was up to the discretion and recommendation of the school principal who was a keen and important partner in this research. Purposeful, snowball sampling was employed as guided by our school partners, where youth participants provided additional snowballing of the participants; purposeful recruitment of youth was done to include information-rich experiences and perspectives from youth.[70] The school principal drafted a list of high school students in Sectors 5 and 6 (ages 15-16, and 16-17 respectively) who "would contribute meaningful opinions on the research questions". The vice principal finalized the participant list on the day of data collection, based on students who were actually present, willing and available to join and participate in the focus groups. There were also few students who were on the preliminary list, but were intrigued and participated. Posters were also posted around the community by our Miyupimaatisiiun community partner; please see Appendix E for the recruitment poster.

Participant recruitment for the key informant interviews was also performed using a purposeful, snowball sampling technique, where our Cree and CBHSSJB partners recommended information-rich participants to interview.

With the help of our partners, we were able to recruit from areas representing the spectrum of health and wellness experiences and youth involvement (Community Miyupimaatisiiun Centre, Cree Nation of Nemaska Youth Council, Youth Gathering Space,

Luke Mettaweskum School), in order to best transfer these results into valid recommendations for the community.

Data collection: Two semi-structured youth focus groups were conducted. A total of 10 Cree youth participated in the focus groups, ranging from 15 to 17 years of age. The objective of these focus groups was to identify key themes that represent youth health and health priorities, as well as how youth engage in their communities. Groups were mixed gendered and age, as recommended by our partners, since this was manner in which youth were comfortable in their peer groups. Each discussion lasted approximately 50 minutes. All focus groups were audio-recorded with signed consent, and transcribed. Snacks were provided to participants as compensation for their time. Focus group consent forms are attached as Appendix F.

The school principal also appointed a youth leader to co-facilitate the groups and increase students' comfort; this youth leader was there from Youth Fusion, a national organization that sets to increase student retention by organizing fun and active extracurricular activities across the country, which had a partnership with the Luke Mettaweskum School. Luckily, I had already met this individual earlier in my community stay, and we already had a positive rapport.

While it has been suggested that members of the community are best suited to lead focus groups,[71] the Cree IAMP Team partners also believed that an impartial, outside facilitator might promote more open commentary that may be critical of community services. As such, in accordance with out CBPR approach, focus groups were co-facilitated by a community Youth Fusion leader and myself, with support from our Cree community partners and the IAMP Team.

Building on the expertise and networks of our community partners, the draft focus group guides were first presented to and discussed with our CBHSSJB partners in order to modify it based on the language and priorities deemed appropriate to youth. The drafts were then presented to the Luke Mettaweskum school principal, vice principal, and Youth Fusion leader for final revision. In the case of a disagreement at either level, discussion continued until consensus was reached.[72] The final focus group guide is attached as Appendix G.

Key informant interviews were scheduled with Cree community members who were involved with youth and youth health engagement and planning; these leaders worked in and represented either the regional- or community-level. A total of five key informants were interviewed. The objective of these interviews was to better understand how youth health services are planned, and existing structures that exist for youth engagement in the community.

Interviews were audio-recorded with signed consent, and transcribed. Each discussion lasted approximately 60 to 75 minutes. Recruitment of key informants was purposeful and used a snowball sampling technique, as guided by our Cree community partners. Interview consent forms are attached as <u>Appendix H</u>, and interview guides for youth council members and youth coordinators are attached as <u>Appendix I</u> and <u>Appendix J</u>, respectively.

Data analysis: Thematic Analysis was used to identify, analyze and report themes within the recorded transcripts. Qualitative description relies on thematic coding through constant comparative methods borrowed from grounded theory.[73] Codes and code hierarchies were continuously revised as they are applied to new text, and emergent codes were in turn grouped into overarching themes.[74] Themes were defined as important patterned responses or meanings from the text as they relate to our research questions.[75]

Analysis was inductive allowing codes to emerge from the data alone; since the contextualized phenomenon and knowledge is unexplored thus far, identified themes should remain closely linked to the data without trying to fit the data into a pre-existing frame.

Finally, themes were divided according to the intersection of youth engagement and youth health as previously described in the findings of the conducted literature review. The end goal of the coding was to reveal the common threads among the participants and ensure that they were presented in a meaningful manner.

Analysis was recursive and conducted by the primary author, with virtual coding from the project's co-supervisors. Once preliminary analyses were completed, results were shared with our Cree partners and participants to comply with the project's Memorandum of Understanding, and "ensure accuracy and avoid misunderstanding"[72] to verify that the Cree conceptualizations of health and engagement were considered and adequately described at this level, allowing our work to go beyond mere description and yield rich analysis at the interpretive level.

Data validation: In this research's context, validity and trustworthiness of the data was of particular concern and was incorporated into all stages of the research process. Purposeful snowball sampling techniques, guided by our Cree community partners, was used to recruit information-rich youth representing a variety of perspectives across the youth involvement spectrum. Triangulation of research methods through focus group interviews, individual key informant interviews, and thorough literature review also helped ensure internal validity of the data.[76] Self-reflexivity was also a constant throughout the research process in the form of

journaling, in order to reflect on my position within the study and how my personal beliefs may influence the research focus and findings.[77]

To ensure validity regarding the Indigenous context of this study, validation procedures were discussed in depth within the author's thesis committee and individual community members. Preliminary results were presented to the thesis committee and discussed. In accordance with Section 4 of the Memorandum of Understanding with the CBHSSJB, as well as Article 14 of the Canadian Institutes of Health Research Guidelines for Health Research Involving Aboriginal People (2007-2010),[78] results were then presented to and validated by two representatives of the CBHSSJB, one community representative, and one youth participant. In addition, regular meetings, phone calls and text messages were used as debriefing strategies throughout the process, to ensure the rigour regarding the Cree context and ways of knowledge were honoured. We also hope to return to Nemaska to continue member-checking and validation process with selected youth community members and youth coordinators, to ensure credibility of the analyses[79] prior to any further dissemination or publication of this work.

Data dissemination: In line with the CBPR values and Memorandum of Understanding with the CBHSSJB, all study findings will be interpreted and agreed upon with our partners prior to any dissemination, to ensure partner satisfaction and usage of appropriate methods to encourage the movement results into practice.[61] While the details of the dissemination process have not yet been formalized in detail with the community partners and IAMP team, the primary author has agreed to synthesize all final results with the partners' interpretations and validations in a summarized fashion, and share the agreed-upon qualitative results with individuals and entities that are interested in accordance with the Memorandum of Understanding.

Collaborative dissemination will occur through agreed-upon methods at different levels: i) in Nemaska, through general assemblies and interested community organizers; ii) in the youth community, through youth conferences (such as the annual Inspire Hope Conference) and at the Youth Gathering Space; iii) to the CBHSSJB, for policy-making advising and to inform future youth-related health initiatives and programs; iv) in an international context (as determined by our Memorandum of Understanding with the CBHSSJB, Appendix K) via conferences, seminars and workshops, in collaboration with stakeholders for widespread dissemination.

CHAPTER 4: RESULTS

4. 1 Youth "Engagement" Revisited

Prior to discussing Cree youth engagement, it was important to characterize how participants viewed and defined youth engagement. While there was no one agreed-upon framework, participants generally defined youth engagement as a spectrum: from "just showing up" to "being decision-makers towards action". For the purpose of this manuscript and the ease of results presentation, the following spectrum was outlined using the following terminology.

The first level of youth engagement was described as "participation", where youth showed up and partook in an activity or attended an event; "participation" was considered a less transformative type of youth engagement.[80] The second level of youth engagement was defined as "youth council membership", where youth were nominated to represent the youth voice and were often solicited by decision-makers; "youth council membership" was considered a more transformative type of engagement. The third and highest level of youth engagement spectrum described was youth engaged as "planners", where youth are the decision-makers and lead in planning towards action; "youth planners" were considered as the most transformative type of engagement. These three main categories are illustrated in <u>Figure 2</u> below.

Figure 2. Spectrum of Cree youth engagement

4.2 Perspectives on Context of Cree Youth Engagement

4.2A) Deference and shyness as a youth characteristic in Cree culture

While youth engagement was recognized and well-characterized by the participants in this study, it is important to note that youth deference and shyness was often brought up in discussion; furthermore, Cree youth deference and shyness was described as being part of Cree culture. One youth coordinator related youth deference to the Cree ways of teachings from Elders to youth:

> *"In general, youth are taught to listen, observe and reproduce hands on or manual work. Therefore in our culture… youth are most likely to listen to the Elders verbalize and show them techniques and ways to hunt or build things."*

Another youth coordinator related Cree youth reservation to living and growing up in a small community:

> *"Because it's in a way like part of the culture, and at the same time like I said, we're from a small time so you're more reserved, laid back, shy… yeah."*

Moreover, this coordinator described leaving their small community and exploring bigger cities as a key factor in their own extroverted nature, when comparing themselves to other Cree youth:

> *"…it's like that in pretty much the Cree territory, where there's a lot of like shy and reserved kids… cause we're from a small town… for me, I've always been a little more on the outgoing side because I'm used to the city and I know… I've explored"*

Indeed, one youth participant shared that they felt more comfortable staying at home than going to community events, suggestive of more shy tendencies:

> *"Um, I dunno. Never went to a [community] class before… I feel more comfortable with my family. Mhm."*

Even youth who currently sit on youth councils, and are actively engaged in planning for other youth, pointed to their shyness when growing up:

> *"I was really shy and nervous before. Like before I got into this [youth council] position. I was one of those people who were very shy and nervous. So when I got [this position]… it really boosted up my confidence in leading activities."*

That being said, there were many ways participants discussed to foster greater confidence among youth. Youth coordinators described the importance of providing programs that foster interpersonal skill development. One youth coordinator described:

"One of the things that we talked about here at the youth department is having training programs for interpersonal skills, or identifying yourself… really who you are, what you really want."

The use of social media can also be helpful in this regard, making it easier to reach shy youth who are more shy and less likely to show up:

"Using social media is a big tool for our youth because, there are youth that don't speak and are very shy. So they have Facebook and their own world so they read through that… and maybe you can't reach them in school but you'll be able to reach them alone in their room…"

Similarly, one youth coordinator felt that being behind a computer screen can actually help boost youth confidence to speak their minds and share their true opinions:

"When we have technology, you know, everybody is confident behind their phone or their ipod or they're laptop, whatever. But then you see this kid, you see them somewhere, and they're not going to say like 'Oh I really loved your picture on Instagram, I loved your vacation'… They're not gonna… they're not gonna wanna further talk to you in person."

Youth participants also described how anonymous suggestion boxes could be useful to solicit youth voices that are not necessarily reached through regular means or through the youth councils:

"Suggestions boxes… it could be done once in a while for different topics. I also suggest other communities to do the same thing, because it's really helpful when you see other youth submitting their ideas instead of just the council or department."

In addition, one youth coordinator recommended hosting more opportunities for youth to speak their mind in smaller contexts rather than large assemblies, as the latter can be intimidating for a youth:

"To have more, not necessarily assemblies… maybe like workshops, focus groups sessions… rather than everybody there listening. Like if we had more like smaller groups, I find that always works. I like that setting… when I go to a meeting or a conference or whatever, I like it when they have little focus groups. You get to pick what topic… cause

not everybody has a problem for example with drugs and alcohol… you wanna stick to something that you can relate to, that you wanna learn more about. So, I think a focus group type of approach works. Works well."

4.2B) Youth engagement as a Cree value

Cree youth shyness notwithstanding, participants emphasized the value of those Cree youth who did choose to engage. The idea that youth engagement was necessary for how far the Cree Nation has come, and how far they can go, was brought up amongst participations – particularly youth coordinators. One youth coordinator pointed to a conversation they had with a top-level decision-maker in the Cree Nation Government, and how leaders' narratives for positive change often featured youth as drivers of this movement:

"I remember we had this discussion years ago at the Cree Nation Government, and [top-level government representative] said 'Okay yeah, we're so happy what we have now, but in the future we all can't be councillors and chiefs making big decisions for our community… How do we sustain ourselves and mobilize youth?'. With the Grand Chief too… it was always the same message: 'how do we reach the youth?… I wanna hear them'!"

Another youth coordinator recounted the historical strides of the Cree people, and how they believed this had caused a shift of the mindset of the Cree towards greater engagement and work. According to this coordinator, there were only a few prominent leaders in the past who led Cree successes; now, more community members are able to be involved and contribute to the success of their community:

"I think for most of our parents… there was only a fraction of people that really made decisions… the decision-makers up top. If you see the photos, they had less than 15 people that really changed the course of history for the Cree. Now we do have all of these positions to be filled with the Cree… the second generation that feels like 'Oh… it's not that long where we're put into the workforce'. I think we really didn't see the importance of work, I believe, in the 80's and 90's. Because all the parents were making money, and just spending it on their kids, and foolishly sometimes I could say. But now, we have this realization… because of our trips perhaps to the Western society. It's an eye-opening experience I suppose for a Nation to come from nothing, from tar and shacks, to now home building where homes that are now 4-500,000$. So this generation sees the whole broad perspective of what it

entails to be a normal citizen, and the bills… the loans, and the financial state of their household. So,… I know this next generation will make a big splash, especially like those remarkable achievers from the past."

Another youth coordinator described how the younger generation has the capacity to engage because other critical issues for their people have been addressed, describing a community readiness for change to be led by the youth:

"Well… this younger generation, they do care about what will happen. Whereas, where we started, the fight was for the rights of the Elders – the fight to keep the land so it wouldn't be completely demolished or destroyed… now, we've achieved this magnitude of success and building our own nation, Cree nations, sovereignty. Now, when you look, the youth… look over the table at what was achieved. And now the process is 'okay, we look ahead'…what will sustain [the Cree]? What we do now is what will affect [the Cree] in the next 50 or 100 years?"

Discussions on youth engagement were accompanied by notable pride; one youth coordinator spoke about how other peoples or countries may not welcome youth engagement in leadership at the same level that the Cree do:

"We do have members that are young in each [Cree service] entity, which I'm very proud of, to support compensation of the young members there... Cree Health Board – we see younger generations of board directors. So, everywhere across the region, there is not just only Elders that sit, or professionals, but they have young, educated and fresh people. So yeah. I think it's widely known that that is acceptable. Other countries wouldn't dare have a little young person sit there you know. So we're fortunate enough, blessed enough, to see that happen in our community."

Another youth coordinator noted how Cree youth were politically inclined and wanting to get involved in governance roles:

"…there is a youth movement. So they're very politically inclined. We're a very politically inclined nation, I believe. Especially with the youth."

4.2C) Cree youth motivations to engage

While engagement was described by many youth council members and youth coordinators as a value of the Cree Nation in general, it is worthy to note that when I asked youth participants what motivated them to engage and participate in community activities, many

immediately responded with monetary incentives. Unbeknownst to myself, youth explained how many community engagement opportunities (including participation in sports tournaments, traditional snowshoeing events, and even delegation to sit on youth councils) were accompanied by monetary compensations for youth's participation or if they won the competition.

When speaking with youth coordinators, many shared strong opinions on this extrinsic form of motivation. One youth coordinator described their perspective on the origin of this now-commonplace incentive:

> *"Paying them… It's something that was established years ago. I'll be honest, I worked at the [community name] youth department. They did that. There was more funding within the youth sector... I know others receive more funding than we do. But they used to give out these crazy prizes just to get youth socially engaged, happy... whereas they're all coming there for the wrong reasons."*

Indeed, many youth coordinator shared ethical frustrations with this youth engagement strategy, describing how youth should not be bribed to engage even though it works:

> *"I hate saying this... but [laughs], another way to attract them is to just bribe them. I don't like it though. I don't like the fact that you have to bribe them to come to you or anything. But it does work. [Laughs]. You're creating these individuals that are gonna be entitled, you know. 'I want something', you know… I don't want to develop that mentality that you have to pay them to come to something. They have to find it within themselves that they want it, that they wanna make a change, they wanna be part of it. It has to come from within, otherwise it's never gonna change. I don't wanna pay anybody. I hate seeing that."*

This idea was furthered by the following youth coordinator, who felt that monetary incentives have made non-incentivized youth engagement more difficult:

> *"Now, when you're trying to host a training program, they're not gonna have that motivation just to come there - 'Oh yeah, am I getting paid to come here?'. I don't wanna pay anybody... it's difficult. We have to change youth, not only locally but regionally, that we don't have to give our honorariums for everything that we do. And not everybody sees it my way, because they want the easy way out. But you got to start today, and it's gonna be difficult for a while, but it's gonna change eventually."*

Furthermore, for some activities, there are application processes for youth to participate – often including restrictions such as sobriety and good behaviour to join. Indeed, one youth participant shared how they were prevented from participating in a traditional canoe trip because of their misconduct:

"I wanted to [participate], I was accepted, but I did something I wasn't supposed to so they kicked me out of my group… There's a lot of rules. No drugs and alcohol."

That being said, there were some youth participants who did describe their intrinsic motivation to be engaged and lead positive change, including this former youth council member:

"I've had this big flame in me that says, you know, I wanna do something with my life. I wanna do something that's gonna help someone."

4.3 Perspectives on Current Cree Youth Engagement Levels

4.3A) Youth participation in the community

When asked about current youth participation levels in their community and across Eeyou Istchee, participants were of differing opinions. One youth council member described how youth did show up and participate, both in their community and regionally:

"In my community, it is often for [the youth] to participate. But also it's the same thing for other communities from what I've seen during my travelling. I know that youth enjoy participating in things that they enjoy doing, and it depends on what the community provides."

One youth coordinator also pointed to the fact that their local community recreation complex was usually crowded, with many activities held for the youth:

"If we look at the complex, it's full. And we have running… a full functioning training center, fitness area. We also have a lot of leagues within the community."

Others, including the following youth coordinator, felt that youth participation could be better; when asked about youth participation in their events, this coordinator replied:

"Participation… it's okay, you know. Those [youth] that come are the ones that want to be there. I'm not gonna... it's not a high level participation, but, you know, it depends on certain projects too. I think it's partially if it's the right programs, but also… It's just the matter of trying to find other avenues to try and engage them."

One youth coordinator observed that the level of youth participation in general can change considerably based on the youth council composition in a given year, and the level of leadership demonstrated by the council members in that year:

"... it's not always the best youth council that arises in certain years. Sometimes councils drop the ball, some have more initiative than others,..."

While there seem to be high levels of youth participation in community and recreational activities, it is worthy to note that some youth still felt bored, especially when at school:

Facilitator: "So you feel bored at school?

Participant: All the time.

Facilitator: What about when youth activities are planned at and around school?

Participant: Mmm... I don't even know. It's still school."

4.3B) Youth council membership in the community

Participants explained how a youth could become further engaged in Eeyou Istchee beyond participation: by joining local and regional youth councils. They explained how youth who demonstrated leadership qualities and who were outspoken about youth issues were nominated by peers and community members to sit on the community's local youth council; should they accept their nomination, they run for the annual position. Each of the nine Cree communities has one local youth council (eg. Nemaska Youth Council). Each local youth council is composed of 8-10 members, led by one Deputy Youth Chief and one Youth Chief. The purpose of the local youth councils is to serve, represent and empower their community's youth.

