EVALUATION OF THE HEALTH AND SOCIAL SERVICES SYSTEM IN NUNAVIK: THE USERS' PERSPECTIVE

AS PART OF THE 2021 NUNAVIK REGIONAL CLINICAL PLAN

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RÉGIE RÉGIONALE DE LA NUNAVIK REGIONAL
SANTÉ ET DES SERVICES BOARD OF HEALTH
SOCIAUX DU NUNAVIK AND SOCIAL SERVICES

Nunavik Regional Board of Health and Social Services
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Régie régionale de la santé et des services sociaux du Nunavik
P.O Box 900 // C.P 900
Kuujjuaq (Québec) J0M 1C0
Toll-free // ᐊᑭᖃᙱᑐᖅ // Sans frais : 1 844 964-2244
Phone number // ᐅᖄᓚᐅᑎᒃ // Téléphone : 819 964-2222
info@sante-services-sociaux.ca
www.nrbhss.ca

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“The Inuit must become the architects of their society and their institutions. They themselves must develop the plans and determine the content of the region’s programs and services. The professionals and management personnel arriving from outside the territory are part of the Inuit toolkit. Their purpose must be to support us in pursuing our objectives.”

—Minnie Grey,
Executive Director,
NRBHSS

A Letter from the Executive Director

It is with great pride that we are publishing this report, which offers a critical look at the perspectives, thoughts and propositions put forth by the users of the healthcare system in Nunavik: users like you and I, as well as our families, Elders, youth and communities, all of whom have a distinct experience of the health and social services provided to us in Nunavik and at times in Montréal. Respecting these experiences, and the knowledge with results for them, are at the core of improving the quality and relevance of the care offered to us.

Indeed, it is only through the recognition of the value of the users' knowledge and perspectives that the managers and professionals who run our healthcare system will be able to build a solid partnership with the Nunavimmiut. This is one of the main objectives of this document: to provide access to the perspectives which make Nunavik realities both collectively and particularly unique.

A second objective of this document consists in acknowledging the significant contribution of the Nunavimmiut, their unique way of engaging with our healthcare system. As Inuit, we have our own way of looking at health, in all of its forms: *ilusiq* (physical health), *qanuinngisiarniq* (well-being) and *inuuqatigiitsianiq* (the quality of our relationships). This way of looking at health is a key component of our experience of the healthcare system, and the propositions we make to improve it.

This document's third objective is for us, managers and professionals of the Nunavik health and social services system. Relying on our service users' knowledge and viewpoints should encourage us to take action in partnership with users and their families in order to initiate the changes which are needed for us to better achieve our mission.

Promoting improvements to the health of the Nunavummiut, by whatever means and measures deemed appropriate, is indeed the mission entrusted to the Nunavik Regional Board of Health and Social Services under the James Bay and Northern Québec Agreement. A more rigorous consideration of the Nunavik's users' viewpoints, values, life goals and of what brings them genuine well-being, clearly represents one of the best ways of fulfilling our responsibilities towards the population we serve.

Minnie Grey
Executive Director,
Nunavik Regional Board of Health and Social Services

Acknowledgments

We would like to begin by expressing our sincere thanks to all the Nunavimmiut who participated in the paper and online survey, conducted in the spring 2018. We wish to also thank all the participants in the interviews held in the communities of Ivujivik, Inukjuak, Kangiqsujuaq, Puvirnituq, Tasiujaq and Kuujjuaq. The results of the survey and interviews combined enabled us to hold focus groups with Inuit form all Nunavik communities, and we are grateful to all of them for their invaluable contribution to the results.

We would also like to extend our gratitude to the municipal councils of Ivujivik and Inukjuak, the Kangiqsujuaq Landholding Corporation, the day centre for new mothers of Puvirnituq, the municipal council and CLSC of Tasiujaq, and the municipal council of Kuujjuaq and Katittavik, which allowed us to use their offices to hold interviews.

We were touched by everyone's patience as well as for accepting to contribute to this process; many have shared their disillusionment of having been repeatedly asked for their opinions on these matters, without ever seeing any real change to the situation afterwards.

Task Force

SUPERVISION

Minnie Grey
Executive Director, RRSSSN

Fabien Pernet
Assistant to the Executive Director, NRBHSS

DESIGN AND RESEARCH

Annie Baron
Advisor for Cultural Safety, Executive Management, NRBHSS

Amélie Breton
Planning and Programming Officer, Users' Perspective, Executive Management, NRBHSS

Sébastien Dubé
Analyst, Coordinator of Quality, Evaluation, Performance and Ethics, NRBHSS

RESEARCH SUPPORT

Mathilde Dherissard
Advisor, Information Management, Clinical-Administrative Component, NRBHSS

Christian Brunet
Consultant, Nunavik Regional Clinical Plan, NRBHSS

TEXT

Amélie Breton
Planning and Programming Officer, Users' Perspective, Executive Management, NRBHSS

With the valuable collaboration of
Faisca Richer
MD, MSc, FRDPC, Independent Consultant

VISUAL CREDITS

Isabelle Gingras-Breton
Graphic Arts

Amélie Breton
Photography

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Executive Summary

What were the main objectives of this evaluation?

- This evaluation primarily sought to:
  - Accurately document the Inuit perspective of Health and Social Services provided for them;
  - Better understand the improvements Inuit would like see to ensure a more accurate response to their needs.

What was the context of this project?

- This project was conducted as part of the elaboration of the Nunavik Regional Clinical Plan, so that service planning puts greater emphasis on the users' perspective.

What was the methodology of this assessment?

- A mixed assessment methodology was used, combining the results in three phases:

  1. An online survey among the population;
  2. Comments gathered during individual interviews;
  3. Group interviews.

What were the principal results of the population survey?

- The expectations of most respondents appeared to be relatively well met when it comes to the health care system, namely in terms of the users' perspective of the referral system, user-provider communication, as well as safety and cultural safety of the services;
- However, a considerable number of respondents reported believing they do not have the same level of access to care as the residents of other regions of Québec.

What were the principal findings of the individual interviews?

- The relational aspect of health (Inuuqatigiitsianiq) was reported as central to the interviewees' vision of health , and this appeared to extend to their attachment to the traditional territory, as well as to the quality of the trust established between users and caregivers.
- The effects of colonialism were stated as having greatly affected the population's state of health in the past. Its consequences are perceived as the main source of mental health issues, addictions and violence, fundamentally affecting the population's health to the present day.
- Aspects of the health care system which are most appreciated include the pertinence and effectiveness of services, the fact that they are provided free of charge, as well as the fact that they provide access to qualified personnel; on the other hand, aspects of the system most often identified as requiring improvement were the users' feelings of insecurity, the lack of cultural safety of services, and the gaps in the continuity of care.

Of all the topics identified by the participants of Phases 1 and 2, which ones were the priorities of the focus groups (Phase 3)?

- The exercises of establishing priorities led to the following order of issues:
  - The poor access to mental health services and the urgent need for healing;
  - The importance of promoting healthy lifestyles for children and young families;
  - The improvement in the attitude of workers from outside the territory and need for training for both Inuit and non-Inuit personnel;
  - The need for addressing issues related to the quality of patient care services and improving the retention of experienced and qualified personnel.
- Several solutions were proposed in relation to these issues, including:
  - Improving the access to mental health and addiction services, as well as the possibility of hiring more natural helpers, and psychosocial workers;
  - Reinforcing cultural safety, equity in access, continuity, quality and safety of services;
  - Developing more community-based services providing support to families;
  - The strategy most often mentioned as the number one priority for action was the increase in the number of Inuit caregivers.

What are the top three recommendations based on the results of this evaluation?

1. Improving access to healing and mental health services

- The intergenerational impacts of Nunavik colonial past on the health of the Inuit population are still strongly felt today; further, services are deemed clearly insufficient to adequately respond to the needs of individuals suffering from the psychological distress, mental health and addiction problems resulting from the effects of complex trauma.
- There is thus an urgent need to set up a full continuum of mental health services , including holistic healing services, prevention and promotion programs in the area of mental health, addictions, and support to young families, as well as front-line clinical services for detection, diagnosis and care for common psychosocial difficulties.
- Hiring, training, and adequately supporting Inuit staff will enable deployment of services accessible at all times, and in all the communities, while ensuring interventions are consistent with Inuit values and practices.

2. Reinforcing the cultural safety of services.

- Considering the importance of relationships in the definition of Inuit health and wellbeing, we understand why the creation of a relationship of trust between caregiver and user is essential to the Inuit users' perception of what constitutes quality of care; for many, the attitude of non-Inuit workers need be characterized by empathy, respect and openness toward the Inuit culture and the communities' local realities.
- Improvement of cultural safety of services will therefore require the implementation of multiple, yet complementary strategies, including:
- The reinforcement of the key role played by Inuit staff in the direct service delivery, whether as professionals, paraprofessionals or natural helpers;
- More attention need to be given in the selection and training of non-Inuit workers, to ensure they understand and value the principles of decolonization, self-determination of Inuit and cultural safety of services.

3. Developing a complete continuum of care in Nunavik.

The people consulted all mentioned that they would like to see more services delivered in their community, not only to limit transfers to the South for health reasons, but also to improve the efficiency of follow-up and the quality and continuity of services within the communities.

- To do so, two complementary strategies should be applied:
- Improving the availability of service in the region, including the full scope of basic, primary health care services, and the development of some of the most commonly used specialized services;
- Increasing the support to users in navigating services at all levels of their trajectory of care, ensuring continuity of information between various service providers in the South and in the region.

Introduction

What are the key messages of this section?

- The present report primarily aims at better documenting the Inuit population's perspectives of the health and social services provided to them, as well as of the developments which would be required for the health care system to better respond to their needs.
- This work was conducted as part of the Nunavik Regional Clinical Plan, so that the services thus planned put the users' perspective in their decision making.
- This evaluation was carried out over a period of two years, and was based on a mixed methodology combining the quantitative data of an paper and online survey with the qualitative information gathered during individual and group interviews conducted in various communities.

Nunavik: A Unique Health Care Context

The Nunavik Regional Board of Health and Social Services (NRBHSS) has the legal mandate of planning, implementing and monitoring the quality of health and social services and programs in Nunavik. As is the case elsewhere in the country, these services must respond to recognized criteria of accessibility, safety, and quality of the users' experience.