From these local youth councils, each Youth Chief then sits on the regional Cree Nation Youth Council, led by one regional Youth Grand Chief and one Deputy Youth Grand Chief, for a total of 11 regional Cree Nation Youth Council members. The purpose of the regional Cree Nation Youth Council is to: 1) advise Cree Nation Government on all matters concerning youth; 2) conduct studies; 3) furnish information relating to youth; and 4) serve as a "training camp" to prepare youth to assume the responsibilities of leadership within the Cree Nation and towards youth development in areas such as administration and management, business and political skills, social and economic arena.[81, a]

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[a] One non-Cree CBHSSJB partner remarked how health promotion and other related health skills were not included as a goal of the Cree Nation Youth Council entity.

4.3C) Youth involvement in decision-making

Participants shared divergent feelings about the extent to which youth are engaged towards the end of the engagement spectrum – where youth are engaged in health decision-making that ended in action. There were a variety of beliefs expressed from youth, youth council members, and youth coordinators alike. One youth coordinator pointed to that the fact that there are entire councils created for the youth voice (ie. youth councils), and this suggests that youth are listened to. One youth participant agreed that decision-makers often ask for the youth's opinions and were, from their experience, receptive to the youth voices brought forward. Here, however, the participants began to nuance the difference between decision-makers listening to the youth voice, and decision-makers acting on the youth voice; some youth felt that while decision-makers may listen, they do not necessarily act – and this is further discussed in the next section.

4.4 Perspectives on Youth Engagement in Health Decision-Making Towards Action

4.4A) Current media to support youth involvement in health decision-making towards action

Youth and youth coordinators explained the current media that exist to support or serve as a platform for youth engagement in health decision-making towards action. They described a system where planners ask for the youth voice when making decisions towards action, and they described a system where planners asked for youth representatives to be at the table where decisions are being made.

Firstly, participants described a system where planners ask for the 'youth voice' when making decisions towards action, through: general assemblies, community consultations, and surveys.

Participants explained how general assemblies are often a main source to consult youth and gather youth voices in the community, and have always been used by the Cree in their community-based governance and decision-making:

> "We usually have workshops or assemblies that youth are invited to. And [we youth are] asked, like what would you like to see in our community, and our messages go towards the upper people in the system. Like the Chief. Well sometimes the Chief makes it there, sometimes not. But our messages are usually delivered to him. Or, if we want more tournaments, they deliver that to the recreation department. Or if we want more cultural

activities, they deliver to the culture department. Or if we want more movie nights or like
stuff like that, youth council will get it.”

Similarly, participants also explained how, if there is a particular initiative or event to be organized, planners will often fly to each community and hold focus or discussion groups as 'community consultations' to hear opinions from each major stakeholder group. However, one youth coordinator mentioned how community consultations with youth as a one-time venture may not be the most effective method to gather their voices for planning an activity:

“We did the consultation 'tour'. From my extent, I wouldn't recommend going... you
know, 'here's the schedule, here's the date, we invite you all to come'. There's always
some [event conflicting]... it doesn't work like that… if you're gonna go do a consultation
tour, one day won't help you. You'll have to go in kinda once or twice,... different times.
Let's say a month later, come back again – see if there's more youth that will join that
session. What we did was we did a two-day consultation tour, and I don't know if it was
timing or something, but we didn't have the numbers that we wanted. We still had people.
People that were there and happy to be there, and very happy to respond, and to give us
their input. But, we were hoping for bigger numbers that time. I just don't think it works”

Surveys were another method described as useful to gather youth voices for planning. This avenue was highlighted as being particularly effective when youth coordinators sought large response numbers:

“Recently, we had an online survey for the cannabis management stuff… a Cree Health
Board management survey… on the legalization of cannabis for recreational use. And
that avenue was a success - they had more than 200 survey respondents on their online
survey. I thought it was a success. We didn't have a lot of time, it was only one week to
prepare it and get it out there, so [response] was good. But I also think it was because of
the specific topic itself (laughs)...”

Secondly, and beyond asking for the youth voice, youth and youth coordinators described a system where planners ask youth representatives to physically join meetings when decisions are about to be made towards action. For example, the Grand Youth Chief of the Cree Nation Youth Council was often invited to sit on regional and local planning committees to serve as the youth representative at these tables.

"Sometimes [the Grand Youth Chief gets] invited to meetings, and that's when they ask [the Grand Youth Chief] questions of the youth, or if [the Grand Youth Chief has] any suggestions or ideas. Just to represent the youth and to be part of the whole planning session."

It is worthy to note that in the abovementioned systems, planners are still "asking" the youth for their voices and opinions – in other words, it is still not the youth who are the health planners. This issue was described by participants and is presented in the next section.

4.4B) Disconnect between youth voices and action

Participants stressed the importance of not only gathering and listening to youth voices, but also acting upon those voices. And according to some participants, there is sometimes still a disconnect between youth voices and action.

Youth council members explained how after youth voices were collected, it was still often up to the youth council to provide those voices to the right entities and decision-makers for appropriate action:

"For us, the [Cree Nation Youth Council], following the youth general assembly, one of our priorities was to find an avenue where we could promote awareness on the topic… I spoke to a couple entities… we did send something out to all the Chiefs and development coordinators, with what the youth were mentioning that they wanted to see, so that they could initiate something"

Moreover, one former youth council member highlighted that simply providing youth voices to decision-making entities was not enough – it had to go to the correct entities and include follow-up:

"I think we could do a better job at the Cree Nation Youth Council of presenting the voices of the youth… we have to be responsible to ensure that we put it in the right platform - you know, bring it to the Cree Nation Government at their general assembly, as a request. However, we have to bring it to the right entities, which is important as well… it's not easy. You can send out an email to the Director of Cree Justice in regard to this issue... however, it's bringing his staff and our staff together and coming up with or developing resources. It's sometimes not easy, but it's creating a platform where it's more open communication. We have a lot to do to reach out... we all need to elevate how we bring the youth voice. To everybody."

Furthermore, some youth shared their frustration with decision-makers who listened but did not act. One youth council member explained:

Participant: "They just listen. I don't know…

Facilitators: Are there things you've recommended that haven't actually been acted on?

Participant: Mhm.

Facilitator: So how can youth voices best turn into action?

Participant: Guess we have to wait till we're adults."

***Repercussions when youth give their voices but see no action from planners*:** Many youth participants underscored the importance of community members seeing action and change occur, and how community members need to see follow-up action from all the consultations they've partaken in:

"…What happens is that there's a lot of consultations made in communities, and I find that at that point sometimes people are looking for responses to those consultations, and there really isn't none"

Youth participants highlighted how a lack of action can deteriorate the trust that youth have towards their leaders and community coordinators:

"You must be listening to the youth and what they're saying, and you are taking action. So when the youth see that, that's when they'll be more interested… to trust their leaders, or the councils, or the coordinators."

Potential reasons for disconnect between youth voices and action: One youth coordinator shared how, when making decisions and planning activities for youth, they tried to balance what the youth have voiced that they want, with what they believe that the youth need:

"I'll be very honest. Sometimes some of the youth respondents tend to be younger, and sometimes they wanna play, have fun, and games... but you gotta make sure that there's a balance of not only giving them what they want, but giving them what they need. It helps the development... making sure that we're finding and targeting the right types of skills or development training for them. So there's a balance."

Youth coordinators described a need for patience and recognition that change takes time:

"Trying to get through procedures and implementing a program… this is where we meet the most challenges cause it takes time. And time gets people irritated… you know, with time, people get irritated: 'where was this when I needed it?'"

Another rate limiting step to acting on youth voices, as described by this youth coordinator, was funding:

> *"Funding… that's always our issue. Like we have all these ideas but we gotta find money… for example, we're trying to start a breakfast club at the school because it's a need. We did a survey with the kids, and my results showed like 96 or 94% of the students would like to see… kids would complain and say 'we're hungry… we don't have food at home'… breakfast is the most important meal of the day. You know it's beneficial for the child, and the school, that kids are more focused when they have something to eat. Even studies show that. And we felt that you know, it's a good project that's a need… still funding is the issue"*

4.5 Future Youth Engagement in Health Decision-Making Towards Action

To summarize, participants shared how they perceived or valued youth engagement in the Cree Nation, and how they perceived current youth engagement levels, including their involvement in actual decision-making towards health action. For better youth engagement that leads to health action, youth and youth coordinators underscored the importance of the following themes: A) allowing youth to be health planners; B) recognizing the interconnectedness between youth health and youth engagement; and C) using more fair evaluation of youth engagement in health programs.

4.5A) Allowing youth to be health planners

From the abovementioned discussions, it became evident that opportunities for youth to plan and lead health initiatives were important next steps for many Cree participants. In fact, one participant described one such program called the Sports Academy, a youth-led initiative that incorporates a holistic approach to health:

> *"The Sports Academy I mentioned, it's all youth members in that program. Youth are leading an activity, they have these planning sessions... it's a really great program, and I suggest that all communities should have it. They also have events - not just about sports - they also have health workshops or events, like healthy eating, or making healthy smoothies... stuff like that. It's a really great program."*

Furthermore, participants discussed an array of benefits that arise when youth are given opportunities to lead, for youth leaders themselves but also for the community and wellbeing in general. These benefits include: utilizing role modelling for youth to engage; building on pre-

existing trust between youth; longevity of youth engagement when youth lead; and, can leading to better promotion and uptake of health programs.

Utilizing role modelling for other youth to engage: Repeatedly, participants highlighted the importance of role modelling in Cree youth culture, and how youth can inspire other youth towards more healthy behaviours. One youth coordinator observed how younger youth model off older youth in the gym:

> *"Actually, I've seen kind of younger kids coming in, from 12 to 15, trying out the 5 pounders. I guess trying to, you know, the same as the older teenagers going to the fitness… they wanna try that too…*

In the same vein, one youth coordinator shared how, even as an adult, they hoped to inspire health behaviours by first leading by example for the community:

> *"I try to maintain a lifestyle of active and being out there… I only live by example… my parents used to do that back when [the fitness centre] first opened and they set up a trend. All the Elders came because they had a pool too in the community… all of their friends came… it was very interesting to see how many people... one person does it and the others just follow. So that's the example that I wanna set for this community where, you know, our family could live up to a standard where we inspire people."*

One youth put it simply; when a youth leads, other youth will follow:

> *"If youth see other youth leading the activities or the programs, it will definitely get their attention."*

Builds on pre-existing trust between youth: One youth council member suggested that the age of the person who is leading an initiative can be an important factor to a youth opening up and fully engaging:

> *"I think the fact that I am young gets them to be engaged… they speak."*

Another youth council member felt that it was important for a youth to not only lead the initiatives create a more comfortable and trusting environment for other youth to join in:

> *"I lead and participate in [activities]. Like I join them, so they can feel comfortable to join as well. It takes a while for a youth to get comfortable. So... basically I lead and join them. And welcome them."*

Similarly, one youth participant highlighted how rapport was important in engaging other youth further, and how being a friend to other youth is an ideal way to build trust and truly understand their needs:

> *"I talk to [youth], and am a friend to them. And that's how they can know you and understand and know what's going on…youth council members know a lot of youth, and are well-known. They talk to the youth, they hang out with them, or you know, just being a friend to them. So when a youth council member asks questions to other youth like 'what do youth want to see based on health or Cree culture or other stuff', the youth can give a lot of ideas… and we can take note on their ideas and take it to the table"*

Longevity of youth engagement when youth lead: Youth coordinators are actively engaged in planning and decision-making different programs for the youth in their communities. Notably, all youth coordinators who participated in this study were also former youth council members, and had been working with and for the youth for quite some time. It is hence worthy to note how these youth leaders got to be where they are, and their motivations to lead Cree youth engagement initiatives in their communities and across Eeyou Istchee. Youth coordinators explained intrinsic motivations they have always felt towards lead the changes they want to see in the youth of their community:

> *"What motivates me... there's so much... I guess I could say I have this channel, this desire to be a part of making change. From my experience when I was young, I guess I could say I was pretty observant - 'how come nobody's doing this' or 'how come there's no basketball league game'... So I think I started developing that as a teenager, that 'I want this, so I'm gonna coordinate it.'... Let's play some scrimmage, there's the ball, let's get some teams, twenty guys, we'll get three teams going... little things like that. It started to develop into: 'You know what. Somebody needs to do something. I'm somebody. Alright - I'll do it.' "*

One youth coordinator shared their belief that the youth who are currently engaged in leadership are going to be the future leaders of the Cree people:

> *"...when there's an event, not every youth will attend, but a certain majority will, and those are the majority that will make a difference and are the ones that are gonna be leaders."*

Furthermore, one youth participant described how having youth involved in planning and leading can increase the relevance and longevity of the actual program, to truly address the health needs of the youth:

"Having the youth involved in the planning part, I think that would be helpful. So youth know what [youth] want and what they need, or what they're interested in. And it will definitely boost up the whole planning part. So you have a better understanding of who they are and what they need in their lives, as an individual or as a group… having the youth involved in the planning and the leading would be better."

Finally, one youth coordinator highlighted the importance of including youth to sit in on decision-making boards, because those positions are ultimately their futures:

"When we have our big meetings… yes they're 18, but we can still welcome them. Cause they're gonna be sitting up there in a few years."

Can lead to better promotion and uptake of health programs: Many youth coordinators discussed how youth being more engaged in the planning and outreach of programs can lead to better success of the youth programs:

"Link the activities… like let's say canoe brigade, is a really important moment in a youth's life… and let's say they have a team that will hop on with them and really support them through that brigade, and also explain to them, you know, healthy living ways and not being doubtful of the Cree Health Board and the services offered, be there to understand what it is,… I think that the Cree Health Board and its services would be a little more utilized and understood, and the trusted… I think that there is a lot more outreach to be done in the communities because that's the way Cree people are."

Similarly, another youth coordinator proposed the creation of a youth promoter to advertise and promote services and projects from the Cree Health Board:

"There's a program called [program name] – it's not really working as it's supposed to right now and I think it's the fact that they're not really linking with the right people and the right youth to do it. So in order to have a better impact in the schools, with youth, there should be you know youth health delegates in school that advocate for services that are part of the program…that's what I find works in the communities with youth, having them engaged and advocating the services on the health level in different contexts… and I believe that in each school there should be a youth health delegate working, and maybe

even compensated to do it, but advocating the services of the Cree Health Board, taking
part, and doing awareness in the schools, in the classes sometimes, with some of the staff
from the Community Miyupimaatisiiun Centre."

Finally, incorporating feedback and testimonials from youth who have participated in these health-related activities was also described as a way for youth to inspire youth to engage in health activities. One youth coordinator shared a relevant personal anecdote:

"I hope these individuals inspire the others. I think we could do a better job of... when
we're completing, let's say, a project, that there's a feedback from everybody… to get the
message out there. I mean yeah, [a previous participant] was telling me how much better
she was feeling, but it doesn't necessarily mean that everybody knows it... reporting back
or getting that feedback out there, I'd like to do that more."

4.5B) Recognizing interconnectedness between youth health and youth engagement
Considering the fact that youth engagement was described in the context of youth wellbeing, participants often mentioned the interconnectedness between youth health and youth engagement and how one was necessary for the other; participants particularly alluded to the social nature of planning and youth events, which fosters sense of wellbeing and purpose for the youth.

Health as a holistic concept: Given that participants' conceptualizations of health influences how they view their engagement in and planning of health-related activities, understanding their conceptions of health was essential. All participants were asked to reflect on their personal definitions of health and wellbeing, and asked how this may be similar to or differ from their definitions of Miyupimaatisiiun. While many nuances and differences were noted (and are detailed in Appendix L), youth participants described a holistic conceptualization of health and wellbeing. Thematic analysis of discussions with youth revealed the following as important for youth to feel well: being physically active and fit, feeling calm and peaceful, feeling in touch with their Cree identity and culture, and partaking in social community gatherings. Youth's priorities for health change were also explored with the youth participants, which may differ from those who are leading the planning and decision-making in the Cree Nation; youth priorities for health change are described in Appendix M.

Youth need to be healthy to be engaged: Many youth engagement opportunities and activities organized in the community require an application process, where healthy behaviour is

a prerequisite. When asked why these rules were in place, some youth described how they needed to be holistically well in order to be able to participate. For example, one youth described that being able to participate in traditional hunting activities required mental and physical strength:

> *"You have to be quiet to hunt. You have to be patient to hunt. You have to be smart too. You have to be strong. You have to go places a lot, you have to walk, and sometimes there may be snow or grass, big trees, lakes."*

Other youth spoke to the fact that rules to be healthy can serve as a stepping stone towards long-term healthy changes:

> *"They're trying to make the youth healthy you know… If you think you can go one week without drugs or alcohol, it makes you think you can continue."*

Youth also raised the notion that one person cannot fully engage and help others before they help themselves reach a state of Miyupimaatisiiun:

> *Participant: "Miyupimaatisiiun also means like… words. Like, have respect.*
> *Facilitator: Respect for others? Or for yourself?*
> *Participant: It's always you that comes first. So both.*
> *Facilitator: Why is it always you that comes first?*
> *Participant: If you can't forgive yourself then you won't be able to forgive someone else. And if you can't respect yourself, you won't be able to respect someone else. It seems conceited, but still. Yeah."*

Similarly, another youth felt it important to take care of oneself before being able to help not only other people, but also the land and environment:

> *"…if you want to engage and take care of our land and people, we need to take care of ourselves first."*

Youth need to be engaged to be healthy: Participation in community activities were fundamental to youths' wellbeing, as expressed by the following youth participant:

> *"Being back in the bush… you spend more time with your family. Like, you talk… without service of wifi… disconnected from some people, but you're connected with other people – whether you like it or not… and you're being active everyday – not a bad thing but… it's probably a good thing."*

In addition, participating in community gatherings and activities elicited an important social dimension of youth's health:

> *"What I notice in the communities is that when people gather together, there's a lot of laughter and smiles. Everybody's having a great time. And doing that is also beneficial for the individual youth's health. Cause you never know when somebody's having a bad day or something, and they come to these [community] events and they feel better after."*

Beyond participation, opportunities to engage by planning activities were also described as essential to supporting youth health. Youth illustrated how being given the opportunity to lead cultural activities, in collaboration with their Elders and knowledge keepers, can enhance their traditional knowledge connect them to their own health:

> *"It's a way of life in the Cree region: walking, spending time in the bush, learning about medicine in the bush, leading more Cree-based cultural activities… but that also can connect with healthy living"*

One youth coordinator illustrated how planning for fitness competition can foster all aspects of health, and supports strong mindsets for the future:

> *"Cree Nation Summer Games… I think that this was something gives youth hope. If you're a runner, a canoer, or if you play basketball or a team sport, this was something that you looked forward to, something that you trained for so they could represent their communities. It wasn't only healthy and being active and training and preparing themselves, but it was a goal – the mindset of preparing and planning. And also just the passion – that there's something coming up to look forward to."*

Being given opportunities to lead and plan can also help increase confidence and positive self-esteem for some youth, as one youth council member highlighted:

> *"So when I got involved… it really boosted up my confidence in leading activities. So... I suggest that youth get involved with these activities. Like, let them do the work. Let them plan, let them lead. And if there's a collaboration going on, or if the department is providing a new program, I suggest it should be open to the youth so they can have the opportunity to lead and break their bubble."*

A current youth council member also described how the planning process in and of itself is enjoyable to them, as helps feed their social health:

"I like planning stuff. Like for the youth especially. Knowing what they like, and, especially what I like, getting to talk to them… And then when it comes to the activities, like on that day… I get to see my friends."

Intersectoral approaches are needed to best address youth engagement in health action: From youth participants' holistic conceptualizations of Cree youth health, it became evident that any and all community youth activities can be viewed as health-related; theoretically, all activities can be associated with one or more dimensions of health as characterised in Appendix L. Correspondingly, participants described how many different entities have a stake in planning health-related activities for youth, including: the Cree Nation Government, Cree School Board, Cree Health Board, Youth Protection, Recreation Departments, Culture Departments, Youth Departments and the Youth Council. Examples of such intersectoral health-related activities that were mentioned include: interpersonal skill training, snowshoe walking, canoe brigades, sports tournaments, post-secondary education workshops, arts-based programs, mental health conferences, skill development workshops, traditional culture lessons, movie nights and more.

Accordingly, a few youth coordinators underscored how a more intersectoral approach, including the Cree Nation Government as the highest level of governance, to addressing youth health was essential since youth health should be a priority for all:

"I think the Cree Nation Government are seeing the youth health issues, and they want to have it as a priority. So it's nice to see that other departments [other than the Cree Health Board] are planning health-related activities or programs for the people."

Youth council members also described the importance of all stakeholder entities joining forces in order to implement effective change for Cree youth and people:

"Why not have an annual meeting with all the Chair persons - the directors, chiefs, youth could come together in one setting. I don't see why there's no annual meeting where every Cree entity comes together. And we could see what the new leadership is, what projects youth had in mind, and share the workload. It's just better to ensure that these things are implemented. Let's say for the Cree Nation Youth Council, we really wanted to host a health conference.... But it was a matter of okay, we know this entity needs to be part of it, and this entity needs to be part of it, these people need to all be part of it…. it was a matter of getting people together. So if there was an annual meeting where every entity

comes together,… 'here's our idea, we need one of you', and Cree Health Board could
say 'here's how we could contribute to that'. You know, everybody could present their
idea. Some might help, and some might not be ideal partners on something, but still. We
have to do better together. It's the only way things can change"

This ideal intersectoral approach to finding a solution for youth health change parallels the intersectoral approach taken when a youth in the community is undergoing a crisis. One youth coordinator who also volunteers with Youth Protection explained the intersectoral process taken in these instances:

"Under the Youth Protection, after 5PM, if someone needs to report an incident or
there's a child being neglected… they will call the RTS (Retention Treatment
Signalement)... the RTS then calls me… it is my responsibility to have to go with the
police… during that whole period of going to the house with the police, I have to pack
their clothes, call the foster home and let them know that there's people coming... you
have to deal with the doctor, and get the children assessed… It's a whole process, and
it's sad, but somebody's gotta do it… Then we contact our consultants and people from
way up, and take mandates from, you know, the upper people."

Specifically regarding youth health improvements, one youth participant suggested that each stakeholder department could focus on bettering one aspect of youth health, or that all departments could target all aspects; regardless, the more the better:

"The more the merrier… it would be nice to see like a lot of different departments doing
different things, instead of having the same ones.... like, it would be great to see if one
department focuses on mental health, and the other department focuses on physical… or
they could focus in all of them. Like physical, mental, emotional and spiritual. And they
just have different activities or programs for it."

In the same vein, it is worthy to note that many participants could themselves be described as intersectoral – in that they are involved in different roles and different departments simultaneously. For example, one participating youth coordinator's official full-time position was under the Cree Nation of Nemaska, but this participant was also semi-affiliated with the Cree Health Board, did part-time work with the Cree Justice Department, conducted work in Tourism, volunteered time for this research project, and was regularly asked to sit on decision-making boards in Nemaska and regionally across Eeyou Istchee.

4.5C) Appropriate evaluation of youth engagement and health programs

Throughout our discussions, youth spoke about the difficulties that they encounter when coordinators and planners want better youth engagement; specifically, how planners often use youth attendance rates and numbers as indicators of a program's success. One youth described how an activity's attendance rate does not necessarily indicate activity's value for the youth:

"I think numbers shouldn't matter. It, it should be more focused on the issue and set it as a priority.... for an example, we have Education. Sometimes there are days when a teacher provides an assignment or a new subject, and the teacher doesn't have a lot of students coming in. But the teacher still goes on with the assignment or the new subject, because it's on the agenda, it's part of the school system... the teacher is doing what she's supposed to do, with a full class or not. So I think it should be the same for all departments and organizations, to keep going with their projects and stuff."

Moreover, one youth described a program that was meaningful to them and made them feel well, but was terminated on the basis of low attendance, and how this can be problematic:

"I remember there used to be an art program... I really enjoyed that program, but it stopped... So that's the other thing that I noticed when people or coordinators or departments wanna do something new in the community, and their expectation is having a lot of people or youth to come. And once they start having the program or the activity, at first, it's not as you expect it to be - like having a lot of youth coming in. It takes time to start something new. So maybe asking the youth what they like to see in the community would be helpful, instead of just looking at the numbers. I know there are some new activities or events that have been provided, but they stopped them because of the lack of numbers. I understand it has to do with the budget and all that stuff, but what if those, let's say, 5 youth participants had a rough week, or things were rough for them, and going to that activity or program could change their mindset - like they could have motivation to do more, be more"

Indeed, certain youth coordinators depicted the importance placed on numbers to indicate priorities for health change:

"...for example, teenage pregnancy. I'm sure you're aware of the high rates in the Cree Nation... it's scary to think, to know, that the Eeyou Istchee have the highest rate of STDs... and then you put two and two together... like it shows you there's something

wrong there. The numbers are there. Obviously there's something wrong why these

numbers are the way they are."

Another youth coordinator echoed similar values placed on participation rate as the main

indicator of an event's success:

"I'm coming from a coordinator's perspective. You always wanna have, to be honest,

double or triple the amount of participants that you have."

Cree are optimistic for youth's future: There was a marked desire for the community to

succeed, pride towards their culture, and strength-based optimism demonstrated by almost every

participant who shared their thoughts with us. Especially when it came to the youth and the next

generation, one youth coordinator shared the following feelings:

"[Working with the youth], it's my joy, it's my pleasure. Because I want this community

to succeed and you know to be vibrant. Of course we have our challenges, but you know.

There's a lot of people out there that want their community to run well… I know this next

generation will make a big splash, especially like those remarkable achievers from the

past."

CHAPTER 5: DISCUSSION

5.1 Contributions to New Knowledge

Indigenous youth represent a highly diverse population of individuals and communities, who share unique experiences of re-claiming and re-occupying their traditional Indigenous cultures and traditions, while stepping into the increasingly modernized society of today's Canada. We recognized that much of the literature on youth health lacks actual voices from youth themselves, and sought to alter this trend. Working in collaboration with the CBHSSJB and Cree community members, including youth, we have explored ways in which youth and youth coordinators describe Cree youth engagement in the community, on councils, and in health decision-making, and how Cree youth would like to see this enhanced or ameliorated in the future. We also discussed ways in which youth engagement and youth health are intertwined, and how greater Cree youth engagement was a value held by many.

Firstly, our participants explained the context of Cree youth engagement in Eeyou Istchee, and identified youth deference as a contextual Cree youth characteristic to consider as underlying this study. One participant identified their travel to larger cities as reason for their extroversion; similarly, one eastern James Bay Cree youth in Hayes' study explained how they learned to be more outgoing because they went to school in the south where people were more outspoken in classes, unlike the youth in their community. Hayes also mentioned that younger eastern James Bay Cree youth (14 to 18 years of age) were shy and reluctant to interview, and Radu associated James Bay Cree shyness with a fear resultant of residential schools and feelings of inferiority towards white people. Shyness among other young First Nations peoples has also been described: First Nations youth in Ontario in Crooks et al.'s study described the importance of youth breaking away from their shyness in order to be the best leaders and mentors for the younger generation; First Nations youth in urban Calgary in Woodland et al.'s study spoke about youth's shyness and quietness specifically when talking about sexual health, and attributed this to values of sexual modesty and morality; and, coastal First Nations parents in British Columbia in Smethurst et al.'s study described how they hoped their children would make new friends by engaging through traditional tribal journey activities in order to be less shy. While Radu's study suggested a potential reason for Cree youth shyness as the historical silencing of Cree peoples and trauma experienced, in this study, some participants attributed youth shyness to traditional

interactions between youth and Elders or teachers in Cree life. One Cree partner described how youth were supposed to be listeners and imitate their Elders by example in order to learn best. This explanation could suggest that, instead of shyness being a product of cultural interference, it could actually be a product of cultural continuity. This contradiction relates back to the discussion about what is authentically "Cree" or "Indigenous", and what is a result of external forces.[82] It is worthy to highlight here that Indigenous identity is complex and self-identifying, with many individual and group-level reconstructive factors in play.[83] With Cree cultural identity and continuity identified by participants in our study as a key part of Cree youth health and wellbeing, this question is a noble area for further research by Cree and Indigenous peoples themselves.

Regarding their engagement in traditional and cultural activities, Cree youth admiration and appreciation for engaging in bush-life was notable in this study. Many youth participants nostalgically regarded bush-life as an ideal way of living Cree, in contrast to the boring town-life school days that they had to endure. That being said, youth highlighted the importance of hockey and other recreational engagement opportunities as important to break this boredom, and expressed how these activities excited them. These feelings agree with the youth in Hayes' study, where town-life was characterized by idleness and substance abuse, while bush-life was characterized as sacred; however, the idleness associated with town-life was in contrast to the vibrant recreational opportunities that youth also associated with town-life. Taken together, these findings suggest the importance of recreational activities being held for youth. Furthermore, previous studies have pointed to youth recreational and community activities as important prevention for youth, since opportunities to engage "give them something to do and prevents them from being involved in crime or other bad things",[50] and youth boredom and inactivity were claimed to be systemic issues and key reasons that youth get into trouble.[52]

Youth also described their motivations to engage in their community and community activities as both extrinsic and intrinsic. It is worthy to further explore one notable extrinsic motivator that our participants described as effective in engaging youth: money. Both youth and youth coordinators described bribery and monetary compensation for youth engagement, to encourage youth to participate in recreational activities as well as become a youth council member, and commented on its effectiveness at doing so. Financial incentives have in fact been shown to attract and retain high school-aged youth in previous studies.[84] That said, one youth

coordinator expressed clear moral qualms with this form of motivation, expressing how they did not want youth to feel entitled to gain something by showing up. Although, youth still described how youth coordinators and decision-makers were not listening; Kaitlynn Hester Moses, one of our Cree youth partners and the current Youth Grand Chief from the regional Cree Nation Youth Council, reflected on this disconnect and suggested that it could be indicative of a gap between youth coordinators' approaches to engagement, and youth's desires to engage. To our knowledge, monetary strategies for Indigenous youth engagement and the potential resultant impacts have not been directly explored in previous Indigenous youth engagement research from Canada; this could indicate that monetary youth engagement incentives are not happening in other Indigenous communities, or that they are not being discussed. Moreover, the fact that the James Bay Cree are able and have the budget to provide youth honorariums for participation could be perhaps unique to this people; the James Bay Cree successes as a people have been related to their strong self-governance and control over their own health, education and development services, resultant from the James Bay and Northern Quebec Agreement of 1975.[85] Regardless, there are many and differing opinions on the eventual repercussions of extrinsic motivation for youth's engagement. Previous studies have pointed to potential problems when youth are solely extrinsically motivated, including eventual disengagement in the absence of rewards.[86] In contrast, one study also found that youth do not necessarily need to enter a program already intrinsically engaged, but that their motivation can and must be fostered through a program by providing opportunities for the following factors: learn for the future, develop competence, and pursue a larger purpose that is meaningful to them.[87] It is of note that all three of these factors were raised in our study; youth reported the importance of decision-making for their futures and the future of Cree Nation youth, building confidence and traditional knowledge, and feeding a spark and agency towards making change for their youth and communities. Furthermore, participants described youth onus and community readiness to shape and focus on a better future for the Cree, associated with previous Cree victories, that can also be viewed as intrinsic motivators for Cree youth to want to engage towards a better future. However, it is important to note that this finding cannot and does not represent all Cree youth, Cree individuals, or Eeyou Istchee communities, and different peoples or communities may be at different levels in terms of looking to the future; literature from other Indigenous populations emphasized that there was still much to be learned and healed from the past, and a better understanding of the

reverberating impacts of colonialism on their peoples was still their priority before looking to the future.[51,52] In the same vein, we must also emphasize that reconciliation and looking to the past or future can indeed look different to each individual.[88]

The levels of youth engagement in Eeyou Istchee, according to the spectrum including "participation", "youth council membership" and "planners" as outlined in Figure 2, were characterized and explained. While youth leading health planning as planners was described as an ideal level of youth engagement, a few Cree youth expressed dissatisfaction with current health decision-makers who listened but did not act. One youth felt they simply needed to wait until they were older to be taken seriously in planning decisions, and another participant described the deterioration of trust associated with a lack of action on their voices by current leaders – notwithstanding the youth coordinators' given reasons that could explain this lack of action. These exclamations can relate back to Kaitlynn Hester Moses's previous reflection on an existing disconnect or miscommunication between those who coordinate for youth and youth themselves, and the associated lack of trust in some of these leaders. Furthermore, Kaitlynn Hester Moses provided the following thoughts worthy of inserting verbatim here:

"I can see that we are missing something. Is it the way we raised, educated or promoted our youth? The older generation were raised by 'survival', and it is different to ours today. In today's generation, we are living in technology. The older generation did not have these in their youthful days. So I think has also been challenging for them to raise their children in the way they were taught. Times are different… You can see that an adult's mindset is so much different than the youth's. How they think about the same view, but have a different perspective. It is like, 'Many have the image, but only a few get the picture.' Many have an image of youth, and only a few get the picture."

With all this in mind, Cree participants also stressed that the described disconnect between youth voices and action could be bettered if decision-makers capitalized on the importance of being a friend for Cree youth. One youth participant described how being a friend to the youth was ideal to build trust and truly understand their needs. Another youth participant explained that when one youth leads, their friends tend to follow. In fact, one youth coordinator mentioned their struggle to obtain high engagement and numbers of youth in their one-time consultation tours; indeed, this difficulty could be another argument for and connected to the importance of building rapport with Cree youth to fully engage them. Beyond the trust innate to

a friendship, one youth participant believed it was the simple fact that they themselves were young that encouraged other youth to engage and spoke up in a particular activity they described as leading; hence, the program leader's age could also be a hierarchal factor to consider in youth opening up and fully engaging. Issues of hierarchy in engaging youth have been previously characterized, especially with "high-risk" youth, and the associated dynamics of power.[89] The importance of informal role modelling for Cree youth and people was also described as a perhaps longstanding, integral aspect of being Cree youth teachings with their Elders, which has been recognized in other Indigenous cultures as well.[90] Moreover, this agrees with previous evidence that good role modelling and mentoring can promote positive health behaviours in young people, and can play into the impact of 'connectedness' of Indigenous people as a factor in Indigenous health and wellbeing.[91]

Ultimately, a few participants spoke to a need for greater and more genuine Cree youth engagement as health planners. A need for better Indigenous youth engagement as health planners was also a finding in our literature review; most youth engagement discussed in the literature was in the youth council member capacity, where youth voices were solicited to bring to (presumably adult) health planners.[54] That being said, our participants highlighted the sustainability and longevity of youth engagement when they were given the chance to plan and lead. The intrinsic spark and motivations that youth felt they always had in order to create change was noted as continuing into adulthood, and participants described how youth leaders could: help ensure that the program lasts by accurately identifying underlying issues, use effective role modelling for lasting change, build on pre-existing trust, and lead better promotion to encourage other youth's engagement and retention. Indeed, one participant shared their belief that, if youth understood the values of a health initiative and could share this with or advertise this to other youth, the services of the CBHSSJB would be better used. This is congruent with the literature on engaging Indigenous youth as planners Indigenous youth health research, as they are best suited to identify, understand, and interpret their own health problems.[54,56] Moreover, in the same way that youth planning health research can make the science of the health research better, youth planning health services could also help make the impact of the health services better. Sustainability of projects under Indigenous youth leadership could also be explained by Jagosh et al.'s finding that a transfer of ownership often takes place when, through participatory research approaches, one allows those who are directly involved in the project or program results

to lead.[92] Finally, another reason given for youth engagement in health planning was that it was good practice, as youth would ultimately be filling these positions in the future; this idea is in agreement with the youth in Blanchett-Cohen's study who advocated for communities to view youth engagement as a benefit to the whole community and as a future investment.[52]

In order to better engage youth in the future, specific social media strategies, particularly Facebook, were characterized as important platforms for outreach and engagement of young Cree people. The ubiquity of these media and their importance for Indigenous youth engagement has not been mentioned by studies included in our literature review, which focused more on arts-based and peer-to-peer mentorship methods to increase youth outreach and engagement. However, our participants highlighted Facebook as important to solicit youth feedback, to advertise to youth, and particularly reach marginalized youth. Indeed, the fact that our youth focus groups were held in collaboration with the community school implies that youth who came and participated were already attending school; youth who are not in school, young parents, less involved, or dealing with addictions were not reached in this study – a challenge acknowledged in previous publications.[93] One participant pointed to Facebook to gain access to marginalized youth within the comforts of their own homes, and described how posting a health fact or service on Facebook could hopefully reach them and make them ponder. Hence, social media could be a valuable tool for health planners and service providers to consider especially when reaching out to these marginalized youth. Anonymous online polls or suggestion boxes, as another participant recommended, could also prove useful in this regard.

Finally, one explicit finding of this study was the interconnectedness between Cree youth health and their engagement, and how one was needed for the other. The idea of needing to be holistically healthy before being able to engage was described by the youth in this study. Namely, youth participants highlighted the importance of helping yourself before being able to engage and help others and the land; even though, as one participant described, prioritizing yourself could be seen as conceited. The importance of working on oneself was echoed throughout this study, and may be suggestive of a fundamental Cree value. Furthermore, this finding could be related to the influence of role modelling in Cree teachings as described – and how, in order to lead positive health behaviours in others, you must first embody positive health behaviours in yourself. In this view, self-care would not be attributed to selfishness but rather working on oneself to ultimate help others and the whole community. In addition, youth

described how they needed be physically and mentally well to engage in traditional activities. This idea resembles Smethurst's finding on the physical and mental strength required for youth to partake in tribal journeys. Our participants also explained the sobriety rules required to partake in traditional activities, which parallels Warren's descriptions that drinking and drugs were forbidden in powwows and ceremonies. Moreover, youth participants shared the potential long-term benefits of sobriety prerequisites; Cree youth described how they want to engage in traditional activities, and hence must make these small changes that can eventually lead to bigger ones and healthier behaviours. Taken together, these results underline Cree youth's strong desires to engage in cultural activities, perhaps enough to give up unhealthy behaviours. Considering the aforementioned interconnectedness between youth health and youth engagement, this phenomenon of health behavioural change could either be a cause or consequence of youth engagement.