Meeting these performance criteria is a complex undertaking in Nunavik, not only because of the precarity of all remote health care systems, but also (and perhaps mostly) due to the consequences of the region's colonial past on the creation of a very peculiar context of care where the Inuit population is being served by a majority of non-Inuit service providers.

Indeed, it is widely recognized that cultural differences between caregivers and users tend to affect the quality and accessibility of services being provided, the health system often reflecting the social and intercultural power relationships of its surrounding society.[1] The present work thus aimed primarily at documenting the Inuit users' perspective of the health and social services currently being provided in Nunavik, as well as their suggestions for improvement. This process was an integral part of the elaboration of the Nunavik Regional Clinical Plan, as a way of integrating the preoccupations and priorities of the Inuit population into the planning and development of the future health care system. Ultimately, it is hoped that this process can contribute to the improvement of the cultural safety of health care in the region, which in turn should help improve the health and wellbeing of all *Nunavimmiut*.

1 Truong M, Paradies Y, Priest N. Interventions to improve cultural competency in healthcare: a systematic review of reviews. BMC Health Serv Res. 2014;14:99

Major Consultations on Health and Social Services in Nunavik

The overall examination of health and social services in the context of the Ilusilirinirmi Pigutjiutini Qimirruniq clinical project undertaken with the participation of all the network's partners in 2009, aimed at contributing to the identification of the regional priorities for developing and improving health services on the Nunavik territory. The Nunavik steering committee on health and social services, composed of more than 70 representatives of some 30 organizations and associations, thus pointed out the problems that must be tackled urgently by the region's actors and their provincial and federal partners, to enable *Nunavimmiut*[2] "*to begin or continue their journey towards healing.*"[3] At the time, they affirmed that "*the improvement of Inuit well-being and the reduction in health-related social inequalities will depend on the commitment of all actors (governments, organizations, communities, families and individuals) to resolve the problems encountered by the Nunavik population*."[4]

Parnasimautik, the broad consultation carried out a few years later among the entire Inuit population of Nunavik in 2013 in response to Plan Nord,[5] also contributed to the formulation of a collective representation of development "*according to Inuit culture, identity, language and traditional way of life so as to protect them now and enhance them for the future*."[6] This emphasized, among other things, the need for the government's recognition of the Inuit as a distinct people with their own history, philosophy, needs and priorities.[7]

Recently, the 2019 Public Inquiry Commission on relations between Indigenous Peoples and certain public services in Québec (Viens Commission) also criticized the limited acceptability and pertinence of many of the provincial services when it comes to adapting and responding adequately to the needs of First Nations and Inuit users.

> *"[…] the existing structures and processes show an obvious lack of awareness of the social, geographic and cultural realities of Indigenous people. The result: in spite of certain efforts at adaptation and a clear will to foster equal opportunity, many existing laws, policies, standards or institutional practices constitute sources of discrimination and inequity, to the point of seriously tainting the quality of the services offered to First Nations and Inuit."*

All the above-mentioned consultations and inquiries have come to the same conclusion: improvement of the quality of the heath care and services provided to Inuit and other Indigenous populations in Quebec must become more culturally safe. Concretely, this means granting Inuit users a more important place at the time of planning programs and services, as it is essential to create spaces where users have the capacity to act, transform and influence the services they receive.

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2 ***Nunavimmiut*** is the demonym of "Nunavik inhabitants."

3 Parnasimautik report, p. 84.

4 Nunavik Regional Public Health Action Plan 2016-2020, Nunavik Regional Board of Health and Social Services. Québec, 2017, p. 42.

5 Plan Nunavik, submitted in 2010, is a document produced as the Inuit response to the Québec Government's Plan Nord. Plan Nord, whose goal is to promote the mining, energy, social, cultural and tourism potential of the Québec territory north of the 49th parallel (https://plannord.gouv.qc.ca/fr/). Facing the urgency of participating in the discussion, the Inuit did not have the time to carry out public consultations before producing Plan Nunavik. However, a change in government slowed down the projects under Plan Nord and gave the Inuit the opportunity to conduct Parnasiamautik, the broad public consultation.

6 Parnasiamutik report, p.1.

7 Parnasiamutik report, p.81.

The Nunavik Regional Clinical Plan

The Nunavik Regional Clinical Plan is a large-scale project aimed at planning the long-term development of the region's health and social services. Although the *MSSS*' standard structure for developing a clinical plan does not yet include integration of users' perspective, the NRBHSS decided to adopt a users' perspective approach to their clinical plan elaboration process, as an important opportunity to foster cultural safety of the services to be provided. It was felt that the objective of improving the Nunavik population's health could only be attained by establishing true collaboration with users, making them effective partners at each phase of restructuring the health services provided for *Nunavimmiut*.

Thus, the project's results presented here contributed greatly to the development of all the components of the Nunavik Regional Clinical Plan, and helped identify the cultural safety guidelines to be prioritized. This process was intended as a first step toward the establishment of partnership with the users and a way of ensuring Inuit participation at all levels of the clinical plan's process. The project enabled the collection of "baseline measurements" in terms of cultural safety and assessing the discrepancy between Inuit expectations and the the quality and accessibility of the current health care provided throughout the Nunavik territory.

Overview of the Present Report

The project used a mixed methods evaluation design, combining the results of several consultation methods of the Inuit population of Nunavik over a two-year period, from 2017 to 2019. A quantitative survey was first conducted, followed by individual and group interviews (focus groups), which results are synthesized in the present.

After a brief overview of Nunavik's population and organization of care, the evaluation's main findings will be presented, followed by a list of potential course of actions and strategies, which could be prioritized to improve the cultural safety of services for the region. The information summarized here allowed to develop a more profound understanding of the Inuit's view on health and well-being, and how is perceived the cultural safety of the services available to them. It is hoped that this understanding will be useful to enhance service development in the short, medium and long term, so that health care can better respond to the needs, values, culture and realities of all *Nunavimmiut*.

General overview of Health Care in Nunavik

What are this section's key messages?

- The existing health and social services system in Nunavik is characterized by the challenges and limits usually observed in other Nordic and remote regions of the country, namely, difficulties in accessing basic primary health care, as well as frequent transfers outside the region to cover the lack of specialized services in the region.
- In addition to the challenges related to geographic isolation, is added many other historical, political, social and cultural barriers which can affect the health care system's capacity to adequately respond to the health concerns of the region's Inuit clientele.
- The principles of cultural safety anchored in the users' perspective approach, were hence used as theoretical frameworks to develop the current evaluation's methodology.

Historical Background

In 2018, Nunavik's population was estimated to be approximately 14 000, 90% of which is Inuit.[8] The population is spread across 14 communities along the coasts of Hudson Bay and Ungava Bay. Since the signature of the *James Bay and Northern Québec Agreement* (*JBNQA*), all health services in Nunavik are considered to be under provincial jurisdiction, with the NRBHSS ensuring regional governance of planning, management and monitoring of the services offered in the region.

Historically, the *JBNQA* ratified a geographic subdivision of service organization: the Ungava Bay sector, which had historically been served by the provincial government since the 1960s, developed its service corridors toward Quebec City and Montreal; the Hudson Bay sector, on the other hand, had mostly been served by the federal government and organized its service corridors toward Moose Factory (Ontario).

Health care Services in the region

To this day, the service provision in Nunavik remains divided into two subregions, with the Ungava Tulattavik Health Centre (UTHC) serving the seven Ungava communities (from Kangiqsualujjuaq to Kangiqsujuaq) and the Inuulitsivik Health Centre (IHC) providing services to the seven Hudson communities (from Kuujjuaraapik to Salluit, along the coasts of Hudson Strait and Hudson Bay). The region's two hospitals, which were built in the 1980s, are located in Kuujjuaq (UTHC) and Puvirnituq (IHC) .

8 Statistics Canada. Estimations démographiques annuelles (régions infraprovinciales, janvier 2021). Adapted by the ***Institut de la statistique du Québec*** and Statistics Canada. 2017. Nunavik Region [Administrative Health Region, December 2017], Québec and Alberta [Province] (table). Census profile, 2016 census, product nº 98-316-X2016001 in Statistics Canada's catalog. Ottawa. Circulated November 29, 2017.

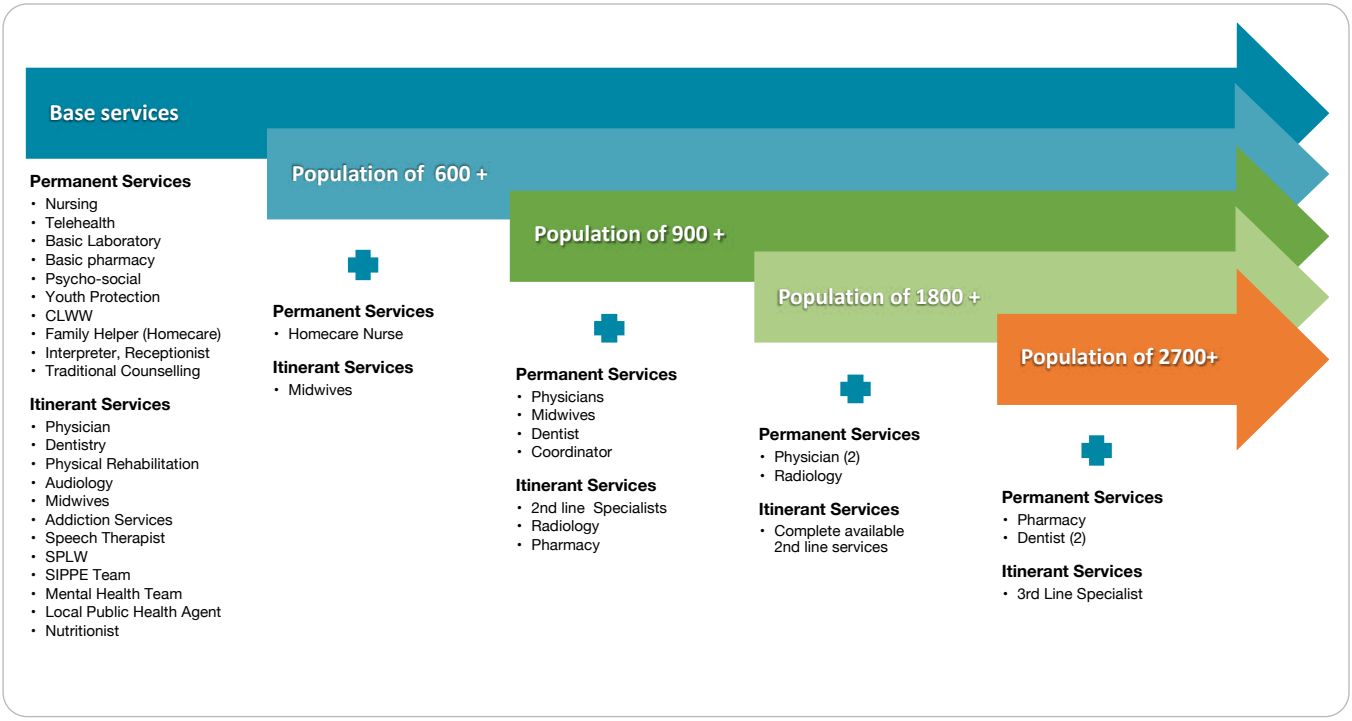

Figure 1: Distribution of services in CLSCs according to population density, Nunavik

As shown in figure 1, the other communities are served by CLSC point of services,[9] delivering primary care nursing services as well as professional services provided periodically by physicians, dentists, midwives, audiologists and so forth). Communities which have a population of more than 600 inhabitants also have access to additional permanent services (such home-care nurses, and midwives, for example). In communities where the population reaches 900 inhabitants, other services are added (such as the presence of a permanent physician, dentist and coordinator, as well as regular specialists' visits , including radiology technologists, pharmacists, etc.)

Thus, all the villages have an offer that follows this logic of distribution of services according to population size (Table 1) In Kuujjuaq, where 15% of the population reside, users have access to the most complete range of services.

Table 1: Population density, by village and coast, Nunavik, 2018 (ISQ) and level of services offered

HUDSON	Population	Level of services	UNGAVA	Population	Level of services
Salluit	1599	900+	Kangiqsujuaq*	991	600+
Ivujivik*	451	Basic	Quaqtaq	426	Basic
Akulivik	666	600+	Kangirsuk	586	600+
Puvirnituq*	1879	1800+	Aupaluk	215	Basic
Inukjuak*	1846	900+	Tasiujaq*	392	Basic
Umiujaq	472	Basic	Kuujjuaq*	2791	1800+
Kuujjuaraapik	709	600+	Kangiqsualujjuaq	991	600+

9 Still commonly referred to as nursing stations, these points of service increasingly offer a broadened range of local services.

Frequent Transfers

For access to many types of health care and services, including front-line services, *Nunavimmiut* must frequently travel or be evacuated by air to the Nunavik hospital serving their village or, if the situation permits, wait until a visiting specialist arrives to provide services. If the region's two hospitals are unable to provide the necessary services, particularly specialized care and services, users have no choice but to travel to Montreal to receive care.

For access to many types of health care and services, including front-line services, *Nunavimmiut* must frequently travel or be evacuated by air to the Nunavik hospital serving their village or, if the situation permits, wait until a visiting specialist arrives to provide services. If the region's two hospitals are unable to provide the necessary services, particularly specialized care and services, users have no choice but to travel to Montréal to receive care.

With a population that has nearly tripled since construction of the northern hospitals in the 1980s, those hospitals are currently unable to house new equipment and provide access to specialized care and services. Moreover, as the Nunavik non-insured health benefits (NIHB) program funds the transportation of Inuit beneficiaries of the *JBNQA* so they can access health services outside Nunavik, the development of these services has tended to focus on Montreal rather than Nunavik.

Thus, in fiscal 2018-2019, the Nunavik institutions reserved close to 22 000 air tickets so their users could access the health care they required, whether in Nunavik or in Montreal. To these, should be added the tickets for escorts (people traveling with the users needing support), as well as those for specialists visiting the North.

Besides the related high and constantly rising costs, such travel is particularly demanding on the patients, who find themselves distanced from their families and community. For them this means having someone care for their children for the entire period of hospitalization, losing considerable income and sometimes outright losing their jobs. To top things off, they often end up alone during a period of uncertainty and vulnerability. They are required to deal with their health condition without the support of loved ones, manage their situation thousands of kilometres from home and the support their community can provide, and communicate in a language in which they are not fluent and in settings of a culture with which they are not necessarily familiar and whose values and medical practices are often very different from Inuit values of health and well-being.

In spite of the presence of the Ullivik[10] in Dorval, which provides lodging as well as transportation and interpretation services for patients in Montreal to receive health care, users often find themselves in a situation of uncertainty. Translation and transportation services are not always fully available when the need arises, and the personnel providing health care and services are not necessarily aware of the reality of *Nunavimmiut* and the cultural barriers they face. All these factors affect the accessibility of care, which has consequences on the users' satisfaction and assiduity for appointments and, ultimately, their state of health.

Although one of the NRBHSS' mandates is to provide equitable access to health and social services for all *Nunavimmiut*, the context is such that barriers—geographic, economic, linguistic and cultural—considerably reduce the accessibility of the service supply, both within and outside the region. These barriers and their consequences on accessibility are difficult to accept for the users, who see great inequality compared to the health care and services developed elsewhere in Quebec.

10 Ullivik is a residential centre for lodging users visiting Montreal to receive health care not available in Nunavik. Costs for Ullivik are fully reimbursed under the NIHB program.

"It is devastating to anyone who must leave their family to be close to medical services, but an Inuk who leaves their family on a permanent basis because they must be near a hospital in order to receive kidney dialysis must endure heartbreak because of the separation."

—Parnasimautik Report, p. 62

Improving Nunavik Users' Experience: Theories and Promising Models

The users' Experience of Health Care: Essential to the measurement of Health Systems performance

Although the improvement of health is one of the primary objectives of any health system, this central goal cannot be achieved to the detriment of equity and reactivity to the expectations of the population served. Indeed, when services do not meet users' expectations of equity, respect and dignity, the users will tend to rely on them as last resort, hence creating delays in access which could in turn hinder the capacity of the services to improve their health.[11]

Thus, the quality of the users' experience cannot be considered an "optional" health care attribute, one that may be desirable but not essential; rather, we must understand that, because of its direct link to service accessibility, the users' experience is intimately tied to all the other elements of health system's performance.[12] As can be seen in the figure below, there are in fact several factors affecting service accessibility throughout users' care pathways, many of which are beyond the users' control but rather are dependent on the health system's capacity to respond to users' needs.[13]

11 https://www.who.int/whr/2000/en/whr00_ch2_fr.pdf?ua=1.
12 Murray CJ, Frenk LJ, World Health Organization. Global Programme on Evidence for Health Policy. A WHO framework for health system performance assessment / Christopher J. L. Murray, Julio Frenk. World Health Organization, 1999. https://apps.who.int/iris/handle/10665/66267.
13 Levesque J-F, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. Int J Equity Health. 2013; 12(1):18.

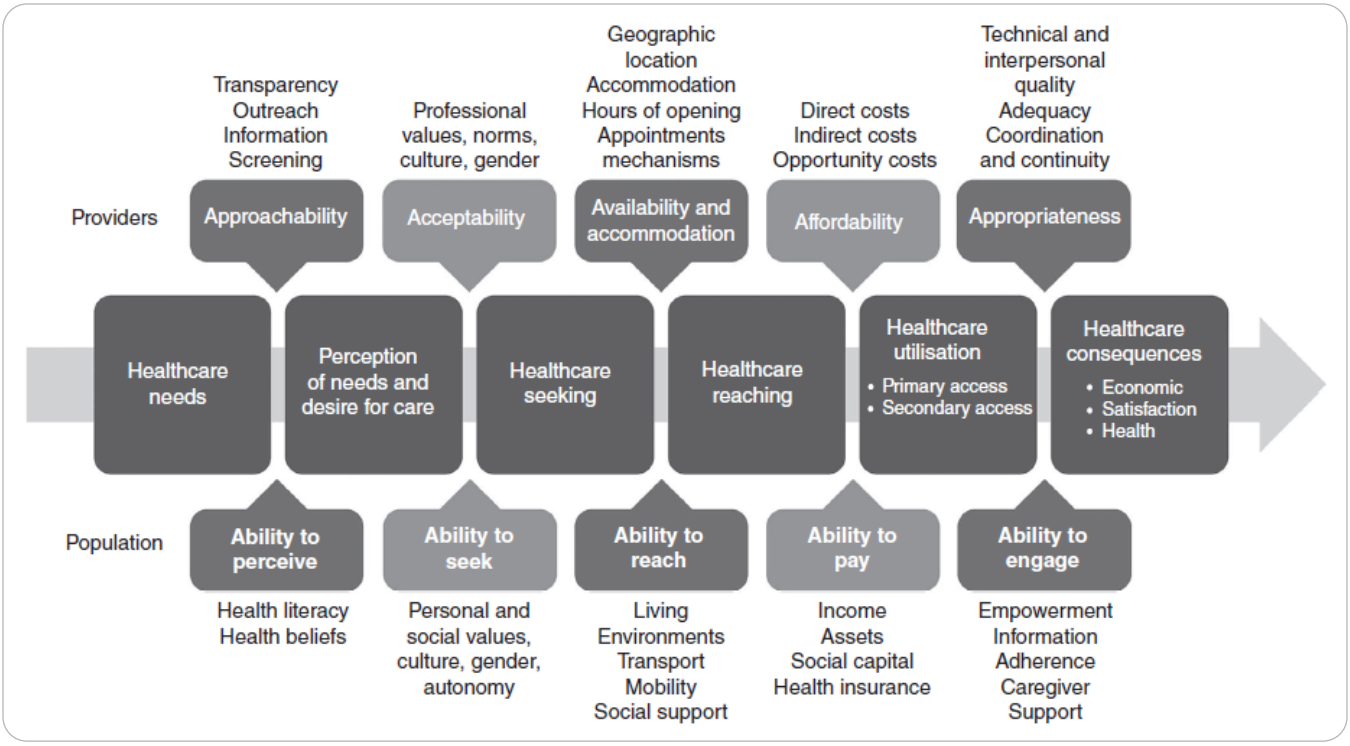

Figure 2: Access to health care: a conceptual framework (adapted from Lévesque et al. 2013)

This model reminds us that, beyond the effect of geographic distance on service availability, several other factors influence access to services for users in remote regions, such as whether users' perceive services as efficient, useful, and pertinent.[14] On the other hand, the model also illustrates how the obstacle of distance can be easily mitigated by providing transportation for example,[15] or supporting[16] families in providing informal care.[17] Furthermore, this model confirms the importance of many of the health care access barriers which were reported in the *Parnasimautik* consultation, including the high personnel turnover rate, and the lack of cultural awareness of the caregivers from outside the region.