To this point, participants also described how engagement opportunities could lead to better health. The positive effects of Indigenous youth participating in sports and physical activities as described above, and giving them something to look forward to, can be related to the well-characterized ability of physical activity to strengthen youth resiliency and development.[94] Youth participants also shared how their engagement helped increase their self-confidence, and one youth shared how membership youth councils helped them break out of their shell. This finding agrees with previous Indigenous youth literature that links youth engagement with increased social skills and pride[56,95] and permitting their true selves to come out.[49] In addition, the fact that engagement opportunities allowed youth to foster the social component of their wellbeing is also worth highlighting. The positive health impacts of making new friends through community gatherings and sports activity participation, being friends with other youth through youth council membership, and the opportunity to take care of others and the land through as a planner, all tie into youth building social health through their engagement in multiple capacities. Another example offered emphasized by a participating youth coordinator was youth's engagement in traditional canoe brigades to foster a healthy goal-setting mindset. This participant expressed how the Cree Nation canoe brigade was valuable to teach youth how to prepare, plan and set goals. Goal-setting as a skill has been established as one of the most robust human motivators in the field of applied psychology,[96] and is transferable to other key components of healthy youth development including social competence,[97] building resilience,[98]

goal setting surrounding substance abuse,[99] and building capacity towards decision-making.[100] In addition, being engaged in their traditional activities, away from technology, with their families and communities, and immersed in the Cree ways of living, were the components of traditional activity participation that youth attributed to their feeling healthy and well. This is congruent with Blanchett-Cohen's finding that the impact of gatherings on Indigenous youth cannot be quantified, and it is the less tangibles aspects of this social dimension that affect youth wellbeing.

Indeed, the quantification of youth health ties well into our participants' opinions on the quantification and evaluation of youth participation. This was a notable point of divergence between some youth and youth coordinator participants. While one youth coordinator used high participant numbers to indicate that their event was a successful, one youth participant emphasized that low participant numbers should not mean a program is unsuccessful and should stop. Youth participants' emphasis on the inability for numbers to indicate an activity's full value or success could perhaps be mitigated by incorporating qualitative evaluation methods. Qualitative evaluation techniques provide contextual data to explain complicated issues, and can complement quantitative data to reveal a more holistic evaluation of a given phenomenon[101]; moreover, one participating youth coordinator also recommended the use of testimonials in their health programs to allow youth to share their sentiments and inspire other youth. Testimonials are a form of qualitative evaluation that could offer meaningful feedback for youth coordinators and financial decision-makers when planning for youth programs in Eeyou Istchee, so long as the feedback comes from the voices of the participating youth themselves.

5.2 Researcher's Reflections on Youth Engagement

The media has been recognized to unfairly portray Indigenous youth as disengaged, substance abusive, failing out of school, criminals, suicidal, and overall problems to the society.[47,102,103] In addition, much of the research done with Indigenous peoples and youth focuses on their deficits compared to other groups, pessimistic statistics, and problems or issues requiring external help to overcome. My experience and interactions with Indigenous and Cree peoples, individuals, and youth, has seriously negated this deficit-based narrative.

As soon as I arrived into the Nemaska community, I witnessed the high participation and engagement of youth and children in the community. The youth gathering space in the local community centre, the school, and the streets were almost always filled with youth hanging out, playing sports, or socializing with their friends. The children under age 14 were curious and

vibrant, and very curious about me – they asked me what my name was, where I was from, if I was a teacher at the community school, and if I would be staying. That being said, the older high-school aged youth I interacted with were indeed on the more quiet side, but were always very respectful and kind when I asked them questions or for information. I quickly picked up on the sarcasm and sense of humour part of Cree youth and people's communication. During the focus groups, some youth barely shared their thoughts despite the quasi-nominal fashion of discussion that we conducted; however, some youth expressed and shared plenty. In this regard, I can definitely vouch for the value of having a community leader be present and co-leading the focus group discussions, to help myself and the youth present feel more comfortable and to create a culturally safe space.

There were plenty of activities organized by the Nemaska Youth Council and different Cree entities and individuals for youth in the community; for example, youth movie nights, general assemblies, fashion shows, swim nights, pool tournaments and fitness classes. In fact, once a community leader discovered that I am a Zumba instructor, she organized an impromptu Zumba class after-school in the community gym that was relatively well attended.

That being said, many community members and participants alluded to the difficult challenges that they did deal with, and some thoughts shared in this manuscript could be viewed as pessimistic; however, these challenges were almost always followed up with the positive futures that they looked forward to building for the Cree Nation. As a result of this reflection, it was with deliberative intent that I sought a strengths-based approach and perspective for this entire project. The community-based participatory research framework and the extensive validation process with our Cree partners helped in this regard, to allow for the real experts in this research to comment on the challenges they saw and faced, and provide culturally safe recommendations for their futures as a Cree Nation.

5.3 Implications for Policy, Practice and Future Research

One of the primary initial mandates of this research and work was to provide insights to the CBHSSJB to help inform their current and future health plans for youth in Eeyou Istchee. Available evidence, including our novel contributions from Cree youth themselves and an overview of the existing literature from Indigenous youth across Canada, demonstrates that youth can and perhaps should be engaged as health planners in their own health and wellbeing activities and programs. The value of having youth sit on and lead health-planning teams is

backed by a solid body of evidence on the advantages of youth engagement in the relevance of the program, the sustainability of the program, and the developmental and health benefits for the youth themselves. Current positive examples of youth-led initiatives in Eeyou Istchee, including the Sports Academy program, can also help shape future CBHSSJB decision-making.

To reach a more optimal level and capacity of youth engagement in health planning for the Eeyou Istchee, Cree participants in this study have suggested and recommended the following points of action:

- Create positions for youth to be health planners and lead or collaborate in CBHSSJB and other health-related efforts, to better the engagement, relevance, trust in, sustainability and promotion of the initiative.
- Create positions for youth to be health delegates, and to share knowledge of and promote existing CBHSSJB and other healthcare services in schools and in the community amongst youth groups.
- Highlight youth role models and include youth testimonials to capitalize on youth inspiring other youth.
- Incorporate a social media plan for youth communication, and continue to try and reach marginalized youth and solicit their particular needs.
- Include anonymous suggestion boxes and online polls for youth to provide their feedback or identify their priorities for change in a more comfortable manner.
- Continue to support and invest in all forms of engagement opportunities for youth, including participation, youth council membership, and health planning capacities, in recognition of the interconnectedness between health and engagement for Cree youth.
- Initiatives and approaches to prioritize youth engagement and health should be intersectoral, and assemblies or meetings should be organized where representatives from each entity in the Cree Nation share ideas, priorities, and resources – especially when dealing with youth issues.
- To ensure that Cree youth health is being prioritized and fostered in an intersectoral and holistic fashion, each Cree entity could devise a specific mandate to address one component of Cree youth health (physical, mental, emotional or spiritual health); or, all Cree entities could devise a mandate to better all components of Cree youth health and ensure they deliver activities addressing each component.

- Implement regular and holistic evaluations of youth positions or programs, incorporating the use of qualitative evaluation methods such as testimonials in addition to attendance rates, to better understand Cree youth investment and engagement with given opportunities and programs in Eeyou Istchee. In addition, better communication and understanding about why a youth program was terminating, and the effects on youth who relied on these programs, is warranted.

While not the focus of the body of this thesis, a discussion was had with participating Cree youth and youth coordinators on the practical priorities for youth health change as described in Appendix M. These priorities are summarized below:

- More education needed: More formal education on holistic Cree health and wellbeing is needed as part of the school curriculum. These sessions should include particular topics of relevance such as young motherhood, and should include promotion of and education on existing healthcare services for youth (including the roles of community health workers).

- Self-care first: The importance of taking care of one's holistic health, including physical, mental, emotional and spiritual health, should continue to be emphasized to youth.

- More traditional culture: More opportunities to learn about traditional culture should be supported by relevant Cree entities, including programs for young mothers, opportunities for youth to connect with their Elders, and continuous outdoor traditional activities for the youth.

- Physical health as a precursor: Opportunities for youth to engage in physical health activities should continue to be offered and supported, such as fitness challenges or intra- and inter-community sports tournaments, since physical health can be a precursor to Cree youth's health in all other domains of their wellbeing.

- Stopping the cycle: Many Cree youth health challenges are associated (as are youth health components overall), hence improvement in one aspect of a youth's complex health case can often lead to improvements in other aspects of their health, too.

Regarding future research implications, further exploration of Cree youth's definitions of health and wellbeing as commenced in this work and included in Appendix L is worth pursuing. While an operative definition for health was revealed for the purposes of this work, there were interesting concepts and divergences that came about, including the differences between health and Miyupimaatisiiun from youth's perspectives, and potential changes that the CBHSSJB or health-related entities (which, as described using an intersectoral approach to health, are all

entities in Eeyou Istchee) may want to consider in order to make their initiatives more resonant and relevant to Cree youth. In addition, one of our CBHSSJB partners suggested the need for further exploration of the links between youth structures and adult structures of engagement, and how future research could look at the extent to which Cree entities and local administrations have developed youth services and approaches beyond funding youth activities and infrastructures.

One notable divergence in our study compared to previous studies on youth engagement in health and health planning was the lack of discussion on youth substance abuse and alcohol. While many factors can explain this omission, including our limited sample size or the fact that Nemaska is a dry community, substance abuse has been raised as a youth issue in previous studies and reports from this region[29,104] and many Indigenous populations, and is worthy to note.

5.4 Limitations and Mitigating Strategies

- Researcher's non-Cree perspective: As an external non-Cree person, there are limitations to what I was able to understand and interpret. Therefore, the validation process was necessary and essential to ensure Cree people identified with what is presented in this work. Extensive review from two Cree partners (one of which is a youth), and incorporation of their interpretations helped in this regard. In addition, my eight-day immersion in the Nemaska community was also important, and focus groups were co-led by a community youth leader to ensure youth comfort and cultural safety throughout the data collection process.

- Limited sample size: This study uses a limited sample. There were other perspectives that we could have gathered given more time and more development in the partnership, which could have included representation from a few more perspectives such as: more youth, nurses, doctors, community health workers, Nishiiyuu workers (traditional approaches sector of CBHSSJB), Maanuuhiikuu (mental health sector of CBHSSJB), parents, Elders and teachers. In this case, because of the discussions' focus on youth engagement in health, we chose youth, youth council members and youth coordinators to be the focus of this project's scope.

- Researcher's hierarchy towards youth: One of our Cree partners highlighted the important consideration that, to some youth, my position as a researcher could cause me to be seen as someone who is superior or wiser; hence, some youth may be quieter or feel uncomfortable replying to my questions and asking to learn from them. Our partner associated this to the youth deference and shyness characteristic as described. We tried to mitigate this through co-

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leading the focus groups with a youth leader who was already integrated in the schools, and using icebreakers as introductions; yet, this is an important factor to consider.

- Limitations due to sample and setting: This study was only conducted with youth in Nemaska, although a few youth and youth coordinators represented regional voices. It is expected that intra- and inter-community differences exist among between residing in Nemaska and youth residing in other James Bay communities, which limits the study's representativeness and generalizability. In particular, our Cree youth partners pointed to the fact that regional and local youth councils, and their effectiveness in empowering youth voices or engaging them in health planning, were highly variable across the years and communities. However, these results can still be valuable and transferable to other communities and youth in similar contexts, not only within James Bay but beyond for other Indigenous communities.

- Limitations due to methods: The qualitative descriptive study design allowed for a deep and contextual understanding of relatively few information-rich youth members in one Cree community, but does not include statistical analyses that can be replicated or repeated. However, together with our partners, we believe that the contextualized understanding brought forth through this design is what makes it valuable to health policy makers.

With the abovementioned considerations, together with our partners, we believe it necessary to share what was found with Cree leaders and decision-makers, to contribute to health planning decision-making in Eeyou Istchee and to advocate for the importance of Cree youth voice inclusion in these matters. In addition, we have learned lessons about how to do better next time, and where we can add representation in future additions to this work.

CHAPTER 6: CONCLUSION

To conclude, James Bay Cree youth and youth coordinators in this study characterized current levels of youth's engagement in their communities and in health planning, and methods to further strengthen youth's engagement across the Cree Nation. Cree youth and youth coordinators described youth engagement as participation in community, sports and physical activities, membership with local and regional youth councils to represent youth voices, and engagement in decision-making and as planners in health-related initiatives. Youth described the use of social media, general assemblies, and inviting youth to decision-making tables as positive steps towards more extensive youth engagement.

Youth further nuanced the difference and disconnect between gathering or contributing youth voices, and acting on youth voices. Youth explained the loss of trust that could result from inaction on youth voices, and youth coordinators described potential barriers to action on proposals raised by youth in their communities. Youth and youth coordinators suggested practical ways to advance youth engagement towards action for the future of the Cree Nation. Specifically, youth recommended the creation of more formalized positions for youth as health-planners. They described how this would allow for positive role modeling amongst youth, build on pre-existing trust and comfortable spaces between youth and their peers, encourage youth to realize their full potential, engage youth as long-term advocates, and ensure sustainability for health programs or initiatives via more relevant targets and better youth promotion and buy-in.

As a holistic health notion underpinned these youth engagement discussions, youth and youth coordinators further explained the interconnectedness of youth health and youth engagement; youth needed to be healthy to engage, and needed to be engaged to be healthy. They also described how, in order to best enhance youth health and youth engagement in their communities, intersectoral approaches and prioritizations were required.

Ultimately, this study contributes valuable Cree youth voices to the limited volume of Indigenous youth voices as documented in Canadian research literature. These results offer practical strategies for greater youth engagement for the Cree Nation, as well as point to policy implications for the Cree Board of Health and Social Services of James Bay and all Cree decision-making entities involved in Cree youth wellbeing. As a relatively novel area of research, this study also has implications for future research to be conducted in partnership with Cree people of Eeyou Istchee, and in partnership with Indigenous peoples of similar contexts.

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APPENDICES

Appendix A: Literature Review Concept Matrix and Search Strategy

Concept Matrix:

Concept #1: Qualitative Research	AND Concept #2: Youth	AND Concept #3: Indigenous Canada	AND Concept #4: Health Planning

Search strategy in MEDLINE:

("qualitative research"[MeSH Terms] OR qualitative[ti] OR qualitative research*[tw] OR qualitative study[tw] OR qualitative studies[tw]) OR (mixed method*[tw] OR mixed studies[tw]) OR ("interviews as topic"[MeSH Terms]) OR ("Surveys and Questionnaires"[MeSH:noexp]) OR (interview*[tw]) OR (focus group*[tw]) OR ((action[tw] OR participatory[tw]) AND research[tw]) OR ("community based participatory research"[MeSH Terms]) OR (grounded theory[tw]) OR (phenomenolog*[tw]) OR ("narration"[MeSH Terms]) OR (narrat*[tw]) OR (conversation*[tw]) OR (discourse*[tw]) OR (ethnograph*[tw] OR ethnomethodolog*[tw] OR autoethnograph*[tw]) OR (hermeneutic*[tw]) OR (constructivis*[tw]) OR (case study[tw] OR case studies[tw] OR field study[tw] OR field studies[tw]) OR (participant observ*[tw] OR participants observ*[tw] OR field observ*[tw]) OR ((purpos*[tw] OR theoretical[tw] OR judgement[tw] OR "maximum variation"[tw] OR convenience[tw] OR "critical case"[tw] OR "deviant case"[tw] OR "key informant"[tw] OR snowball[tw] OR cluster[tw]) AND sampl*[tw]) OR ((lived[tw] OR life[tw] OR personal*[tw] OR patient[tw] OR patients[tw] OR survivor*[tw]) AND (experience*[tw] OR perspective*[tw] OR perception*[tw] OR meaning*[tw])) OR (thematic analys*[tw] OR content analys*[tw]) OR (group discussion*[tw]) OR (cope[tw] OR copes[tw] OR coping[tw] OR thrive[tw] OR thrives[tw] OR thriving[tw] OR "health surveys"[mesh])
AND
("Adolescent"[Mesh] OR "Young Adult"[Mesh] OR youth[tw] OR youths[tw] OR young adult*[tw] OR adolescen*[tw] OR teen*[tw] OR young person*[tw] OR young people[tw] OR "adolescent health services"[mesh] OR "adolescent development"[mesh])
AND
(Indians, North American[mesh] OR Inuits[mesh] OR Health Services, Indigenous[mesh] OR Ethnopharmacology[mesh] OR Athapaskan[tw] OR Saulteaux[tw] OR Wakashan[tw] OR Cree[tw] OR Dene[tw] OR Inuit[tw] OR Inuk[tw] OR Inuvialuit*[tw] OR Haida[tw] OR Ktunaxa[tw] OR Tsimshian[tw] OR Gitsxan[tw] OR Nisga'a[tw] OR Haisla[tw] OR Heiltsuk[tw] OR Oweenkeno[tw] or Kwakwaka'wakw[tw] OR Nuu chah nulth[tw] OR Tsilhqot'in[tw] OR Dakelh[tw] OR Wet'suwet'en[tw] OR Sekani[tw] OR Dunne-za[tw] OR Dene[tw] OR Tahltan[tw] OR Kaska[tw] OR Tagish[tw] OR Tutchone[tw] OR Nuxalk[tw] OR Salish[tw] OR Stl'atlimc[tw] OR Nlaka'pamux[tw] OR Okanagan[tw] OR Sec wepmc[tw] OR Tlingit[tw] OR Anishinaabe[tw] OR Blackfoot[tw] OR Nakoda[tw] OR Tasttine[tw] OR Tsuu T'inia[tw] OR Gwich'in[tw] OR Han[tw] OR Tagish[tw] OR Tutchone[tw] OR Algonquin[tw] OR Nipissing[tw] OR Ojibwa[tw] OR Potawatomi[tw] OR Innu[tw] OR Maliseet[tw] OR Mi'kmaq[tw] OR Micmac[tw] OR Passamaquoddy[tw] OR Haudenosaunee[tw] OR Cayuga[tw] OR Mohawk[tw] OR Oneida[tw] OR Onodaga[tw] OR Seneca[tw] OR Tuscarora[tw] OR Wyandot[tw] OR Aboriginal*[tw] OR Indigenous*[tw] OR Metis[tw] OR red road[tw] OR "on reserve"[tw] OR off-reserve[tw] OR First Nation[tw] OR First Nations[tw] OR Amerindian[tw] OR (urban[tw] AND (Indian*[tw] OR Native*[tw] OR Aboriginal*[tw])) OR ethnomedicine[tw] OR country food*[tw] OR residential school*[tw] OR ((Medicine, Traditional[mesh] OR traditional medicine*[tw]) NOT Chinese[tw]) OR Shamanism[mesh] OR shaman*[tw] OR traditional heal*[tw] OR traditional food*[tw] OR medicine man[tw] OR medicine woman[tw] OR autochtone*[tw] OR (Native*[tw] AND (man[tw] OR men[tw] OR women[tw] OR woman[tw] OR boy*[tw] OR girl*[tw] OR adolescent*[tw] OR youth[tw] OR youths[tw] OR person*[tw] OR adult[tw] OR people*[tw] OR Indian*[tw] OR Nation[tw] OR tribe*[tw] OR tribal[tw] OR band[tw] OR bands[tw]))) AND (Canada[mesh] OR ("Canada"[all fields] OR Canadian*[all fields] OR British Columbia* [all fields] OR "Colombie Britannique"[all fields] OR Alberta*[all fields] OR Saskatchewan*[all fields] OR Manitoba*[all fields] OR Ontari*[all fields] OR Quebec*[all fields] OR Nova Scotia*[all fields] OR "Nouvelle Ecosse"[all fields] OR New Brunswick*[all fields] OR "Nouveau Brunswick"[all fields] OR Newfoundland*[all fields] OR "Terre Neuve"[all fields] OR "Labrador"[all fields] OR Prince Edward Island*[all fields] OR "île du prince edouard"[all fields] OR "Yukon Territory"[all fields] OR "NWT"[all fields] OR "Northwest Territories"[all fields] OR "Nunavut"[all fields] OR "Nunavik"[all fields] OR "Nunatsiavut"[all fields] OR "NunatuKavut"[all fields]))
AND
("Health Planning"[Mesh] OR healthcare planning[tw] OR health care planning[tw] OR healthcare goal*[tw] OR health care goal*[tw] OR planning health*[tw] OR healthcare priorit*[tw] OR health care priorit*[tw] OR health services priorit*[tw] OR ((plan[ti] OR plans[ti] OR planning[ti] OR priorit*[ti] OR goal[ti] OR goals[ti]) AND (health[ti] OR healthcare[ti])) OR "health services needs and demand"[mesh] OR "Adolescent Health Services/organization and administration"[mesh] OR healthcare[ti] OR health care[ti])

Search strategy in SCOPUS:

TITLE-ABS-KEY ("Athapaskan" OR "Saulteaux" OR "Wakashan" OR "Cree" OR "Dene" OR "Inuit" OR "Inuk" OR "Inuvialuit*" OR "Haida" OR "Ktunaxa" OR "Tsimshian" OR "Gitsxan" OR "Nisga'a" OR "Haisla" OR "Heiltsuk" OR "Oweenkeno" OR "Kwakwaka'wakw" OR "Nuu chah nulth" OR "Tsilhqot'in" OR "Dakelh" OR "Wet'suwet'en" OR "Sekani" OR "Dunne-za" OR "Tahltan" OR "Kaska" OR "Tagish" OR "Tutchone" OR "Nuxalk" OR "Salish" OR "Stl'atlimc" OR "Nlaka'pamux" OR "Okanagan" OR "Sec wepmc" OR "Tlingit" OR "Anishinaabe" OR "Blackfoot" OR "Nakoda" OR "Tasttine" OR "Tsuu T'inia" OR "Gwich'in" OR "Han" OR "Algonquin" OR "Nipissing" OR "Ojibwa" OR "Potawatomi" OR "Innu" OR "Maliseet" OR "Mi'kmaq" OR "Micmac" OR "Passamaquoddy" OR "Haudenosaunee" OR "Cayuga" OR "Mohawk" OR "Oneida" OR "Onodaga" OR "Seneca" OR "Tuscarora" OR "Wyandot" OR "Aboriginal*" OR "Indigenous*" OR "Metis" OR "red road" OR "on reserve" OR "off-reserve" OR "First Nation" OR "First Nations" OR "Amerindian" OR "ethnomedicine" OR "country food*" OR "residential school*") OR TITLE-ABS-KEY ("urban"

AND ("Indian*" OR "Native*" OR "Aboriginal*")) OR TITLE-ABS-KEY ("traditional medicine*" not AND chinese) OR TITLE-ABS-KEY ("shaman*" OR "traditional heal*" OR "traditional food*" OR "medicine man" OR "medicine woman" OR "autochtone*") OR ALL ("Native*" AND ("man" OR "men" OR "women" OR "woman" OR "boy*" OR "girl*" OR "adolescent*" OR "youth" OR "youths" OR "person*" OR "adult" OR "people*" OR "Indian*" OR "Nation" OR "tribe*" OR "tribal" OR "band" OR "bands") AND ("Canada" OR "Canadian*" OR "British Columbia*" OR "Colombie Britannique" OR "Alberta*" OR "Saskatchewan*" OR "Manitoba*" OR "Ontari*" OR "Quebec*" OR "Nova Scotia*" OR "Nouvelle Ecosse" OR "New Brunswick*" OR "Nouveau Brunswick" OR "Newfoundland*" OR "Terre Neuve" OR "Labrador" OR "Prince Edward Island*" OR "île du prince edouard" OR "Yukon Territory" OR "NWT" OR "Northwest Territories" OR "Nunavut" OR "Nunavik" OR "Nunatsiavut" OR "NunatuKavut"))

AND

TITLE-ABS-KEY ("Health Planning" OR "healthcare planning " OR "health care planning" OR "healthcare goal*" OR "health care goal*" OR "planning health*" OR "healthcare priorit*" OR "health care priorit*" OR "health services priorit*") OR (TITLE ("plan" OR "plans" OR "planning" OR "priorit*" OR "goal[ti]" OR "goals[ti]") AND TITLE ("health" OR "healthcare")) OR "health services needs and demand" OR "Adolescent Health Services/organization and administration" OR TITLE ("healthcare" OR "health care")
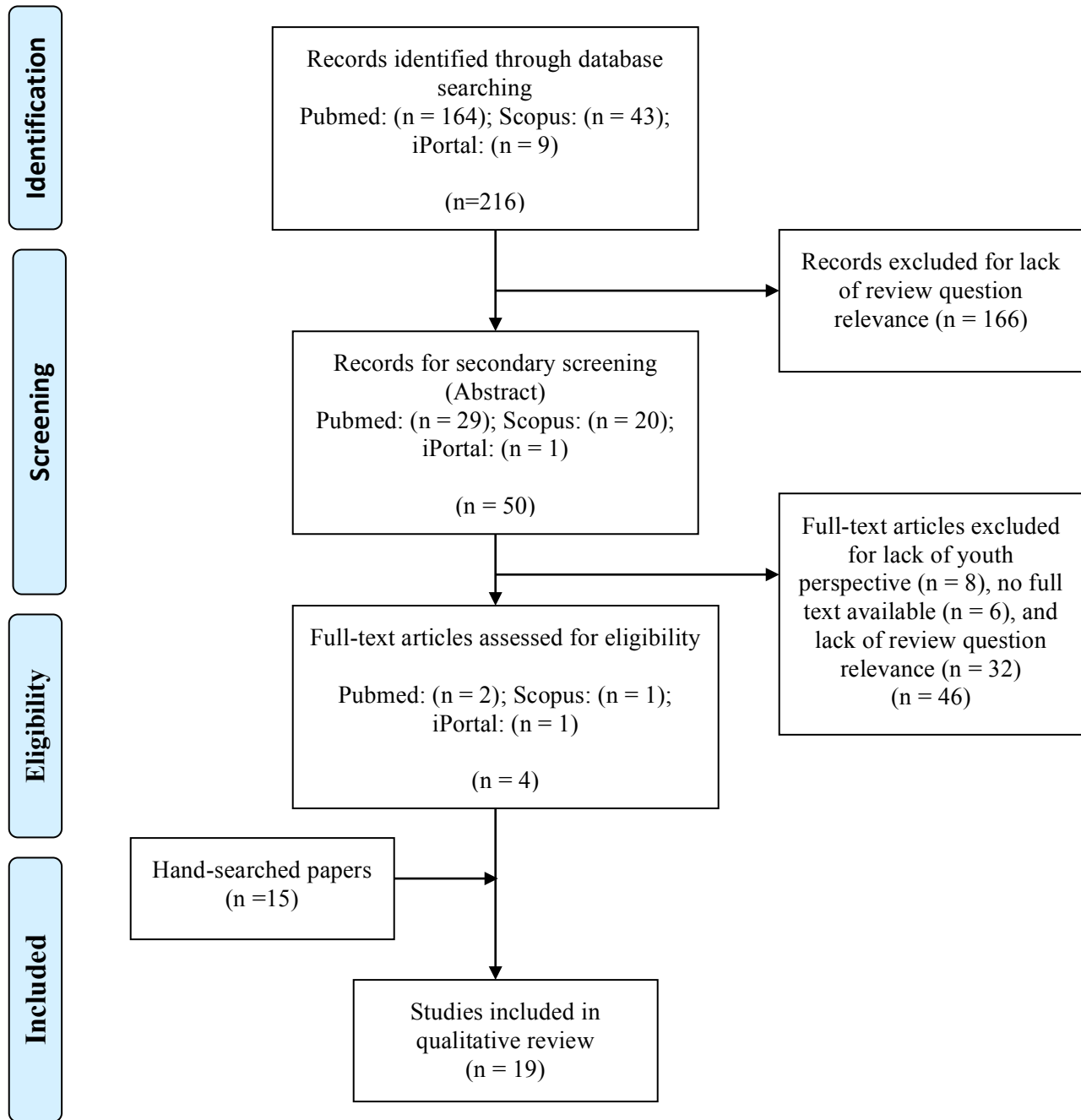
AND

TITLE-ABS-KEY ("Adolescent" OR "Young Adult" OR "youth" OR "youths" OR "young adult*" OR "adolescen*" OR "teen*" OR "young person*" OR "young people" OR "adolescent health services" OR "adolescent development")

AND

TITLE-ABS-KEY ("qualitative research" OR "qualitative research*" OR "qualitative study" OR "qualitative studies" OR "mixed method*" OR "mixed studies" OR "Surveys and Questionnaires" OR "interview*" OR "focus group*") OR TITLE ("qualitative") OR TITLE-ABS-KEY (("action" OR "participatory") AND "research") OR TITLE-ABS-KEY ("community based participatory research" OR "grounded theory" OR "phenomenolog*" OR "narration" OR "narrat*" OR "conversation*" OR "discourse*" OR "ethnograph*" OR "ethnomethodolog*" OR "autoethnograph*" OR "hermeneutic*" OR "constructivis*" OR "case study" OR "case studies" OR "field study" OR "field studies" OR "participant observ*" OR "participants observ*" OR "field observ*") OR TITLE-ABS-KEY (("purpos*" OR "theoretical" OR "judgement" OR "maximum variation" OR "convenience" OR "critical case" OR "deviant case" OR "key informant" OR "snowball" OR "cluster") AND "sampl*") OR TITLE-ABS-KEY (("lived" OR "life" OR "personal*" OR "patient" OR "patients" OR "survivor*") AND ("experience*" OR "perspective*" OR "perception*" OR "meaning*")) OR TITLE-ABS-KEY ("thematic analys*" OR "content analys*" OR "group discussion*" OR "cope" OR "copes" OR "coping" OR "thrive" OR "thrives" OR "thriving" OR "health surveys")

Appendix B: PRISMA Diagram of Qualitative Literature Review

Identification

Records identified through database searching
Pubmed: (n = 164); Scopus: (n = 43); iPortal: (n = 9)

(n=216)

Records excluded for lack of review question relevance (n = 166)

Screening

Records for secondary screening (Abstract)
Pubmed: (n = 29); Scopus: (n = 20); iPortal: (n = 1)

(n = 50)

Full-text articles excluded for lack of youth perspective (n = 8), no full text available (n = 6), and lack of review question relevance (n = 32)
(n = 46)

Eligibility

Full-text articles assessed for eligibility

Pubmed: (n = 2); Scopus: (n = 1); iPortal: (n = 1)

(n = 4)

Hand-searched papers
(n =15)

Included

Studies included in qualitative review
(n = 19)

Appendix C: Characteristics of Included Studies

Authors (Year)	Study title	Indigenous group, location, youth age, sample size, study type	Research approach, qualitative methods	Youth engagement capacity	Main health findings
PEER-REVIEWED					
Beatty et al. (2013)	Northern Voices: A Look Inside Political Attitudes and Behaviours in Northern Saskatchewan: Northern Aboriginal Political Culture Study.	- Northern Woodland Cree, Dené and Metis - 8 communities across northern Saskatchewan - 18 to 25 y.o.s - n = 30 - report from International Centre for Northern Governance and Development, University of Saskatchewan	- Participatory (but not explicitly stated) - main investigator was Indigenous and part of community - focus groups with youth	- to understand the political culture of urban Aboriginal populations, especially youth who are increasingly a large part of the population	- youth were consulted in focus groups about preferences for community/political (municipally, regionally, and locally) activities
Blanchet-Cohen et al. (2011)	Indigenous Youth Engagement in Canada's Health Care	- many different nations - conducted in two cities in BC - 19-29 y.o.s - n = 20 - peer-reviewed article	- participatory (but not explicitly stated) - focus groups and key informant interviews	- one indigenous youth activist was on the research team - youth consulted in FGs	- Indigenous youth feel the current healthcare system is ineffective and disrespectful of youth and culture - place and nature of culture in providing health care is critical - Indigenous youth are eager to be part of a shift in health, and want to be involved in the design and delivery of health programs, using diverse and creative responses to health
Bradford et al. (2017)	Perspectives of water and health using Photovoice with youths living on reserve	- Yellow Quill Saulteaux First Nation (YQFN) - Saskatchewan - 16 to 18 y.o.s - n = 19 - youth from a Junior Rangers (northern branch of the Canadian military) - peer-reviewed article	- CBPR - Photovoice (postervoice) followed by sharing circle discussion	- youth took pictures over the course of 3 days in their Junior Ranger program - decided where to take the pictures, how to format the posters, and how to disseminate the posters	
Clark N, Walton P, et al. (2013)	Melq'ilwiye: coming together – intersections of identity, culture, and health for urban Aboriginal youth	- "urban" Aboriginal youth - Kamloops, BC - 12 to 25 y.o.s - n = 2	- CBPR mixed methods design - 4 talking circles	- to create new knowledge and research capacity by and with urban Aboriginal youth	- youth engaged as "peer researchers": sat on project advisory board, trained in research tools, data collection and analysis - youth feedback quotes provided

Authors (Year)	Study title	Indigenous group, location, youth age, sample size, study type	Research approach, qualitative methods	Youth engagement capacity	Main health findings
Crooks et al. (2010)	Strengths-based Programming for First Nations Youth in Schools: Building Engagement Through Healthy Relationships and Leadership Skills	- Oneida Nation of the Thames, Chippewas of the Thames, and the Munsee-Delaware First Nation - London, Ontario - middle and high school - n = 23	- evaluation of different school-based initiatives undertaken with youth - surveys with qualitative data, interviews, FGs, official school data	- early formative evaluation of a number of school-based initiatives that focus on increasing youth engagement through building on strengths and the promotion of healthy relationships	- youth consulted in interviews about leadership/mentorship projects/ initiatives/ conferences/ courses
Fletcher S, Mullett J. (2016)	Digital stories as a tool for health promotion and youth engagement	- First Nations - Vancouver, BC - 13 to 25 y.o.s - n = 8	- evaluation of a digital story telling workshop - recorded oral reflections	- to provide opportunities for intergenerational knowledge sharing	- youth engaged as "youth research team": trained as facilitators and hosted healthy lifestyle workshop - youth feedback quotes provided
Genuis et al. (2015)	Partnering with Indigenous student co-researchers: improving research processes and outcomes	- Alexander Cree First Nation - Alberta - 16 to 18 y.o.s - n = 9	- CBPR - youth co-researchers conducted semi-structured Photovoice interviews, with debrief after each interview	- youth as co-researchers - youth were trained as co-researchers to interview kids, present their results to research committee, and disseminate findings	- partnership between university researches and Indigenous co-researchers potential for future health promotion - co-researchers developed skills, gained understanding of health challenges, and initiated health promotion
Hatala et al. (2017)	"I Have Strong Hopes for the Future": Time Orientations and Resilience Among Canadian Indigenous Youth	- Plains Cree and Métis - Saskatoon, SK - 15 to 27 y.o.s - n = 28	- modified grounded theory - 38 qualitative interviews	- youth consulted through interviews to understand how the concepts of time and the future inform resilience among Indigenous youth	- a future time orientation emerged as central to processes of resilience, support by a sense of belonging, developing self-mastery, and cultural continuity - distressing times can impact youth's ability to conceptualize a future
McClymont Peace and Myers (2012)	Community-based participatory process – climate change and health adaptation program for Northern First Nations and Inuit in Canada	- Northern First Nations and Inuit communities (not specified) - Whitehorse, Yellowknife, and Ottawa - youth age not specified - n not specified	- CBPR - interim evaluation of the workshops and program with general feedback was solicited	- 3 capacity-building workshops were held to support creation of community-based proposals for projects to tackle climate change, and receive funding from Health Canada	- did not specify, but mentioned that many of the projects supported through this program were youth-led or youth-focused
Monchalin et al. (2016)	"When you follow your heart, you provide that path for others": Indigenous models of youth leadership in HIV prevention	- mix of First Nations, Metis and Inuit - across Canada -16 to 26 y.o.s - n = 18 - peer-reviewed article	- CBPR - individual semi-structured interviews	- subset of youth leaders reviewed transcripts and developed hybrid coding framework from transcripts - member checking 1 year later in follow-up retreat to review and reach consensus about themes and prelim analyses	- identified qualities of an Indigenous youth leader including healthy - described challenges of being a youth leader - described ways in which Indigenous youth demonstrate leadership - provided recommendations for future Indigenous youth leadership support

Authors (Year)	Study title	Indigenous group, location, youth age, sample size, study type	Research approach, qualitative methods	Youth engagement capacity	Main health findings
Stewart S, Riecken T, Scott T, et al. (2008)	Expanding health literacy: indigenous youth creating videos	- First Nations - Victoria, BC - 'school-aged children' from alternative Indigenous program in high school - n = 6	- PAR digital filmmaking - post-project interviews	- to understand how digital filmmaking can contribute to expanding health literacy in Indigenous youth	- youth engaged as "student videographers": created videos of interviews with community members to understand health and wellness - youth reflections on research captured in post-project interviews
Watson et al (2012)	Identifying gaps in asthma education, health promotion, and social support for Mi'kmaq families in Unanma'ki (Cape Breton), Nova Scotia	- 5 Mi'kmaq communities - Cape Breton, NS - 8 to 12 y.o.s with their caregivers - n = 21	- CBPR qualitative study - purposive and snowball sample - with youth: semi-structured interviews	- youth consulted in interviews	- youth knowledge of asthma triggers does not necessarily lead to avoidance - youth rely on caregivers to supply and administer inhalers during asthma attacks - youth indicate primary supporters as 1) family & mothers, or 2) teachers then 3) peers when parental care is absent
NOT PEER-REVIEWED					
Caron and Dehghani, CBHSSJB (2017)	Community consultations in planning Cree youth-friendly health services in Eeyou Istchee	- James Bay Cree - Mistissini, Wemindji, Waskaganish, Waswanipi, Whapmagoostui - age not specified - n = 21 (interviews & FGs) - PH department document	- deductive and inductive approach at recommendations - one-on-one interviews, focus groups, survey (sessions were not recorded, only notes)	- youth consulted in interviews and focus groups	- Results of the document include: priority health problems for the youth, youth vulnerability factors, views of existing services, views on establishing a youth clinic. A list of recommendations for healthcare providers and planners is provided for future projects (according to partners, there is currently a youth clinic pilot in one/more communities)
Hayes (1998)	Global and transnational flows and local Cree youth culture	- Red Bank James Bay Cree - northern Quebec - 14 to 28 y.o.s - n = 19 - M.A. thesis (Concordia)	- ethnography - individual interviews and participant-observation	- youth consulted in interviews	- ways Cree youth use cultural flows and symbols, in particular mass media and Pan-Indian ceremonies, to shape their own cultural space
Radu (2015)	Miyupimaatisiiun in Eeyou Istchee: healing and decolonization in Chisasibi	- James Bay Cree - Chisasibi - youth age not specified - youth n not specified - M.A. thesis (Concordia)	- PR documentary making and interviews	- youth consulted in interviews	- Chisasibi model of decolonized Miyupimaatisiiun includes fostering creative potential, cultural revitalization, and social justice (not specific to youth)
Smethurst (2012)	Well-Being and Ethnic Identity Promotion for Aboriginal Youth: A Community Based Mixed Methods Study of Tribal Journeys	- Coastal First Nations - Victoria, BC - 15 to 23 y.o.s - n = 21 - M.Sc. thesis (U Vic)	- CBPR - interviews about Tribal Journeys: wilderness program for Coastal FN youth	- youth consulted in interviews: how how they view connection between land and mental health promotion	- goal to develop an evaluation tool-kit that satisfy mainstream funding standards as well as community, cultural standards - created a tool-kit to reflect mental health youth experience from