It therefore appears that this model can (at least in part) help us better understand the reality experienced by many Nunavik users when trying to navigate the complexities of our health care system.

The models described above therefore apparently reflect the reality experienced by Nunavik users to a certain degree. Many research projects have also demonstrated that engaging users of remote or isolated regions in evaluation of the health-care system fosters consistency between the service supply and the users' expectations and thus raises their satisfaction with the care received,[18][19] their compliance with treatment and the feeling of having access to a better quality of life.[20]

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14 Example in Appendix 1: Service Trajectory gives an idea of the complexity of the users' trajectory and the necessary perseverance to obtain the health services their condition requires.

15 Field K, Briggs D. Socio-economic and locational determinants of accessibility and utilization of primary health care. Health and Social Care in the Community, 2001; 9(5): 294-308.

16 Richards H, Reid M, Watt G. Socioeconomic variations in responses to chest pain. BMJ 2002; 324: 1308-1310.

17 Hanlon N, Halseth G, Clasby R, Pow V. The place embeddedness of social care: restructuring work and welfare in Mackenzie, BC. Health & Place 2007; 13(2): 466-81.

18 Hadorn D. The role of public values in setting health care priorities. Social Science and Medicine, 1991; 32(7): 773-781.

19 Wensing M, Jung HP, Mainz J, Olesen F, Grol R. A systematic review of the literature on patient priorities for general practice care. Part 1: description of the research domain. Social Science and Medicine, 1998; 47(10): 1573-1588.

20 S Wong, S Regan. 2009. Patient perspectives on primary health care in rural communities: effects of geography on access, continuity and efficiency. Rural and Remote Health 9: 1142 (online), 2009. Available from: http://www.rrh.org.au.

That said, it is relevant to add to these models an element of complexity to ensure better response to the health needs and the territorial, social and cultural realities of Nunavik. As a matter of fact, this would involve taking the significant historical, political, social and cultural roots into account in the process of decolonization of the policies, systems and institutions undertaken in Nunavik.

The Concept of Cultural Safety

The concept of *kawa whakaruruhau* (cultural safety) first saw light in New Zealand in 1989; its directives were drawn up in 1991 by Irihapeti Ramsden, a Maori nurse. Cultural safety places emphasis on self-reflection as repository of culture, on the historically significant social and political influences on health practices, and on their impacts on the development of caregiver-user relations that lead to trust and respect.

In Nunavik, initiatives aimed at improving the cultural safety of care have been under way for quite some time already. In the context, cultural safety means that non-Inuit health care professionals provide services in a way that takes into consideration Inuit population's life experiences, worldview, as well as the impacts of Nunavik's colonial past on the political and social struggles faced today. This may seem complex but, overall, it means seriously listening to the users, treating them with empathy, and respecting and recognizing their uniqueness.

Developing this attitude of humility and openness requires that caregivers' demonstrate willingness to learn about Inuit history and contemporary realities, and establish genuine relationships of trust with clients. Cultural safety thus excludes any action that diminishes, belittles or weakens Inuit cultural identity or personal well-being. It is a multistep learning process and requires an effort on the part of caregivers to ensure users feel comfortable when consulting them, such that evaluation of the level of cultural safety of a service received is entirely and exclusively up to the users.

Creating an environment of culturally safe health care requires the presence of certain prerequisite conditions, or steps, through which the caregiver's perspective evolves from "I" to "we."

1. Cultural Awareness:

Learn to recognize that there is a difference between persons of different cultures.

2. Cultural Sensitivity:

Learn to recognize that this difference is legitimate, that one's own realities are no more valuable than those of others and have an impact on how one treats others.

3. Cultural Competency:

Use one's knowledge and skills to adopt an attitude of openness and to listen to the needs of the person one is trying to help. Seek strategies that enable a better response to the need, the life project of the person one is supporting.

4. Cultural Safety:

Cultural safety is the result of an educational process and gives a voice to those receiving the service, so they themselves can evaluate whether the service is culturally safe or not.

Whereas cultural awareness, sensitivity and competency are skills caregivers can acquire through training or field experience,[21] the notion of cultural safety involves a change in paradigm: a sharing of power to act on the situation. It requires integration of the users' point of view, not only their experiential knowledge but also their cultural depth, as force for change within the organization. According to the Health Council of Canada, cultural safety means that Indigenous persons feel they can trust their caregivers because of their efforts at cultural competency.[22] The notion of cultural safety therefore means enabling the Inuit to recover this faculty of self-determination lost during the colonial enterprise and the development of the health system in Nunavik. Among other things, they must recover the power to assess whether the service is culturally safe or not and the power to guide the changes in practice necessary to improving the services destined for them.

The IQI Model for Health

Figure 3: Inuit IQI model of the determining factors of health

The NRBHSS uses a model for health based on Inuit knowledge. The model selected was developed in a process of close collaboration with *Nunavimmiut* over several years. Consolidated with the data gathered under the community-health component of the 2017 *Qanuilirpita* health survey, the IQI—Ilusirsusiarniq, Qanuingngisiarniq, Inuuqatigiitsianiq—model is centred on Inuit knowledge, concepts and methodologies and enables assessment of a community's health in a culturally relevant manner.[23]

21 Brascoupé and Walters 2009, CCS 2012, ONSA 2008, Ramsden 2002, Wepa 2005.
22 Health Council of Canada 2012:5.
23 Fletcher, Christopher. Qanuilirpitaa? Nunavik Regional Health Survey, Community Component Report, Definition of an Inuit Cultural Model and Social Determinants of Health for Nunavik.

According to the model, there are three primary categories in the concept of health and well-being in the Inuit experience (Figure 3):

1. **Ilusirsusiarniq:** Closely linked to physical health, but its meaning is rooted in the sense that "things take their destined form," a conceptualization of health at once open to the difference between bodies and peoples and to a spiritual causal agent without origin;
2. **Qanuingngisiarniq:** Refers to a feeling of well-being, satisfaction, free of worry and pain. The term is often translated as "well-being" in English, but it encompasses a broader existential field that can be mental (avoiding worry), physical (feeling comfortable) and social (sharing joy with others);
3. **Inuuqatigiitsianiq:** Refers to relationships between persons sharing a place. An important aspect of health for the Inuit, the quality of relationships with family, friends, neighbours and community members (including non-Inuit) is a key dimension of the experience of health.

The eight determining factors of community health are presented at the core of the model: community, family, food, territory, identity, knowledge, economy and services.

Besides this model, Table 2 presents the conditions favorable to health and well-being for Inuit (Surraigutiit). This valuable information enables greater familiarization with the Inuit life experience and better focus on what the users apprehend as having a real impact on the health. To improve Inuit health, the NRBHSS must make sure that the service supply contributes to respond to the Surraigutiit conditions, which, for Inuit, are essential for health.

Table 2: Conditions fostering health (personal notes, Christopher Fletcher)

Conditions fostering health (Surraigutiit)	
Pigunnasiarniq:	Being competent/capable [in control of one's world and life]
Ippigusutsianiq:	Being aware and observant of surrounding events, environment, others, animals
Kamatsianiq:	Being prudent, aware of what one is doing, in order to think ahead, be prepared for the unexpected, think before acting
Tungngasuttitaq:	Feeling welcome in one's surroundings [not feeling awkward or out of place, not feeling debased, pointed out or ashamed]
Atuutiqatsianiq:	Being useful, occupied and active [boredom is unhealthy; be active and productive]
Aaniagunnailuni:	Living without pain [a fundamental indicator of health; hospitals are designated as places of suffering in Inuktitut]
Saimatsianiq:	Being at peace with oneself and with others [social harmony appears to be widely recognized throughout Inuit Nunangat]
Ilitarijautsianiq:	Being recognized and rewarded for one's efforts and contributions

Users' Perspective in the Nunavik Regional Clinical Plan

Overview of the Process

The assessment of the users' perspective of health care and services was planned according to the abovementioned principles of cultural safety and the IQI model of health but also in terms of evaluating health systems as described in the ministerial reference framework for evaluation of the public health and social services system.[24]

A three-phase process of data collection was used, according to a mixed methodology combining quantitative and qualitative sources. The project's three successive phases offered the opportunity to evaluate the results through triangulation. The table below briefly describes the sources and objectives of each phase of data collection.

Table 3: Description of the phases of the data-collection project

Phase (period)	Sources / method	Target population	Specific objectives
Phase 1 Spring 2018	Population surveys (1) (quantitative)	General population	Evaluate whether the services provided met users' expectations in terms of accessibility, quality, cultural safety, etc.
Phase 2 Sept. 2018 – Apr. 2019	Individual interviews (2) (qualitative)	Interviews held in six communities selected according to size	Gather data on the Inuit vision of health and well-being; Further explore the results obtained in Phase 1.
Phase 3 Nov. 2019	Focus groups (3) (qualitative)	Two key informants from all 14 communities	Validate the results of Phases 1 and 2 and propose priorities and recommendations for improvement.

Note:
(1) More information on these surveys may be found in Appendix 2: Population Survey.
(2) More information on the interviews may be found in Appendix 3: Individual Interviews.
(3) More information on the focus groups may be found in Appendix 4: Focus Groups.

The project's mixed methodology allowed for validation of the information collected, through triangulation of the results obtained from the various information sources.

24 Ministerial reference framework for evaluation of the performance of the public health and social services system, ratified by the steering committee on January 31, 2012.

Results of the Consultations on the Users' Perspective in the Context of the Nunavik Regional Clinical Plan

The results are presented according to the three successive phases of consultation, i.e., the results of the surveys, the interviews, and the focus groups. The methodology used at each of these steps is specific and makes it possible to account for the users' perspective on the care and services received from the network at different levels, in Nunavik as well as in the institutions with which we have service corridors.

A discussion on the integration of the results from the three phases and their implications in terms of suggested solutions will follow.

Results of Phase 1: Population Surveys

What are the key messages of this section?

The surveys of Phase 1 led to the following findings:

- The expectations of the majority of the respondents appear to be adequately met regarding several aspects of the health-care system, namely in terms of the referral process, communication aspects, as well as various elements of physical and cultural safety.
- Many respondents also feel that they do not have access to the same health care as the population of other regions of Quebec

The surveys (both online and paper format) were conducted in June 2018; the results full report was published online in June 2019.[25]

Only the highlights of the report are presented below.