Authors (Year)	Study title	Indigenous group, location, youth age, sample size, study type	Research approach, qualitative methods	Youth engagement capacity	Main health findings
Southern Alberta Child & Youth Health Network (2005)	Report on the Health Status and Health Needs of Aboriginal Children and Youth.	- First Nations - Southern Alberta - age not specified - n = 26 - report by the Southern Alberta Child & Youth Health Network and Aboriginal Health Program of the Calgary Health Region	- participatory community consultation process - focus groups based off the Blackfoot Circle Structure model	- youth were consulted in interviews - youth were in charge of the design, launch and implementation of the social marketing campaign for participation in the consultations	- The recommendations fall into the following categories: basic necessities of life, comprehensive and coordinated health services delivery, education for children, youth and families, community control and empowerment and public policy.
Warren (2013)	First Nations youths' experiences with wellness: a four directions approach	- Cree First Nations - rural Northern Ontario - 15 to 20 y.o.s - n = 5 - M.Ed. thesis	- decolonizing methodology - convenience sample - individual interviews	- youth consulted in interviews	- five themes of youth wellness emerged: balance strategies and challenging, coping strategies, emotional balance, worldview, motivation
Woodland (2008)	Sexual Health: Engaging Urban Indigenous Youth	- urban Indigenous youth - Calgary, AB - 18 to 24 y.o.s - n = 9 - M.Sc. thesis	- semi-structured interviews	- youth consulted in interviews	- critical barriers for youth in accessing sexual healthcare are racism, acculturation, and colonialism

Appendix D: Stakeholder Summary

Stakeholder	From Where	Importance of Stakeholder	Influence of Stakeholder
Youth	- Nemaska community - Luke Mettaweskum community school - Cree Nation Youth Council	- end-users of knowledge - provide necessary contextual knowledge - recipients of plans, programs and policies	- represent population affected, hence important buy-in - can lead to other youth becoming aware/encouraged towards future health planning initiatives - increased youth engagement in research projects such as this one can lead to important advantages for the youth and the research (please see Chapter 5: Discussion for further details)
Youth Coordinators	- CBHSSJB - Cree Nation of Nemaska local government - Cree School Board - Cree Nation Government and Grand Council of the Crees	- coordinators play crucial role in youth programs decision-making - coordinators have valuable internal knowledge/ understanding	- ability to provide contextual information on existing youth engagement structures - responsible for planning for youth recreational engagement and health-related initiatives and plans - represent different entities implicated in youth engagement programs across Cree Nation
Youth Council Members: Nemaska Youth Council	- Nemaska Youth Council (local)	- youth council members are relatively engaged/vocal community members - nominated by fellow peers and community members; knowledgeable of peers' needs	- inclusion of youth chiefs from other communities and across the region can lead to implementation beyond Nemaska
Youth Council Members: Cree Nation Youth Council	- Cree Nation Youth Council (regional)	- highest level of regional youth governance - address/discuss high priority issues for Eeyou Istchee youth	- as the highest youth governance level, represent the most engaged youth and youth voices across Eeyou Istchee - represent youth voices in major regional youth decisions initiated from many Cree Nation entities
IAMP Team: CBHSSJB or Cree Health Board	Previously recruited; CHB regional directors currently involved in the partnership	- CHB are instigators of overarching IAMP project - provide knowledge of policy and decision-making in Cree region - duty to hear local needs for service provision	- regional health authority: high power - ability to effect eventual organizational priorities in regional health plans - responsible for eventual implementation of youth voice findings and recommendations
IAMP Team: McGill Researchers	McGill researchers currently involved in the partnership	- provide research and methodological knowledge - lead logistics, keep research goals on track	- develop initial grants and secure national research funding - ensure scientific rigour maintained
Community Partners	Previously involved in IAMP; members from community	- health planning is community-based issue, hence recipients of policy	- community awareness/dissemination - long-term relationship building for other community research endeavours

Appendix E: Recruitment Poster

CALLING ALL EENOUCH!

Want to help define what Miyupimaatisiiun or wellbeing means to you?

Want to explore how the new mining project may affect Miyupimaatisiiun or wellbeing?

WE WANT TO HEAR FROM YOU!

Join us for a 2-hour focus group to explore what wellbeing means to you, and how the future mining project may impact our community wellbeing…

FROM NOVEMBER 13TH - 16TH

AT THE WELLNESS CENTER,
FROM 7 TO 9 PM

PARTICIPANTS WILL BE COMPENSATED FOR THEIR TIME

TEA AND COFFEE WILL BE SERVED

FOR MORE INFO OR TO REGISTER CONTACT:
STELLA M. WAPACHEE OR ELIZABETH WAPACHEE
819-673-2188

The focus groups are part of the research project "Understanding how mining affects community well-being in Eeyou Istchee" led by Prof. Mylene Riva from the Department of Geography and Institute for Health and Social Policy, at McGill University. If you have questions on the project, you can contact her: 514-398-6331 or mylene.riva@mcgill.ca
This project has been approved by Université Laval's Research Ethics Board: Approbation No 2015-098 A-2 / 26-10-2017

Appendix F: Focus Group Consent Form

A Collaborative Evaluation of Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) Initiative for Cree Health

McGill Project Leads:	**Cree Board of Health and Social Services of James Bay Project Leads:**
Mary Ellen Macdonald, PhD	**Jill Torrie, MSc**
Co-Principal Investigator	Assistant Director of Public Health
Assistant Professor, McGill University, Services	Cree Board of Health and Social
Faculty of Dentistry,	of James Bay
Division of Oral Health and Society	torrie.jill@ssss.gouv.qc.ca
mary.macdonald@mcgill.ca	
Susan Law, MHSC, PhD	**Dr. Robert Carlin**
Co-Principal Investigator	Director of Public Health
Associate Professor, McGill University, Services	Cree Board of Health and Social
Department of Family Medicine	of James Bay
Principal scientist, St. Mary's Research Center	robert.carlin@ssss.gouv.qc.ca
susan.law@mcgill.ca	

Participant Information Sheet and Consent Form

This is an invitation to participate in a research project being conducted by the Cree Board of Health and Social Services of James Bay (CBHSSJB) and McGill University. The research is funded by the Canadian Institutes of Health Research, McGill University and the CBHSSJB. This project is designed to better understand health planning in the CBHSSJB and communities. The project will conduct interviews (30-60 minutes) with community stakeholders and professionals with an interest in or involved with health planning in the communities.
As a research participant, you have the right to know about the purpose and procedures that are to be used in this research study. Before you agree to take part in this study, it is important that you read the following information sheet. Please feel free to ask as many questions as you need to in order to understand what you will be asked to do. Participation in this study is entirely voluntary; refusal to take part will in no way affect your relationship with the CBHSSJB or McGill University.

Purpose of study:
The aim of our project is to better understand the health planning processes used in Eeyou Istchee. We are interviewing persons like you to hear different perspectives and experiences about health planning. What ideas have you had about best practices, challenges, useful collaborations and planning approaches that may be unique to Eeyouch or Eenouch?

Procedures

If you agree to participate, we will arrange to conduct an interview on the phone, via Skype or face-to face, depending on your location, preference and/or schedule. The interview will be audio-recorded and later transcribed for analysis. The length of the interview will be 30-60 minutes, depending on your availability and the information you provide.

Voluntary participation/withdrawal

Your participation in this study is voluntary. You may choose to participate now and decide to stop your participation at any time. Your decision to participate, or not, will have no impact on your involvement with the CBHSSJB or McGill University. If you withdraw from this study, you can choose to withdraw any information shared with the research team.

Benefits and risks

You will not personally benefit from taking part in this study. However, the study results may contribute to improving our health services planning. There are no risks associated with taking part in this study.

Costs and compensation

You will not be compensated for your participation in this study. There will be no direct costs to you for participating in this study, other than time. We will be happy to reimburse you for any small out-of-pocket expenses (e.g., parking or babysitting fees — with receipts).

Confidentiality

We will collect and store identifiable information about you in a file for the purpose of the research study. Only information necessary for the research study will be collected. This information will remain confidential. To protect your identity, your name and identifying information will be replaced with a code (numbers and/or letters); the link between the code and your identity will be held by the research team at McGill University. No information that discloses your identity will be allowed to leave the institution.

Your study information will be kept for 7 years after completion of the study by the research team, after which it will be destroyed.

The study findings will be made available in a report within the region. Later they will be published in research journals and shared with other people at scientific meetings and used in the development of future studies. Please be assured that your identity will never be revealed.

Contact information or questions:

If you have any questions about the study, you can communicate with the researchers in charge of the study: Dr. Mary Ellen Macdonald, McGill (514) 398-7203 ext. 089405, Dr. Susan Law, McGill (514) 345-3511 ext. 3142, Ms. Jill Torrie, CBHSSJB (514) 953-8283 or Dr. Robert Carlin, CBHSSJB (514) 861-2352 ext. 74233

For any questions concerning your rights as a person taking part in this study or if you have comments or wish to file a complaint, you can communicate with Ms. Ilde Lepore, Research Ethics Officer of the McGill Institutional Review Board at 514-398-8302 or with Ms. Louise Valiquette, Interim Commissioner of complaints and quality of services of the Cree Board of Health and Social Services of James Bay, 515, boul. Décarie, St-Laurent (Québec) H4L 3L1. **Phone toll free 1-866-923-2624** r18.complaints@ssss.gouv.qc.ca.

STATEMENT OF CONSENT

I have read/understood the above information and my questions have been answered to my satisfaction. A copy of this information sheet will be given to me. My participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my work with the Cree Board of Health and Social Services of James Bay or McGill University, now or later. I do not give up any of my legal rights by signing this consent form. I agree to participate in this study.

Signature:

_____Date:_____

Name of Participant: _____

PERSON WHO OBTAINED CONSENT

Signature:

_____Date:_____

Name of Participant: _____

Appendix G: Focus Group Guide

Focus Group Guide: Youth

Welcome: Welcome everyone… Thank you for joining us for this talking circle. My name is Nickoo, and I'm working with a group of researchers from McGill university in Montreal on a project to improve health and health planning in the Eeyou/Eenou Istchee region. My specific role in this research is to understand how you, the youth think about your health and what is important to you, and how you engage in programs that focus on the health.
This project is part of a larger project evaluating the IAMP (Iiyuu Ahtaawin Miyupimaatisiiun Planning), a Cree Health Board initiative aimed at gathering grassroots information and perspectives on how to better plan for individual and community health.

[Obtain consent from participants]

Confidentiality and Audio-Recording: We're audio-recording this session because we don't want to miss anything you say. This study may be published, however your names will NOT be reported in any results, and all identifiable comments will be removed and kept confidential. I ask that you all respect the confidentiality of your fellow group members, and that what is discussed here not leave this room.

Facilitator Role: My role as facilitator is to ask questions and listen to responses, but this is also a group conversation so please feel free to respectfully disagree or agree to what your group members have to say, and do not feel that you have to respond directly to me! Also feel free to only answer what you are comfortable contributing to. Feel free to get up to get more food or drinks while we continue!

Questions

1. **Introductions.** Tell me a little about yourself: your age and your favorite activity/sport. *keep brief*

2. **What does health and wellbeing mean to you?** We would like to start by exploring together around what you think of the meaning of 'health' and 'wellbeing'. What words do you think of when I say 'health' and 'wellbeing'? We will go around the table and each person can tell us 1 word at a time, and we will keep going around until everyone has shared all of their words.
Use flipchart to write words down. Brainstorm as a group if there is anything missing and what these words mean – group terms together with participants' advice, to end with themes that they have identified.
   a. Do 'health' and 'wellbeing' mean different things to you? In what ways?
   b. In the larger project I work in, we also talk about Miyupimaatisiiun. Does this word have meaning to you?
Go around and give everyone a chance to express themselves on what this means, if anything at all, for example, is it different from well-being.

3. **Existing local health-related activities for youth.** Tell me about what kinds of activities or programs you have participated in that focus on the health and wellbeing of young people (events, sports, clinics, workshops or other focus groups, special presentations, awards, etc.).
    a. Why did you participate? What makes you want to participate?
    b. What works well? What could be better?
    a. What activities, programs or opportunities are missing?

4. **Engagement in planning, organizing or evaluating health initiatives**. Of the activities that focus on health and wellbeing of Eenou youth…
    a. In what ways did you engage in these activities?
        i. knowing about it
        ii. showing up
        iii. asking for it
            1. who do you ask?
        iv. organize/planning/evaluating it
        v. leading it
    b. If you have organized/planned/led an activity, what motivates you to do so? What do you get out of it?
        i. What worked/went well? What could have been better?
    c. If not, why don't you participate?
        i. Is it difficult to participate? What makes it difficult?
        ii. Would you prefer being able to participate?
        iii. What makes other activities more attractive?

5. **Youth voice and leadership.** How do you feel about youth voices in the community?
    a. In what ways are youth listened to by those who plan and organize health services in the community?
        i. What helps to have youth voices heard by people who plan and organize services for your community?
        ii. What other services should be involved in hearing your opinions for services in the community (eg. school, police, social services, health clinic, housing, etc.)?
    b. In what ways are youth given the opportunity to plan or lead health-related activities and services in the community?
        i. Why do you feel youth should/should not lead and plan health-related activities in the community?
        ii. What strategies could help engage more youth in planning health-related activities?

6. **Mining and health.** Based on your previous definition of health and wellbeing, how would the mining project in your community affect health and wellbeing?
    a. How does mining affect what we've been talking about?
    b. Is the mining project positive or negative to you? In what ways?
    c. Is the mining project positive or negative to your community? In what ways?

7. **Missing parts?** Anything else we should have asked or that you would like to add?
Give a summary of what you heard back to the youth: I heard from you that ___. Would you agree?

a. Are there other people in your community that we should talk to about youth and planning for better health and health services?

[Explanation of what will happen with this data and next steps in the project]
- I will transcribe what you said
- No one will see it except me/McGill supervisors and teammates
    - Will draw out most important points and bring it back to the community to hear your opinions/comments
    - Then CHB will see a summarized and anonimized version of the recommendations
- Working with Stella and the Band Council; hoping this project will lead to increased development in how youth get involved

[Thanks to everyone]

Appendix H: Key Informant Interview Consent Forms

A Collaborative Evaluation of Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) Initiative for Cree Health

McGill Project Leads:	Cree Board of Health and Social Services of James Bay Project Leads:
Mary Ellen Macdonald, PhD Co-Principal Investigator Assistant Professor, McGill University, Services Faculty of Dentistry, Division of Oral Health and Society mary.macdonald@mcgill.ca	**Jill Torrie, MSc** Assistant Director of Public Health Cree Board of Health and Social of James Bay torrie.jill@ssss.gouv.qc.ca
Susan Law, MHSC, PhD Co-Principal Investigator Associate Professor, McGill University, Services Department of Family Medicine Principal scientist, St. Mary's Research Center susan.law@mcgill.ca	**Dr. Robert Carlin** Director of Public Health Cree Board of Health and Social of James Bay robert.carlin@ssss.gouv.qc.ca

Participant Information Sheet and Consent Form

This is an invitation to participate in a research project being conducted by the Cree Board of Health and Social Services of James Bay (CBHSSJB) and McGill University. The research is funded by the Canadian Institutes of Health Research, McGill University and the CBHSSJB. This project is designed to better understand health planning in the CBHSSJB and communities. The project will conduct focus groups (60-75 minutes) and interviews (60-75 minutes) with youth in the community with an interest in or involved with health planning in the communities. As a research participant, you have the right to know about the purpose and procedures that are to be used in this research study. Before you agree to take part in this study, it is important that you read the following information sheet. Please feel free to ask as many questions as you need to in order to understand what you will be asked to do. Participation in this study is entirely voluntary; refusal to take part will in no way affect your relationship with the CBHSSJB or McGill University.

Purpose of study:

The aim of our project is to better understand how you define health and wellbeing in your community, what your priorities are for health change, and how you engage in health planning processes used in Eeyou Istchee. We are interviewing persons like you to hear different perspectives and experiences about health and health planning engagement. While not all of these questions will be relevant to your own involvement, we can adjust our questions accordingly and you may choose to answer certain questions and not others.

Procedures

If you agree to participate, we will arrange to conduct an interview with you at your location of preference. The focus group will be audio-recorded and later transcribed for analysis. The length of the interview will be 60-75 minutes, depending on your availability and the information you provide.

Voluntary participation/withdrawal

Your participation in this study is entirely voluntary. You may choose to participate now and decide to stop your participation at any time. You may also request at any time during the focus group to take a break, not answer a question, or leave the focus group. Your decision to participate, or not, will have no impact on your involvement with the CBHSSJB or McGill University. If you withdraw from this study, you can choose to withdraw any information you had already shared with the research team.

Benefits and risks

You will not personally benefit from taking part in this study. However, the study results may contribute to improving our health services planning. There are no risks associated with taking part in this study.

Costs and compensation

You will not be compensated for your participation in this study. There will be no direct costs to you for participating in this study, other than time. We will be happy to reimburse you for any small out-of-pocket expenses (e.g., parking or babysitting fees — with receipts).

Confidentiality

We will collect and store identifiable information about you in a file for the purpose of the research study. Only information necessary for the research study will be collected. This information will remain confidential. To protect your identity, your name and identifying information will be replaced with a code (numbers and/or letters); the link between the code and your identity will be held by the research team at McGill University. No information that discloses your identity will be allowed to leave the institution.

Your study information will be kept for 7 years after completion of the study by the research team, after which it will be destroyed.

The study findings will be made available in a report within the region. Later they will be published in research journals and shared with other people at scientific meetings and used in the development of future studies. Please be assured that your identity will never be revealed.