Respondents' Profiles

In total, 438 forms were completed. In general, the final sampling turned out comparable to the Nunavik population in terms of the variables of age, sex and community, except for a slight overrepresentation of young persons aged 14 to 18 years and underrepresentation of men (25%). The majority of respondents (84%) were beneficiaries of the *JBNQA*.

25 https://nrbhss.ca/sites/default/files/health_services_clinical_plan_report_fr.pdf

Respondents' perceptions of various aspects of services

The purpose of the survey aimed to evaluate, from the point of view of Nunavimmiut, the accessibility and quality of the services offered to them, as well as their cultural safety. It was therefore a question of evaluating the extent to which the service offered met their expectations, not their satisfaction. The complete methodology is presented in the "User's Experience Survey Report".[26] The quality, accessibility and cultural safety of services were measured through six themes, detailed and presented below, drawn from the Ministerial reference framework for evaluation of the performance of the public health and social services system ,[27] to which the aspect of cultural safety was added.

- **Service accessibility**
  - Accessibility: Are the users aware of the service offered, are they informed of what they should have access to and do they effectively have access to the service?
  - Equity in access: Do they consider the access to be equitable between communities and with the rest of Quebec?
- **Service quality**
  - Efficiency: Do they consider the service to be truly efficient? Or do they consider it so inefficient that there are no services?
  - Safety: From their point of view, are there risks involved with seeking help?
  - Reactivity: When they consult the services, do they feel that the nurses and physicians are able to adapt their practice to the Nunavik realities?
  - Continuity: Is the care trajectory easy to follow?
- **Cultural safety:** Do they feel they can trust their caregivers? Do they feel caregivers make efforts to be culturally safe?
  - Communication: Do they understand what is being explained to them? Are they able to ask all the questions they have to make an informed decision regarding treatment and other health-related questions?
  - Pertinence: Was the services perceived as useful and adapted to their values and overall situation?

26 More information on the significance of this distinction, interested readers can refer to full methodology in the survey report (https://nrbhss.ca/sites/default/files/health_services_clinical_plan_report_fr.pdf..

27 Ministerial reference framework for evaluation of the performance of the public health and social services system, ratified by the steering committee on January 31, 2012.

Users' Perception According to Various Aspects of the Services

The next figure describes a combination of scores by aspect (categories of questions dealing with the same aspect of the services). The aspects with the lowest scores are in orange, those with the highest scores are in green.

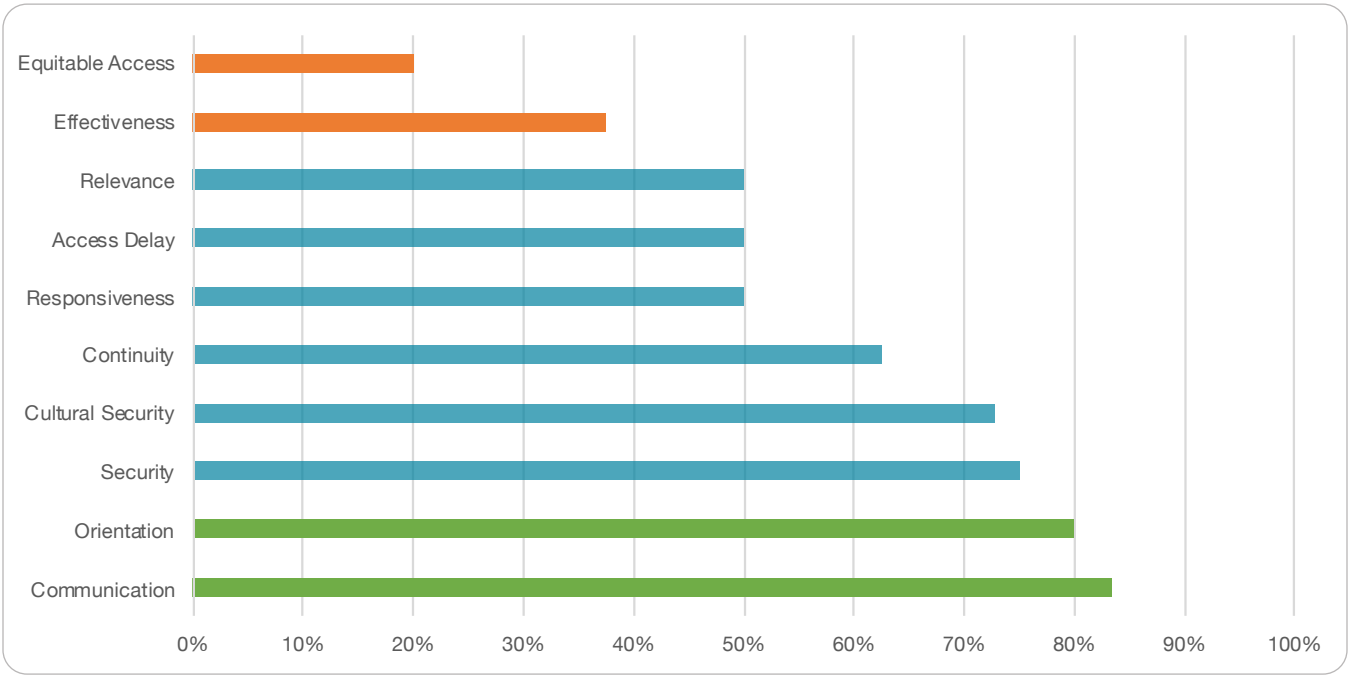

Figure 4: Perception of services in terms of compliance with most respondents' expectations

Except for equity in access and effectiveness, the aspects apparently meet expectations adequately. We should specify that these results are nuanced significantly according to the variable "I feel healthy," with scores higher among respondents who consider themselves in good health.

Perception of service efficiency and access equity were the performance components which appeared to be rated the least favourably by participants. In fact, these two components are likely to be highly correlated; indeed, having to be transferred to a hospital in the South for services will tend to influence users' perception of access equity, as well as their perception of the overall services efficiency. These results seemed to suggest that respondents would like to have access to a more efficient health care system, which provides the same level of services that are found in other regions of the province.

The relatively high scores for all the other performance components seemed to indicate that services generally meet users' expectations. Indeed, most respondents indicated usually knowing where to go to receive services, as well as feeling safe and reasonably well informed at the time of consultation. However, it is important to keep in mind that scores on the "meeting users' expectations" scale are independent from "quality of the service" variable. For example, if users' expectations of the services are low, the "meeting expectation" scores could be high, but the service quality could still be quite low.

Detailed Scores by Community and Age Group

In general, the data obtained did not show significant variations by age groups, community or JBNQA beneficiary status (Inuit or non-Inuit).

In other words, the results seemed to indicate that whether respondents lived in a large community served by a hospital, such as Kuujjuaq, or in a small community with limited services, such as Tasiujaq, the average scores for most performance component appeared to be more or less comparable. The results, however, revealed some local particularities; for example, access time appeared to be a bigger issue in Aupaluk and Umiujaq than in other communities. These local variations may pinpoint the elements of services which should be focussed on in each community to ensure they better respond to their users' expectations.

The results also revealed that some aspects of the services seemed to meet the expectations of certain age groups more than others. For example, the scores for access equity and efficiency were higher in the 55 years and older age group, than in the younger subgroups, variations which may be the results of different service expectations between the two age groups.

Let us keep in mind that each community of Nunavik has its own history, geography, and culture, in the same way that various age groups have life experiences which differ greatly from one another (often referred to as the intergenerational gap caused by colonialism). Such factors must be considered in the planning and provision of care to the population. By exploring these variations further, we can provide adaptable solutions which actually improve the quality and accessibility of services for all.

Results of Phase 2: Individual Interviews

What are the main findings of this section?

- Most of the people interviewed reported that Inuuqatigiitsianiq (relationships) is central to the inuit vision of health ; this relational aspect of health also appears to extend to the connexion with the traditional territory, as well as the importance placed on the caregiver-user relationship.
- The impacts of colonialism was reported as one of the elements which affected health in the past, and they are still at the root of the most severe health problems in the population today (i.e. mental health, addictions and violence difficulties).
- The aspects of the health system reported as being most appreciated by the persons interviewed are the pertinence and effectiveness of the services received, as well as service provision at no cost to the user and access to qualified personnel;
- On the other hand, the aspects of the system stated as requiring the most improvement are the lack of security, cultural safety and continuity of care.

The interviews were used first to explore the participants' vision of health, according to the traditional knowledge they received from their parents and community. Other topics discussed during interviews included participants' past and present challenges to maintaining good health, .as well as their experiences within the health system, particularly aspects they perceived as positive or negative, and what they wished in terms of future service development.

Profile of Interviewees

For the six villages visited, in total, 63 interviews were held. The short time spent in each community was certainly a limiting factor in obtaining a sampling of respondents more representative of the Nunavik population. In effect, 71% of the respondents were women and 29% men, whereas statistics in 2018 indicated that 49.4% of the Nunavik population is female and 50.6% male.

Table 4: Comparative Gender distribution between interview participants and general Nunavik population,

	Interviewees	Nunavik population
	71%	49.4%
	29 %	50.6%

Among the interviewees, young persons aged 19 to 34 years are somewhat underrepresented, whereas adults aged 35 to 54 years as well as older persons aged 55 years and up are overrepresented.

Table 5: Comparative percentages of interviewees and the population, by age group

Age group	Interviewees	Nunavik population
19-34	22%	29%
35-54	51%	22%
55 +	27%	11%

Analysis of Word Roots: Experience with the Health System Varies According to Community Size

Whereas the approach through surveys and questionnaires revealed few variations or differences by community in terms of the experience of accessibility, quality and cultural safety of the services provided, analysis of the interviews revealed nuances and significant differences according to the size of the respondents' communities.

Analysis of Radicals

In linguistics, a radical is a part of a word responsible for its lexical meaning. Analysis of radicals is done through extraction of words or families of words from the interviews. It enables comparison of words most often used during the interviews.

Here, the finding is that in both the list of 20 radicals arranged by frequency and the word cloud created based on all the interviews, for all communities independent of size, the word *people* lies at the core of the statements made.