Contact information or questions:

If you have any questions about the study, you can communicate with the researchers in charge of the study: Dr. Mary Ellen Macdonald, McGill (514) 398-7203 ext. 089405, Dr. Susan Law, McGill (514) 345-3511 ext. 3142, Ms. Jill Torrie, CBHSSJB (514) 953-8283 or Dr. Robert Carlin, CBHSSJB (514) 861-2352 ext. 74233.

For any questions concerning your rights as a person taking part in this study or if you have comments or wish to file a complaint, you can communicate with Ms. Ilde Lepore, Research Ethics Officer of the McGill Institutional Review Board at 514-398-8302 or with Ms. Louise Valiquette, Interim Commissioner of complaints and quality of services of the Cree Board of

Health and Social Services of James Bay, 515, boul. Décarie, St-Laurent (Québec) H4L 3L1. **Phone toll free 1-866-923-2624** r18.complaints@ssss.gouv.qc.ca.

STATEMENT OF CONSENT

I have read/understood the above information and my questions have been answered to my satisfaction. A copy of this information sheet will be given to me. My participation is voluntary and I can withdraw from the study at any time without giving reasons, without it affecting my work with the Cree Board of Health and Social Services of James Bay or McGill University, now or later. I do not give up any of my legal rights by signing this consent form. I agree to participate in this study.

Signature: _____Date:_____

Name of Participant: _____

PERSON WHO OBTAINED CONSENT

Signature: _____Date:_____

Name of Participant: _____

Appendix I: Interview Guide for Key Informants: Youth Council Member

The purpose of this project is to gather perspectives about how youth health services are planned within Eeyou Istchee, and how best to plan for better health and healthier communities. There are no right or wrong answers, and we encourage you to answer only whatever questions you feel comfortable with! We will use this information to contribute to more effective planning efforts in the future.

1. **Introduction**. Tell me a little about your role and how long you've been working in your position.

2. **Health definition**. In your own words, what does the term *health* or *wellbeing* mean to you?
   a. What words come to mind when I say the words *health* and *wellbeing*?
   b. In the larger project I work in, we also talk about *Miyupimaatisiiun*. Does this word have meaning to you?

3. **Your involvement in health-related activities**. What activities are you currently involved in that relate to youth health and health services?
   b. In what ways are you involved in planning these activities (eg. coming up with ideas, asking for different events, participating, promoting, leading)?
      i. Who leads these activities?
      ii. How do you get young people engaged?
      iii. Are there any example documents of these activities that you can share?
   c. Any examples of totally youth-driven initiatives/events? That are excellent examples of Cree youth engagement?

4. **Youth engagement in health-related activities**. How much/often do other youth participate in health-related activities in your community?
   a. What kinds of health-related activities are best attended?
   b. What works well? What could be better?

5. **Youth voice in health planning.** How do you represent youth voices on the Council?
   a. What are the topics where youth voices usually contribute?
   b. In what ways are youth listened to by those who plan and organize health services in the community?
   c. To what extent do you think the Council and community listen to youth voices and incorporate their perspectives in planning?
   d. Do you think youth could be more involved? How?
   e. What motivates you to be on the Youth Council?

6. **Cree youth health planning**. Can you describe any parts of health planning that are unique to Cree youth?
   a. Are there particular challenges related to planning for Cree youth?
   b. Are there particular benefits related to planning for Cree youth?

7. **Missing parts?** Anything else we should have asked or that you would like to add?

a. Are there any other people/youth in your community that we should talk to about youth planning for better health and health services?

Appendix J: Interview Guide for Key Informants: Youth Coordinator

Interview Guide for Key Informants: Youth Coordinator

The purpose of this project is to gather perspectives about how youth health services are planned within Eeyou Istchee, and how best to plan for better health and healthier communities. There are no right or wrong answers, and we encourage you to answer only whatever questions you feel comfortable with! We will use this information to contribute to more effective planning efforts in the Eeyou Istchee future.

8. **Introduction**. Tell me a little about your role and how long you've been working with youth in Nemaska and across the region.

9. **Health definition**. In your own words, what does the term *health* or *wellbeing* mean to you?
   a. What words come to mind when I say the words *health* and *wellbeing*?
   b. In the larger project I work in, we also talk about *Miyupimaatisiiun*. Does this word have meaning to you?

10. **Your involvement in health planning activities**. What health planning initiatives are you currently involved in that relate to youth health and health services?
    d. In what ways are you involved in planning these activities (eg. coming up with ideas, asking for different events, participating, promoting, leading)?
        i. Who is involved in the project? Who funds the project?
        ii. How do you get young people engaged?
        iii. Are there any example documents that you can share?

11. **Youth engagement in health-related activities**. How much/often do youth participate in health-related activities in the community?
    c. What kinds of health-related activities are best attended?
    d. What works well? What could be better?

12. **Youth voice in health planning.** To what extent are youth voices represented in planning decisions across the region and in the community?
    a. What are the topics where youth voices usually contribute?
    b. In what ways are youth listened to by those who plan and organize health services in the community?
    c. To what extent do you think the Council and community listen to youth voices and incorporate their perspectives in planning?
    d. Do you think youth could be more involved? How?
    e. What motivates you to be on the Youth Council?

13. **Cree youth health planning**. Can you describe any parts of health planning that are unique to Cree youth?
    a. Are there particular challenges unique to planning for Cree youth?
    b. Are there particular delights unique to planning for Cree youth?

14. **Missing parts?** Anything else we should have asked or that you would like to add?
    a. Are there any other people/youth in your community that we should talk to about youth planning for better health and health services?

Appendix K: Memorandum of Understanding with the CBHSSJB

MEMORANDUM OF UNDERSTANDING (MOU) FOR:
A Collaborative Evaluation of Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP)
Initiative for Cree Health
Funded by Canadian Institutes of Health Research, Grant PHE-141801

MEMORANDUM OF UNDERSTANDING

This Memorandum of Understanding is made this __th day of _____, 2016.

BETWEEN

Jill Torrie, MA
Assistant Director of Public Health
Cree Board of Health and Social Services of James Bay
(CBHSSJB)
203 Mistissini Blvd,
Mistissini, Quebec G0W 1CO
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Tel: 418-923-3355

Robert Carlin, MDCM
Director of Public Health
Cree Board of Health & Social Services of James
Bay (CBHSSJB)
277 Duke St, Suite 201
Montreal, Quebec
Robert.carlin@ssss.gouv.qc.ca
Tel: 514-861-2352 Fax: 514-861-2681

(Collectively, and hereinafter, "Cree Health Board Leads")

AND

Mary Ellen Macdonald, PhD
Associate Professor
Division of Oral Health & Society
Faculty of Dentistry
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Montreal, Quebec H3A 1G1
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514-398-7203 ext 089405

Susan Law, PhD
Principal Scientist
St-Mary's Research Center
Associate Professor
Family Medicine
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514-345-3511 ext 6420

(Collectively, and hereinafter, "McGill Leads")

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1. PREAMBLE:

WHEREAS, the CBHSSJB promotes research to support its mission and ensures that such research activities are built upon an Eeyou path to relationships, so that the benefits of the research activity for Eeyouch (the Cree people) will always outweigh the risks and intrusions created;

WHEREAS, the Canadian Institutes of Health Research (CIHR), through its **Partnerships for Health System Improvement Program,** is providing funding to McGill University to undertake a research project titled *A collaborative Evaluation of Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP) Initiative for Cree Health* (the "Project") as outlined in the attached Notification of award (Appendix A);

WHEREAS, Dr. Mary Ellen Macdonald, Associate Professor of the Faculty of Dentistry at McGill University and Dr. Susan Law, Associate Professor of the Faculty of Medicine at McGill University are the McGill-based Principal Investigators ("McGill Leads") for the Project;

WHEREAS, Jill Torrie, Assistant Director of Public Health and Dr. Robert Carlin, Director of Public Health of the Department of Public Health of the Cree Board of Health and Social Services of James Bay (CBHSSJB), the Co-Principal Investigators and "Cree Health Board Leads" are supportive of the Project and wish to collaborate with the McGill Leads to undertake the Project;

WHEREAS, the planning for the Project has been carried out collaboratively between McGill Leads and Cree Health Board Leads;

WHEREAS McGill University and the CBHSSJB wish to enter into this memorandum of understanding (the "MOU") to outline the parties' responsibilities, obligations and rights in carrying out the Project;

NOW THEREFORE, McGill University and the CBHSSJB agree as follows:

2.0. ABOUT RESEARCH PROJECT

2.1 Overview
The goal for this Project is to evaluate a major ongoing community-based health planning initiative – the Iiyuu Ahtaawin Miyupimaatisiiun Planning (IAMP)–coordinated by the CBHSSJB. IAMP involves the entire Eeyou territory in Northern Quebec. Our evaluative focus is to determine IAMP's implications and impact in terms of structures (e.g., committees, staff, services), decision-making processes (e.g., setting health priorities), and early outcomes at the community and regional level. Further, we will assess the potential sustainability and transferability of this planning approach to other remote indigenous contexts.

2.2 Approvals obtained for the Project
Project approval by the CBHSSJB has been provided in the form of an Executive Committee Letter of Approval (see Appendix C), date effective November 15th 2015.

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2.3 Types of Data that this project will generate and data analysis

This research will be conducted according to a Community-Based Participatory Research (CBPR) framework in combination with a developmental evaluation framework. We will focus our evaluation on individual Eeyou First Nations (to be determined by Project leads).

Data collection methods will include: 1. Individual interviews and focus groups (pre-and post-health plan implementation) among key informants from the CBHSSJB, IAMP team members, community health committees, regional representatives and community members. 2. Document review (e.g., community health profiles, community health plans, community asset maps). 3. Structured social media survey for community members. 4. Descriptive data on community engagement (e.g., the number of people who: attend meetings or groups, are members of community groups, participate in civic events and activities). All data collection tools (e.g., interview or focus group, survey items) will be developed collaboratively among members of the Project team but also with collaborators from the broader IAMP initiative (e.g., community health committee members) when appropriate and possible (e.g., developing social media survey).

Data analysis will focus on three levels: 1. collaborating Eeyou First Nations; 2. IAMP team located at the CBHSSJB; 3. regional entities of Eeyou Istchee. Local data from collaborating communities will contribute to our understanding of any concrete changes arising from the IAMP processes made and the degree of community engagement in these planning processes. This will include both in-case analysis (the case being the community) and across-case analysis, looking at the similarities and difference across the contexts. At the level of the CBHSSJB, analysis will address the working of the IAMP team, the challenges and successes of the structures and the processes, as well as the knowledge and learning from this experience. Discussion and analysis of data will take place in collaboration with the entities involved where relevant (i.e., IAMP team members, local health planning committee members), in particular with regards to interpretation of findings and determination of implications. Also, analysis will unfold iteratively and synthesized reports or briefs will be communicated to communities on a regular basis so as to provide them with knowledge and tools to better understand and discuss the IAMP process. In the regional analysis, we will consider the use of the results beyond this Project and for longer-term evaluation, as well as the transferability and scalability of IAMP for other remote indigenous communities in Canada.

3.0. CONDUCTING THE RESEARCH

3.1 Research team and project governance

In addition to the Project members who are signatories of this MOU (CBHSSJB Leads, Jill Torrie and Robert Carlin and McGill Leads, Mary Ellen Macdonald and Susan Law; see their respective positions above) the Project includes a broader circle of experts, both from the *Iiyuu Ahtaawin* (Eeyou community) and from McGill University (see Appendix B). We designate this larger circle of experts the *IAMP-EVAL Advisory Circle.*

3.2 Additional parties

Any individual Eeyou First Nation or Eeyou entity recruited for participation in the Project by the CBHSSJB will become an additional party to this MOU by signing a Letter of Agreement (see Appendix F), approved by Council resolution, in which it agrees to be bound by the MOU. If approved unanimously by

the CBHSSJB and McGill project Leads, new investigators, academic partners or funding bodies may also be added to the research Project. If a new investigator is from a new academic institution, then the new academic institution becomes an additional party to this MOU by signing a Letter of Agreement (see Appendix E) in which it agrees to be bound by the MOU. In addition, partnering academic institutions agree to ensure that employees, researchers and graduate and undergraduate students participating in the Project are informed of the obligations contained in this MOU agreement, in particular with respect to confidentiality of data. The McGill Leads will annually provide the CBHSSJB with an up-to-date list of all such employees, students and associates working on the Project.

3.3   Ethics

Project approval on the part of the CBHSSJB has been obtained by the CBHSSJB Partner (see Appendix C, Letter of Approval). Any additional indicated research ethics process (e.g., Band Council resolution, letter of approval), for each involved local community, will also be completed.

McGill Leads will submit the Project to the McGill Faculty of Medicine Institutional Review Board (IRB). This research ethics board is bound to the Tri-Council Policy Statement, Ethical Research Involving Humans, in particularly Chapter Nine which details research ethics involving First Nations, Inuit, and Métis Peoples of Canada. As the Project unfolds, McGill Leads will be required to submit addendums to the IRB as appropriate once specific activities have been further determined. This includes documents indicating how individual and collective consent will be obtained and recorded, and how the research data will be stored. A copy of this Memorandum of Understanding will be included in the IRB submission.

3.4   Dispute resolution

In the event that a dispute arises out of or relates to this Project, both parties agree first to try in good faith to settle the dispute together and/or via mediation administered by and agreed upon by a neutral third party before resorting to arbitration, litigation, or some other dispute resolution procedure. If agreed, a mediator could be engaged to assist the parties in finding a resolution that is mutually acceptable.

If a dispute cannot be resolved to the satisfaction of both parties, the research Project may be terminated according to the terms described below.

4.0. COMMUNICATIONS, REPORTING AND DATA MANAGEMENT

4.1   Communicating the results first within the region/plain language reporting

Project results will be first reported within the Eeyou region (i.e., to collaborating Eeyou First Nations, and to other Eeyou entities) before any reporting outside of the Eeyou region. The Leads and the CBHSSJB Public Health Department will approve a communications and knowledge translation-exchange plan for the project results as per expressed interests or needs of the CBHSSJB and communities. Plain language project reports, briefs, and other knowledge translation documents, will be prepared by the McGill Leads, and approved and/or revised by the CBHSSJB Leads. The CBHSSJB Public Health Department's Research Office will ensure wide distribution within the region, through various media.

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4.2 Costs of dissemination of project information

Costs associated with dissemination activities of this project will be covered by the CBHSSJB Public Health Department, except for conferences outside of the region, or unless special arrangements have been agreed upon.

4.3 Scientific reporting and educational use of results

The CBHSSJB promotes dissemination of its research findings to the broader scientific community. As this Project has received funding from CIHR, the results are likely to be of interest to the broader scientific community, in the form of peer-reviewed publications in scientific journals and as presentations at scientific conferences, or for teaching purposes.

The Project leads are responsible for producing at least one manuscript for peer-reviewed publication, and to present at scientific meetings. Authorship and review processes pertaining to these will be discussed and agreed by the Project Leads during the course of the project. Also, periodically, the McGill Leads and other McGill research partners will notify the Research Office of the CBHSSJB of any other presentations at scientific conferences so that these can be added to the bibliographic inventory on projects kept by the CBHSSJB.

The Project Leads will inform each other of every activity involving scientific reporting. When appropriate, the Project Leads will ask members of the Public Health Department, Research Committee and other interested parties to review abstracts, posters and draft research manuscripts and comment on any factual and cultural interpretations of the data that are presented.

Final draft of all texts for publication originating through McGill researchers will be submitted to the Public Health Department as outlined in Appendix D.

Final draft of all texts for publication originating through CBHSSJB and other Eeyou partners will be submitted to the McGill Leads for consensus or to permit a dissenting opinion. CBHSSJB will allow for a 10 business day turnaround time for McGill Leads to respond to manuscripts or reports and 5 business days for responses to abstracts or project briefs.

The McGill Leads are encouraged to promote the use of the results for teaching purposes within McGill or other educational institutions.

4.4 Non-scientific reporting

Project Leads will agree to accountability and to reporting time lines for interim and final reports for the CBHSSJB. All plans for dissemination of project materials or results to the public, other individuals, organizations or media, will be discussed within the Project core team i.e. among Project Leads and associated research or CBHSSJB partners. This section does not apply to communication within the scientific community or to communication within the region.

4.5 Issues concerning confidentiality:

Any data collected that includes the names or identifiable information about individuals or groups will remain confidential i.e. data will be identified using codes for which associated names will be kept stored in separate locked files at the offices of the academic leads at McGill University. Only the academic leads and research coordinator will have access to these files. Most results will be reported in aggregate form – as a summary of findings without reference to individuals or individual data. Moreover, any individual-level data used in reports, briefs, or publications of any sort will be

anonymized, for example, non-attributed or anonymous quotes. If it is decided that attribution is important to understanding the results, permission will be sought from the individual.

4.6   Data management and storage of data and project materials:
Identifiable raw data (i.e., identifiable information about Eeyouch used in the context of the Project) will be kept on the McGill University server, in accordance with Project's evaluative orientation and concerns for confidentiality of interview and focus group participants' data. Non-identifiable raw data (e.g., survey results) will also be kept on McGill server though may also be shared with and placed on the CBHSSJB server. All project health planning documents (e.g., community profiles, asset maps) and reports will be stored on the CBHSSJB server and shared with McGill Leads with the permission from CBHSSJB Leads and their partners.

Within McGill, hard copies and electronic files will be kept in locked files or password-protected computer files of the research team. Access to these documents or files will be restricted to the McGill Lead, their employees, collaborating researchers and students participating in this Project, who have read and agreed to conditions stipulated in MOU. Should such employees, collaborating researchers and students leave the Project, they must return or delete all data. A list of all those participating in the Project and accessing Project documents and files will be updated annually and provided to the CBHSSJB.

Synthesized data will be owned jointly by the CBHSSJB and the McGill Leads. These synthesized data, reports, briefs, and other forms of knowledge translation not involving identifiable raw data may be stored on the Project's Google Drive.

The academic institutions do not have the right to use, whether directly or indirectly and whether for comparative analysis with data from other projects or otherwise, the raw, nor the synthesized data, for other purposes or for research not described in the Project without the consent of the CBHSSJB. Should the academic institutions wish to amend the Project Proposal and use raw or synthesized data for other purposes, they shall obtain the consent of the CBHSSJB. In the case where the CBHSSJB wants to use synthesized data for other purposes, it will need to obtain the consent of the academic institution(s) who jointly own that data.

4.7   Disposal of the Project Data
According the requirements of McGill University, all data collected for the purposes of the Project will be destroyed seven years post publication of final results or as agreed by the Principal Investigators for the project.

5.0. FINANCING OF THE PROJECT
Details of any subsequent project financing from external sources will be appended to Appendix A. In some cases this may invoke section 3.2 before any funding is received.

6.0. TERM AND TERMINATION OF THE PROJECT
It is expected this Project shall end and be terminated by March 31st 2020 unless an extension is requested beforehand. All reasonable requests for an extension from the Project Leads will be accepted. Also, this Project may be terminated by the written notification of either party. In the event of termination, the CBHSSJB has the right to demand that any and all data related to their communities is destroyed and not used in any future parts of the research. Termination of this agreement will not affect the CBHSSJB's standing with Health Canada nor compromise the IAMP process.