Figure 5: Word clouds, by frequency, all interviews

Table 6: Compilation of 20 radicals, by frequency

Top 20 by Community Size		
Large	**Medium**	**Small**
peopl	peopl	peopl
time	time	time
servic	inuit	doctor
lot	hospit	hospit
hospit	doctor	told
issu	start	nurs
surgeri	treat	treat
inuit	pain	physic
start	care	father
person	told	person
care	person	parent
treat	live	children
communiti	lot	mental
children	eat	communiti
south	issu	day
told	talk	rememb
mother	communiti	lot
pain	learn	mother
home	nurs	heart
physic	alcohol	care

Overall View of the Content of Individual Interviews

Whereas the approach through surveys did not reveal variations in experience with the services provided according to the respondents' communities, the analysis of the content of the interviews revealed certain nuances in the preponderance of some topics raised during the interviews with participants from communities that differ in size. For example, the concept of family was raised more frequently in interviews conducted in the smaller communities, along with the words *parent*, *child* and *father*.

As for words used to designate health services, the term *caregiver* was mentioned more often in the small- to medium-sized communities (*doctor, nurses*) than in the larger ones, where words linked to services and specialties came up more often.

Finally, for relational topics, the word *Inuit* was very frequently used in the medium- to large-sized communities, whereas *community* occurred more or less evenly across different community sizes.

Thus, Figure 6 presents the relative frequency of the topics discussed by the participants according to the size of their communities. Where the concepts linked to services were used more often in the speech of individuals from medium-sized communities, those linked to family and community were more frequently used by individuals from smaller communities. Further, the terms linked to the concept of culture were more often used by participants from medium- to large-sized communities than those from the smaller ones.

Moreover, Figure 7 illustrates that neither fear nor trust predominates in the speech of participants from differing community sizes. Thus, a more detailed analysis of speech will be essential to identify the elements that work well and those that work less well, those that inspire trust and those that constitute problems for the users of the Nunavik health system.

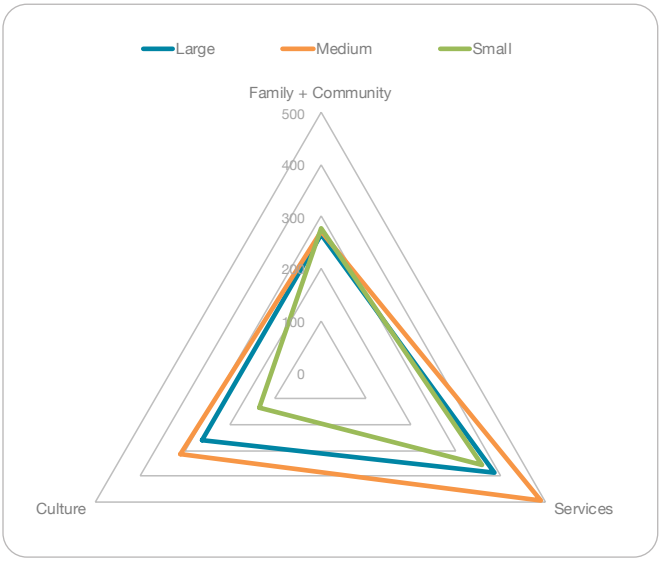

Figure 6: Conceptual illustration, by community size

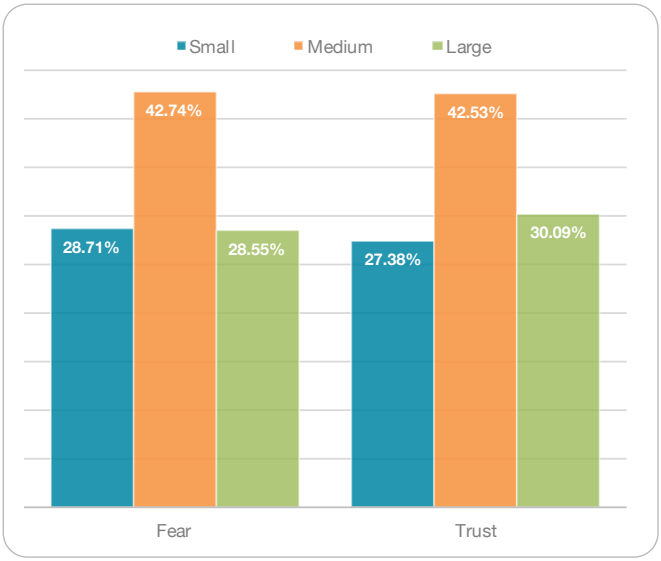

Figure 7: Comparison of concepts, by community size

References to Components of the Inuit IQI Model for Health

Exploration of the Inuit model for health (IQI) according to the frequency of mention of its components during the interviews revealed that the relational aspect of health is central to Inuit narrative around health and well-being. Various facets of that aspect were raised during the interviews, revealing its importance for the development and maintenance of health and well-being among the Inuit.

> *" [being healthy] is being well cared for and helping each other, for the whole family, when there was someone going through some trouble or when they were worried. Kamasutsianiq family member or trying to help each other so the person will be okay. The person to help if they're sick or if they're not sick or if they're going through stress. My parents, I remember someone telling me if someone is going through hard time physically or emotionally or mentally they used to ask our parents to go join them, I remember my older sister saying that they were helping others"*
>
> *- Mary Atagootalook, Inukjuak*

According to the interviewees, it is not only the quality of the caregiver-user relationship which is essential to good health and well-being but also the quality of the relationships with family and community. The relationship with the northern environment—the tundra, food, and elements of peace and well-being that these provide—is a major aspect of Inuit health and well-being. That aspect is currently neglected in the health and social services supply in Nunavik.

Figure 9 shows the relative importance of the topics of the IQI model of health presented above in the general context of the project. The community determining factors of health occupy a predominant place therein, as does the topic of services, very likely due to the subject of the interviews.

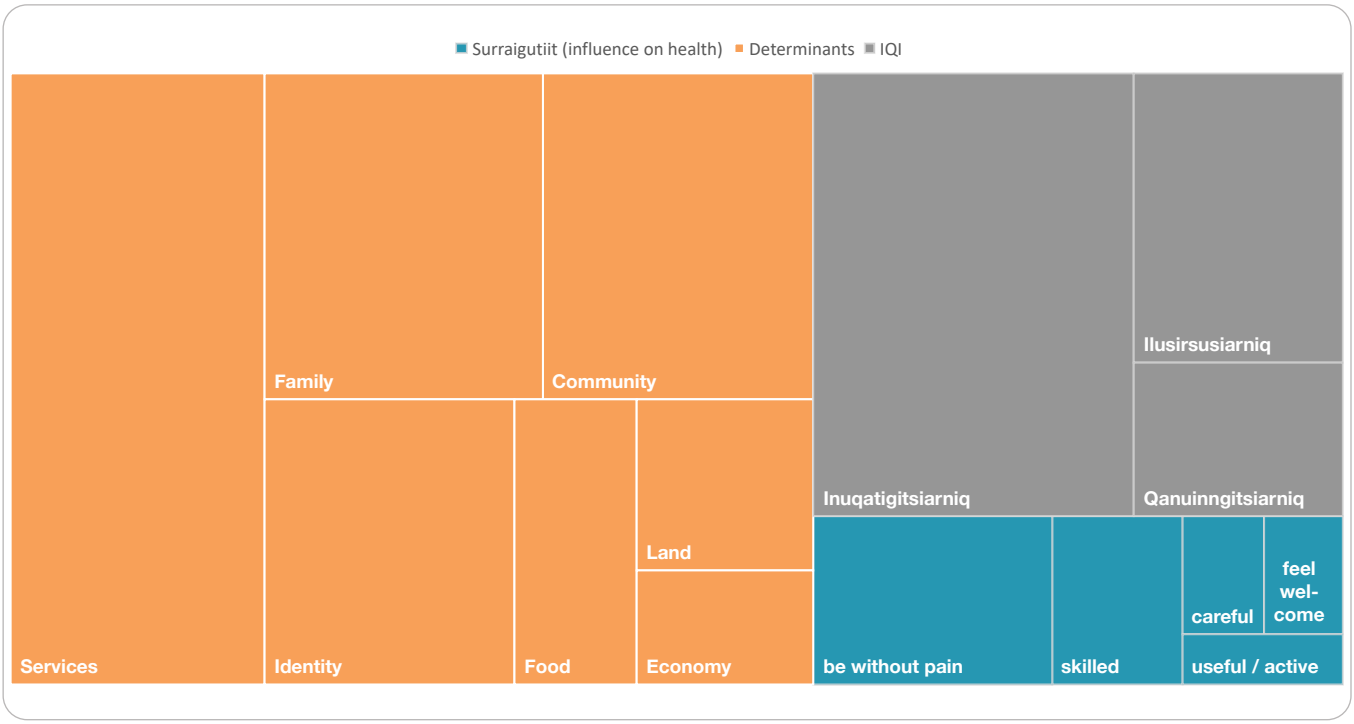

Figure 8: Frequency of mention of the various elements of the Inuit IQI model for health

In the left of the figure concerning the determining factors of health (in orange), the topics of family, identity and community occupy a predominant place in the participants' speech. Likewise, the entire analysis of the IQI model (in grey, centre of the figure) shows that Inuuqatigiitsianiq (the relational aspect) predominates in the participants' speech, and this in front of Ilusirsusiarniq (the more physical aspect) and Qanuingngisiarniq (feeling well, contented).

And finally, the Surraigutiit elements (in blue, at the right of the figure) seem to indicate that the physical aspects of health are considered less important than the other two components. That said, among these, the absence of pain and being skilled , capable of facing situations appear to dominate, in comparison to the other topics: being careful, feeling welcome, being useful, being aware, being acknowledged and being at peace.

Analysis of Issues, by Community Size: Surraigutiit

Figure 9: Conditions conducive to health

Community size does not appear to have an effect on the relative importance of the components of the IQI model.[28] The relational aspect (Inuuqatigiitsianiq) predominates the participants' speech in all the communities, regardless of size. Likewise, for Surraigutiit, the conditions for good health, Kamatsianiq (being careful, aware) and Pigunnasiarniq (being skilled) are the two aspects most emphasized during the interviews. Atuutiqatsianiq (being useful) and Saimatsianiq (being at peace) are the conditions mentioned in all sizes of community, and Ippigusutsianiq, being aware, was emphasized primarily by the respondents in the smaller communities.[29]

28 See the note on methodology for details.

29 For all the figures that follow, the percentages represent the proportion of occurrence of the topic raised. For example, in the figure of the IQI model above, if we look at the results for the larger communities, we note that 27% of the discussions on the IQI model were related to Illusirsusiarniq (physical health), whereas 43% were related to Inuuqatigiitsianiq (relational aspect) and 30% to Qanuingngisiarniq (feeling well, contented), for a total of 100% for this topic.

Identification of Issues Linked to Maintaining Good Health in the Past

When interviewed on the obstacles to maintaining good health during their youth, the participants from all the communities, regardless of size, raised three main elements: illness, being in a survival situation and the effects of colonialism.

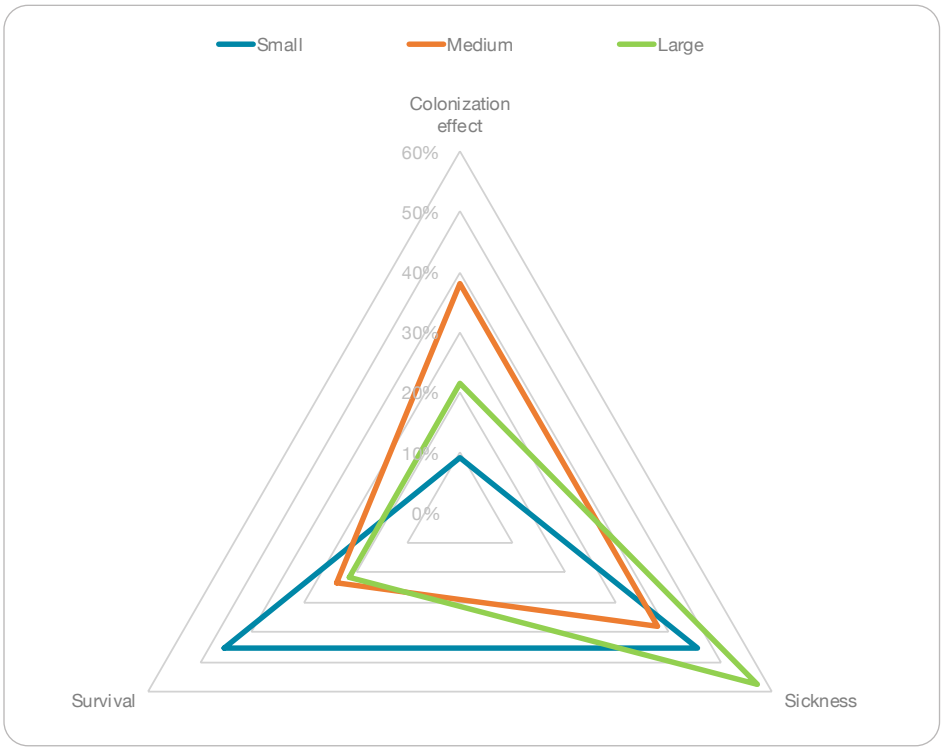

Figure 10: Issues in maintaining good health in the past

Illness

For the interviewees, being sick would be a true obstacle to attaining several conditions necessary to health according to the IQI model. Indeed, the person sometimes ends up in a situation where he[30] can no longer care for himself or his family. Sickness therefore threatens not only the physical aspect of health but also its relational aspect, such as Atuutiqatsianiq (being useful) and Saimatsianiq (being at peace), for example.

Further, dying from a disease at a time when there were no permanent physicians in Nunavik was one of the issues most often raised during the interviews, regardless of community size. However, the participants from the smaller communities insisted on the difficulty entailed by living a nomad lifestyle for persons with a physical handicap, such as blindness.

The respondents from the medium- to larger-sized communities emphasized the particular impact of tuberculosis on Inuit families.[31]

30 In the interest of simplicity, the masculine or feminine form is used in this text to denote either sex.

31 From the 1940s to the 1960s, the Canadian government carried out mass screening for tuberculosis among the Inuit, which led to the transfer of 7 to 10% of the Canadian Inuit population to hospitals in the South. The stays sometimes lasted several years and sometimes ended with the patients' death, isolated from their families (Olofsson, E., Holton, T. L. and Partridge, I. (2008). Negotiating identities: Inuit tuberculosis evacuees in the 1940s-1950s. Études/Inuit/Studies, 32 (2), 127–149. https://doi.org/10.7202/038219ar).

In the past, any sickness, besides affecting physical health, was a true challenge for a person without access to a physician or, in later times, taken under the care of the Canadian health system. As told by Lucassie Napaaluk, the sickness of a loved one directly affects the well-being of the entire family, which must live on in the absence of a parent or child with no news of that person whatsoever.

> *"My mom went away three times before we were ten years old. Sometimes she was gone for a year and we would not hear any news from her. Once in a while through the radio we would hear from her, maybe twice or three times in a year. We had parents, our father, but when our mother started leaving we would go hungry and our clothes were not the best, and the people who were able to sew would make us kamik (sealskin boots) because our mom was away. So this really affected me."*
>
> *—Lucasssie Napaaluk, Kangiqsujuaq*

Survival

The risks associated with polar bears roaming near igloos, dog attacks, drinking contaminated water from melted snow in the winter, and childbirth were some of life-threatening situations which were reported by the participants.

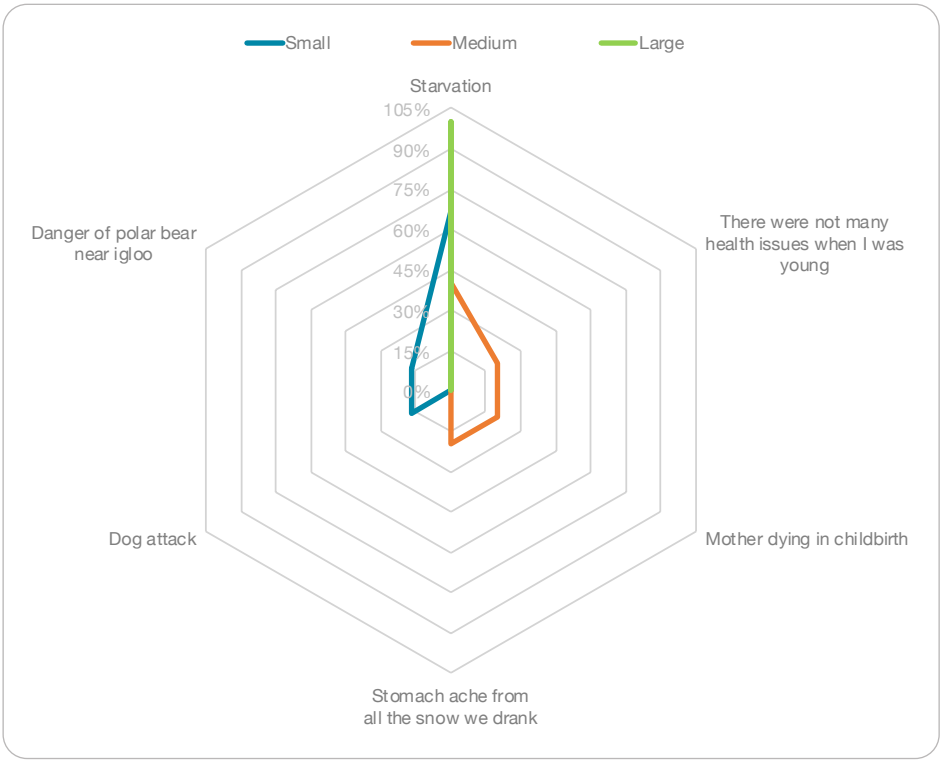

Figure 11: Issues related to survival situations

Participants from all communities agreed on the fact that famine, however, remained one of the greatest threat to survival in the past. Indeed, when game was rare, many of the conditions considered essential to health became difficult to achieve, including the capacity to plan, be prepared, careful (Kamatsianiq) and aware (Ippigusutsianiq).

> *« They used to go hungry even some people died from starvation because they had no food that's what they went through and we have parents that went through so much hardship for us when we were growing up. There was not abundant of food, I used to be hungry when I was a boy. I remember this whatever we're going through today. It's not the same anymore. Sometimes our parents used to leave even before having breakfast to go hunting because we were hungry and they were trying to hunt for us."*
>
> *—Moses Munick, Tasiujaq*

Despite the presence of all these challenges to survival in the past, many interviewees expressed the opinion that there seemed to be far less health problems back then.

The Multigenerational Impacts of Colonialism

In terms of the colonialist measures considered as having had a negative effect on Inuit health, one event was invariably mentioned during the interviews with participants from all the communities regardless of size: the slaughter of sled dogs. The availability of alcohol, the conditions in the sanatoriums and the loss of identity were also mentioned as having been unfavourable to maintaining good health.

Colonialism was raised by the respondents as having led to the loss of many conditions

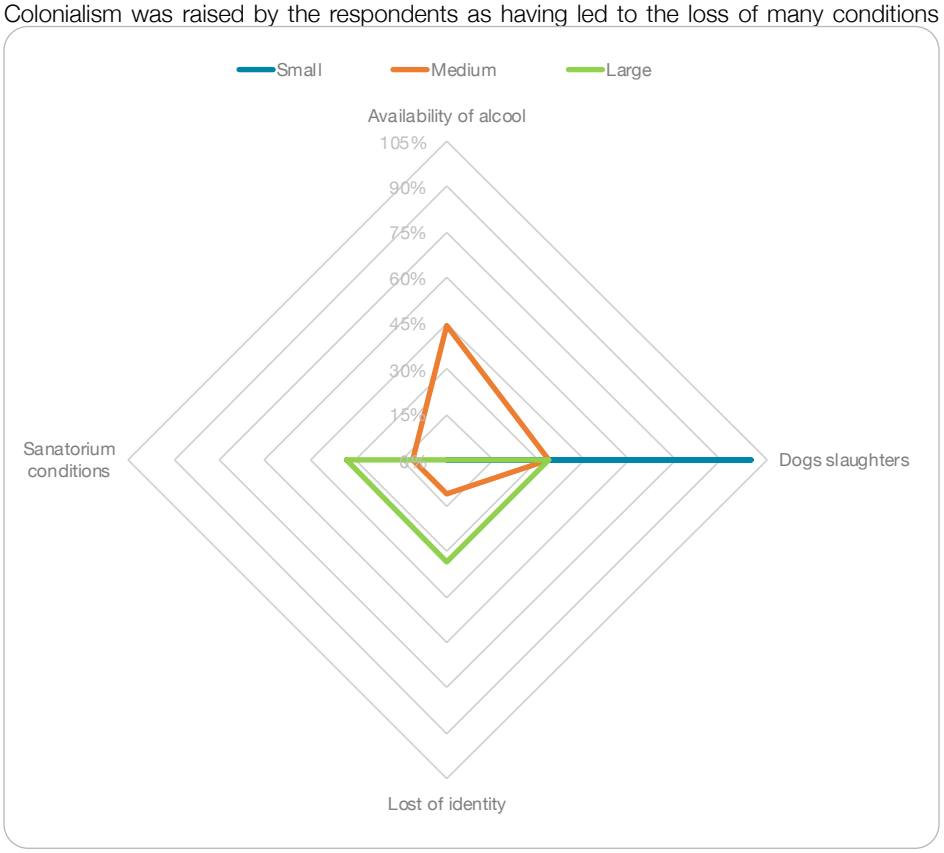

Figure 12: Issues related to colonization

considered essential to health, including recognition of identity, the capacity to feel welcome, competent, useful, free of pain and, finally, the feeling of being at peace. According to the interviewees, all of these elements from the colonial past had repercussions that continue over time and today still directly affect *Nunavimmiut* health, well-being and safety.