7.0. LANGUAGE

The parties acknowledge that they have requested that this document be drawn up in English in accordance with the 'James Bay and Northern Quebec Agreement' (1975).

Les parties reconnaissent qu'elles ont exigé que cette présente entente soit rédigée en anglais conformément à la «Convention de la Baie James et du Nord québécois» (1975) et s'en déclarent satisfaites.

IN WITNESS WHEREOF the Parties have executed this MOU effective as of the start date named in Section 2.2. above, regardless of the date of execution.

Notice Provision

McGill University
C/o
Mary Ellen Macdonald, PhD
Associate Professor
Division Oral Health & Society
Faculty of Dentistry
McGill University
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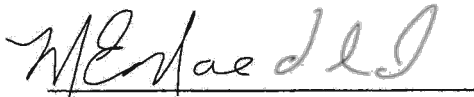mary.macdonald@mcgill.ca
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CBHSSJB
C/o
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Signed on behalf of McGill University

Name: Dr. Mary Ellen Macdonald
Title:
McGill University Faculty of Dentistry
Division of Oral Health and Society
Date:

Signed on behalf of CBHSSJB

Name: Dr. Robert Carlin
Title: Director of Public Health
Cree Board of Health & Social Services of James Bay
Date: 14/01/2016

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Intervention and acknowledgement

Principal Investigator

I, Mary Ellen Macdonald, Principal Investigator, having read this Agreement, hereby agree to act in accordance with all the terms and conditions herein and perform any and all obligations incumbent upon me as a result hereof, and more particularly, I hereby agree to act in accordance with all the terms and conditions and perform any and all obligations provided herein as if I was a party mentioned in said articles and, further agree to ensure that all McGill University participants are informed of their obligations under such terms and conditions.

Name: _____ Date: 18 01 2016
　　　　　Signature

Principal Investigator

I, Susan Law, Principal Investigator, having read this Agreement, hereby agree to act in accordance with all the terms and conditions herein and perform any and all obligations incumbent upon me as a result hereof, and more particularly, I hereby agree to act in accordance with all the terms and conditions and perform any and all obligations provided herein as if I was a party mentioned in said articles and, further agree to ensure that all McGill University participants are informed of their obligations under such terms and conditions.

Name: _____ Date: 18 jan 2016.
　　　　　Signature

Principal Investigator

I, Jill Torrie, Principal Investigator, having read this Agreement, hereby agree to act in accordance with all the terms and conditions herein and perform any and all obligations incumbent upon me as a result hereof, and more particularly, I hereby agree to act in accordance with all the terms and conditions and perform any and all obligations provided herein as if I was a party mentioned in said articles and, further agree to ensure that all CBHSSJB participants are informed of their obligations under such terms and conditions.

Name: _____ Date: 13-01-2016
　　　　　Signature

Principal Investigator

I, Robert Carlin, Principal Investigator, having read this Agreement, hereby agree to act in accordance with all the terms and conditions herein and perform any and all obligations incumbent upon me as a result hereof, and more particularly, I hereby agree to act in accordance with all the terms and conditions and perform any and all obligations provided herein as if I was a party mentioned in said articles and, further agree to ensure that all CBHSSJB participants are informed of their obligations under such terms and conditions.

Name: _____ Date: 14-01-2016
　　　　　Signature

MEMORANDUM OF UNDERSTANDING FOR A COLLABORATIVE RESEARCH PROJECT

Project Core Team members' coordinates

Dr. Mary Ellen Macdonald
mary.macdonald@mcgill.ca

Dr. Susan Law
susan.law@mcgill.ca

Research coordination at McGill University
c/o Martine Lévesque
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Dr. Robert Carlin
Public Health Department- Cree Board of Health and Social Services of James Bay
robert.carlin@ssss.gouv.qc.ca

Jill Torrie
Public Health Department- Cree Board of Health and Social Services of James Bay
torrie.jill@ssss.gouv.qc.ca

Research Office of the CBHSSJB:
c/o Tracy Wysote
Public Health Department- Cree Board of Health and Social Services of James Bay
twysote@ssss.gouv.qc.ca

<u>Appendix L:</u> Youth Health Concept

Thematic analysis of the focus groups and interviews conducted with youth participants revealed the following themes to be associated with youth health and wellbeing.

A) Health as sports and physical activities in the community

Notably, when asked about their health, the first word that most youth (particularly the males, but also many females) expressed was sports:

> *"Health is hockey tournaments. Basketball tournaments. Sports tournaments. I guess… Being active and fun"*

Indeed, there are many sports tournaments and leagues organized in each Cree community and across Eeyou Istchee, which youth outlined as an important way to keep them moving:

> *"… If we want to have a tournament here, our recreation department in Nemaska organizes one, and then they contact all the recreation departments from other communities asking the teams to come play here… we have tournaments in the winter to keep us active."*

One youth coordinator observed how this youth generation's interest in fitness was different than what they experienced in their time:

> *"I've seen younger kids coming in [to the fitness centre], from 12 to 15, trying out the 5-pounders. I guess trying to, you know, be the same as the older teenagers going to the fitness… they wanna try that too. It's awesome to see. It wasn't really normal in my time, I would say, but now it is… I'm excited for them."*

Finally, one youth participant felt that most other youth equated health to physical activity and nutrition only, without recognizing other components:

> *"I think, I know that there are some youth who are interested in health and wellbeing. But most of them don't understand what it is. I think they believe health is just getting active and healthy eating, but it's more than that"*

B) Health as feeling calm

Participants also raised the importance of feeling calm and peaceful with one's inner thoughts. One youth coordinator noted that a quiet space can be difficult to find quiet in the community:

> *"Most people, especially in the community, live in houses where there's 5, 6, 7 people that live there... I think it's not always easy to find that quiet space to, to be just with yourself"*

Moreover, participants described how reaching mental tranquility is achieved by different people through different and personal mechanisms. One youth coordinator how they personally achieved calm through reading:

> *"Somewhere you can find peace and quiet and be alone with yourself... I think we need a place like that. Where you can just walk in, there's so many spots where you could just pick up a book, and start reading... be within your own thoughts."*

Other participants highlighted how traditional Cree activities helped them feel calm and at peace; hunting, fishing, beading, and snowshoeing were all described as therapeutic activities. As one youth coordinator put it:

> *"... I just wanna be outdoors and just... clear my mind. Just the sound of snow-shoes on the ice. Just the sound is amazing. It's the crack, it's the fresh snow..."*

Youth coordinators also stressed the importance of finding one's inner peace through exercise:

> *"We tried yoga at one point. And it wasn't that successful, I'll be honest. But... those are the kinds of things that will help the mind and soul... fitness and health is there to help how we think, how you deal with inner self. Finding yourself, or dealing with that inner self, to find the peace within you."*

C) Health as social gatherings with the community

Some youth participants also shared how they valued when the communities came together for events or traditional Cree holidays and events, and the particular effects on their mental resilience and happiness associated with fathering. One youth illustrated what they observed at these community gatherings:

> *"What I notice in the communities is that when people gather together, there's a lot of laughter and smiles. Everybody's having a great time. And doing that is also beneficial for the individual youth's health. Cause you never know when somebody's*

having a bad day or something, and they come to these events and they feel better

after."

Many youth participants expressed how the health was linked with being smart. One youth coordinator emphasized the need for youth to feel well in order to do well in school:

"I know we're talking about [health], but it's all connected you know. I think education should be more prioritized, emphasized… it goes together. If you're not feeling well, and you're not well, how do you expect to have good students?"

D) Health as being in touch with Cree identity and life

Moreover, youth participants described a "healthy" diet as consisting largely of traditional meats:

"What is healthy… eating a lot of meat or something. Moose, goose, a lot of the traditional meats. Yeah."

Most participants highlighted how understanding one's Cree culture and cultural identity was a fundamental component of their overall health:

"Culture is an important part too. You have to know where you come from in order to feel well…"

Moreover, one youth coordinator described their own connection with their Cree roots, and the importance of fostering Cree cultural identity when raising their kids healthy:

"For me, with my children, I easily could've got a job in the city… I feel like my kids would have better education [if I moved]. But in the end, home is health. I think it's more important for my kids to know where they come from… experience their culture, learn their language… to know who they are and where they come from. And, so, in the future when they leave to go further with school, they know that they'll be able to tell wherever they need, who they are and where they come from. And I feel that, you know, culture is definitely identity. It's a very important part of who you are."

The importance of cultural identity, and knowing who you are and where you come from, is described as important in the long-term, especially if their kids move out of the community; being able to understand yourself for yourself and others is an important aspect of health as described by this participant.

The Cree language was also underscored as an integral component of health; moreover, one youth coordinator observed how speaking in Cree can create an almost visceral connection with youth:

> "I know that a lot of our youth, when you do speak to them in Cree, you immediately attract them… You hit home when you speak your language. It's like when you call the French to come together, you use the French language! I think everybody's proud of their language. Even the French [laughs]."

Furthermore, one youth participant described how Cree cultural identity was such an important part of their overall identity when growing up, that they were bullied as a kid for not appearing to fully embrace that Cree identity:

> "I'm glad I got to see, got to experience, growing up here [in the community] and also having the city life. But of course, like, you have the kids that never left the community… I was bullied. They thought I tried to act white, just because I was more outgoing, different, and more like aware of both worlds"

Youth also portrayed the happiness that cultural activities brought them:

> "The community… they give us holidays, two weeks of holidays, for goose break and moose break… it's good times."

When describing hunting, one youth participant illustrated how this activity made them holistically well: health by hunting for healthy traditional meats, and health by developing respect for every part of the animal:

> "Hunting to get good food. Good food – like moose, goose, beaver… And you cook it, I mean you harvest it, you harvest the skin. The insides you eat them. Then you cook it. Yeah, it's healthy. You show respect to the animal, like you don't throw away the fur… you can use the fur for something…."

Similarly, another participant also described their experiences in the bush with their family and community as providing mental disconnection from social media, and requiring physical health:

> "Being back in the bush… you spend more time with your family. Like, you talk… without service of wifi… disconnected from some people, but you're connected with other people – whether you like it or not… and you're being active everyday – not a bad thing but… it's probably a good thing."

Finally, youth expressed how their own health was intertwined with the community's overall health, and was not necessarily an individual or biomedical phenomenon:

"[Health and wellbeing] is the state that you are individually and the state of the community. So um, I think when people talk about health, it is not necessarily just your own health, unless you go see a doctor… it's our health in general and the wellbeing of our people. And we have just so many events and gatherings that deal with health and wellbeing that's attached to social aspects of whatever issue that is"

Indeed, the notion of community wellbeing was often referred to, as one youth coordinator mentioned *"…I do pray for the community"*.

E) Health versus Miyupimaatisiiun

When discussing the differences and similarities between 'health and wellbeing' as a concept, versus Miyupimaatisiiun as a Cree concept, participants were of markedly divergent minds.

For some youth, the differences between health and Miyupimaatisiiun concepts were unclear; specifically, the concept of Miyupimaatisiiun was less familiar. Some youth claimed that they never heard of it, and others knew about it but did not know how to describe it:

"Miyupimaatisiiun means how you treat people… Or to care?... I dunno."

However, most youth described the concept in general as a good Cree life:

"Miyupimaatisiiun… doesn't it mean healthy?... It means our life. A good life."

Moreover, a few participants viewed health and Miyupimaatisiiun as essentially synonyms of one another, where Miyupimaatisiiun was simply the Cree word for health:

"Well, when [health is] translated in Cree, it's Miyupimaatisiiun. So… It's being health in all 4 aspects of your being… like the medicine wheel. You know you have your physical, your mental, your spiritual, your emotional. So… if you keep a balance of the four aspects, then it's… you know… you're Miyupimaatisiiun… it's pretty much the same. It's just the translation in Cree"

Some participants viewed Miyupimaatisiiun as being one step further than health. For one youth participant, while they viewed health as self-care, they viewed Miyupimaatisiiun not only caring for oneself but also others and the environment:

"Health and wellbeing is basically self-care. To me, Miyupimaatisiiun also means taking care of yourself… but also taking care of others and our surroundings… by loving yourself, others, and the environment. Or like, doing things we enjoy, encouraging and reminding other people to keep going or just complementing them, and cleaning our land. So if you want to take care of our land and people, we need to take care of ourselves first."

Accordingly, since conversations with the participating youth and youth coordinators did not reveal any necessarily substantial difference between the terms health and Miyupimaatisiiun, these two terms are used interchangeably hereafter for the purposes of this manuscript.

Youth's priorities for health change, while not the focus of this work, has also been synthesized and is included in Appendix B; namely, youth priorities include: A) more education needed; B) self-care first; C) more traditional culture; D) physical health as a precursor for general health; and E) Stopping the cycle.

A) More Education Needed*:*

Firstly, participants expressed a desire to incorporate more formal education on what constitutes health and wellbeing, including the particular Cree aspects and definitions of Miyupimaatisiiun, as part of the school curriculum. As one youth put it:

> *"...it would be great to see that health and wellbeing are being taught in the schools. So the youth and the kids will have a better understanding... Because when I was in highschool, I didn't really know what health was. I always thought it was just working out and drinking water and all that stuff. But when I went to college, I had a health class in my program, and I learned a lot. And I was really surprised... I think it would be great to see health classes in our Cree nation... to understand what health and wellbeing is, but also adding the Miyupimaatisiiun and the Cree way of life."*

Furthermore, participants described a particular lack of education surrounding young motherhood. One youth coordinator shared their anxieties regarding young mothers who may not be aware of the long-term implications of risky health behaviours during pregnancy:

> *"It scares me to think sometimes like teenage mothers they think it's okay to have a toke or smoke while they're pregnant, or drinking... it'll create another problem for them and the child most importantly in the future... sometimes I wonder how many people are actually diagnosed, like even people my age, how many people are diagnosed... Maybe they don't know they have FAS or some other mental disability because of... [sighs]. Sometimes I wonder those things"*

In addition, other youth coordinators stressed how there is a lack of understanding surrounding the health services offered to each community member in each community, and addressing this was important for the youth:

> *"...another challenge we're facing has to do with people leaving the communities to go in the cities and get treatments...a lot of them have no idea of what's going on with the Cree Health Board... two years ago...we went, it was called [conference name] and we had a whole PowerPoint on what services are offered in the community up north, and the Eeyou Istchee communities, and what kind of*

realities we're dealing with. So that was a good link… so they know about what the services are, so in terms of referring people and having good communication, that kind of bettered it. But there's a lot of work to do there too."

Also regarding healthcare services, one youth coordinator described a lack of understanding in the role of community health workers as middle-men in the Cree healthcare system, and the associated lack of trust that some youth have towards these workers:

"So right now… a lot of youth are being referred to the psychosocial department, due to behavioural issues… if you did something bad you're gonna see a community worker… it's kind of like a punishment… and that's why, we need to have more transparency, and explaining what the services are exactly"

B) Self-Care First*:*

Many participants emphasized the idea that one cannot help another before helping oneself. This idea was communicated below when youth discussed how respect was a part of being healthy:

Participant: "Miyupimaatisiiun also means like… words. Like, have respect.
Facilitator: Respect for others? Or for yourself?
Participant: It's always you that comes first. So both.
Facilitator: Why is it always you that comes first?
Participant: If you can't forgive yourself then you won't be able to forgive someone else. And if you can't respect yourself, you won't be able to respect someone else. It seems conceited, but still. Yeah."

Similarly, another youth felt it important to take care of oneself before being able to help not only other people, but also the land and environment:

"…if you want to take care of our land and people, we need to take care of ourselves first."

C) More Traditional Culture*:*

Participating youth and youth coordinators alike underscored the importance of continuing Cree culture education in order to keep youth healthy. For example, one youth coordinator described the importance of youth connecting with Elders to pass on

traditional knowledge, better appreciate traditional knowledge, and ultimately connect with that part of their cultural and Soul health:

> "I don't know if you know about Cree people, their babies, they wrap them in like this looks like a little burrito… that's the only way I can describe it to you [laughs]… they call it a moss bag, and then the baby's put in… it's an important part of Cree culture. We were trying to get a program going where, new mothers, first time young mothers… for them to have a sewing night and get more Elders involved. They would be sitting with Elders, and making like a little baby hat… and it would give the Elders and also the new young mothers an opportunity to connect and you know, pass teachings… cause there's so many teachings that are, now, like they're not… they're overlooked."

Youth also shared their desires for more traditional activities. In general, youth expressed that they wanted more traditional Cree outdoor activities, especially winter activities, including snowshoeing, sliding, skiing, skidoo, hunting, snowboarding, skating, and "*learning outdoor stuff*". One youth also described how they wanted to learn traditional Cree fiddle dancing to connect with their parents:

> "I don't know how to dance but I would like to learn. Like fiddle dance… my parents would remember."

D) Physical Health as Precursor*:*

While most youth initially defined health through the physical aspect, many recognized that improving physical health can lead to improvements in all other aspects, including emotional health. As one youth coordinator put it:

> "With health-related activities, there's definitely an increase [in participation]… I think people recognize that there is a need to improve our health overall. I think people are more aware of the fact that, you know, in that physical health you're doing the things that make you feel happy. You're in a better state, I think, when you're just physically active"

Another youth coordinator commented on their experience helping a community member improve their mental and emotional health by first working on their physical activity:

> "We decided to put up this project in our gymnasium… to try to complete the 8-week Insanity training program. We had people from various backgrounds, some

*who were nearly 300 pounds plus. And there was this one lady who was very, you
know, optimistic after two weeks, and she said: 'You know I'm not so tired
anymore. I can breathe… I feel like I can really breathe. I'm more mobile at
home, I have energy throughout the whole day... which wasn't there previously'. If
everybody knows that – if you move, it makes you feel happy… there's a difference
you see. It improves everything around you."*

Similarly, many participating youth described their feelings of excitement and joy when
playing sports, again relating physical activity to mental and emotional health:

*"I like playing hockey… I just love that feeling when I score. I'm like 'oh damn,
did I just do that?'. A little excitement. I never actually feel that outside. Mostly
just bored without hockey."*

Youth also expressed how sports tournaments also tap into the social components of their
health, describing tournaments as opportunities to see and make friends:

"It's fun, playing with friends out of town. Meeting friends."

E) Stopping the Cycle*:*

Many youth coordinators highlighted how one unhealthy behaviour can lead to another
unhealthy behaviour, and that health challenges are often connected. One youth
coordinator described the link between substance abuse and diabetes:

*"I was involved with the Cree Health Board under the National Native Alcohol
and Drug Abuse Program, and from there we were able to go into classrooms and
discuss the effects of alcohol and drugs. I remember a lot about… that it could
cause diabetes in some ways too. In the community there was so much sugar that
they would mix with the alcohol… people were gaining lots of weight… we were
kind of discussing with the youth how that affects you. In your drinks, there's so
much calories in beer and wine and all that stuff."*

Another youth coordinator also observed how the abuse of different substances often
coincides:

*"I know [Cree Health Board] did a study I think with Cree School Board… And it
showed even there the numbers… the numbers of substance abuse, drugs and
alcohol… they all coincide somehow."*