> *[…]this summer, along with a University student we went almost to every house to see what the problems were, it's mostly like mental health, alcohol abuse, family abuse, physical abuse and trauma that we faced for the past hundred years, from the dog slaughter to the government JNBNQA signing and our lands being taken away from us so we have to pay close attention to each person what they're saying and that is will help."*
>
> *—Nigel Adams, Kangiqsujuaq*

During the interviews, many participants mentioned other facets of history, as illustrated in the next figure. Described as harmful events by some or as mere facts of history by others, the finality of the impacts are there nevertheless.

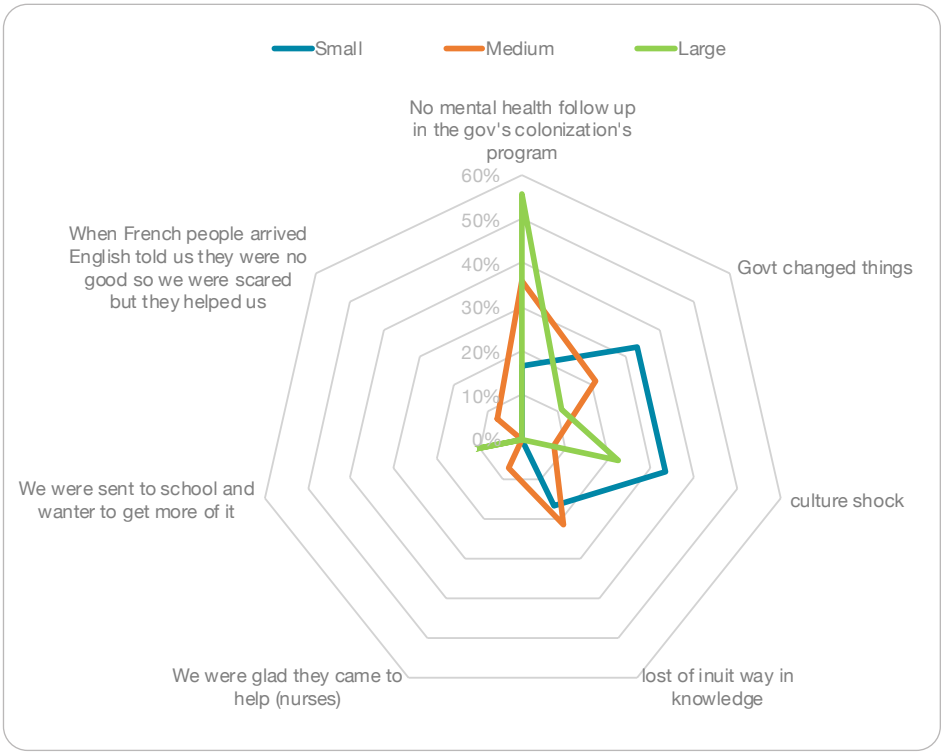

Figure 13: Discussions on the colonial past

Obstacles to Maintaining Good Health Today

Figure 14: Obstacles to maintaining good health today

Interviews seemed to indicate that there are within the Nunavik communities today numerous complex obstacles to health. For the participants of all the communities, regardless of size, substance abuse and mental-health problems are frequent. To these, some participants added the challenges of raising children in environments where most people have been negatively affected by the multidimensional impacts from Nunavik colonialist past.

Problems of violence were brought up mainly in the smaller communities; according to the respondents, whether in the home or at school, experienced as victim or as witness, the damages caused by violence are always very acute. . Other struggles underlined by participants were: feeling resourceless, being a witness or a victim of sexual abuse, having suicidal thoughts or lived through the suicide of a loved one. Also, the interviewees mentioned the challenges of living with food insecurity, lack of housing, or other social problems. Finally, the feeling that Inuit cultural values are compromised was also identified as a major obstacle to the Nunavik population's health and well-being.

Once again, considering the importance of the relational aspect of the Inuit vision of health, the fact that stands out from the interviews is that all of these obstacles are encountered in a social fabric so tightly woven that they inflict true harm to the health and well-being of all the inhabitants of all the Nunavik communities today.

Mental Health difficulties

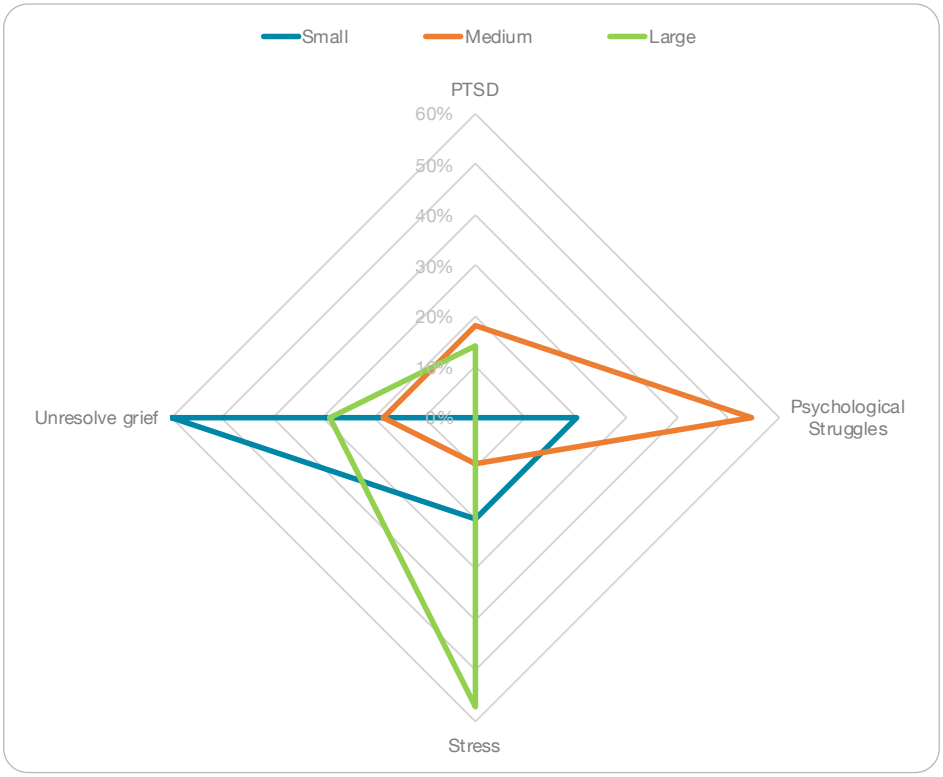

Figure 15: Problems related to mental health

Although the same four mental health problems were mentioned by participants in all the communities visited, the one identified as predominant differed depending on community size:

- psychological distress was primarily raised in the medium-sized communities;
- unresolved grief was mentioned more often in the smaller communities;
- stress was more clearly identified in the larger communities.
- Post-traumatic stress disorder was also stated by some of the participants, but it was thought that the lack of PTSD services in the region may contribute to misunderstanding of the phenomenon among the population.

"Today there's a lot. I think what I've been learning is there is a lot of PTSD post-traumatic stress disorders that are undiagnosed. Also, no proper treatment of them because many are not comfortable with talking about it in English so I think it's a major issue. That's a root for a lot of our problems and it's undiagnosed."

—Allen Gordon, Kuujjuaq

Parenthood and Substance Abuse

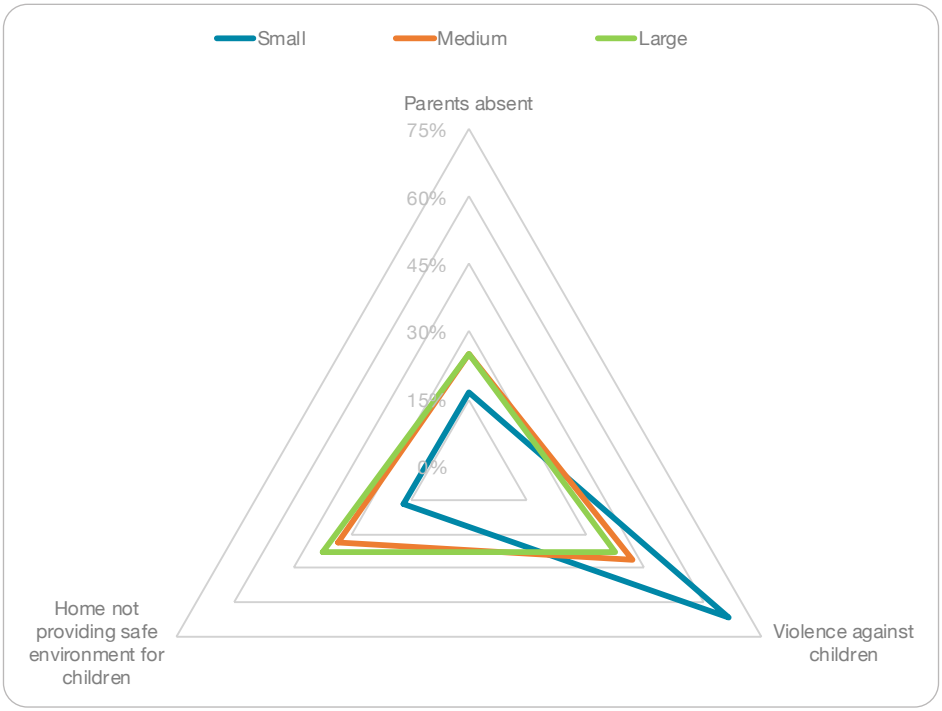

Figure 16: Parenthood

As shown in the next two figures, Participants from all the communities reported violence against children , the absence of parents and the difficulty in providing a safe environment for children as important problems today in the communities. These difficulties were described again as rooted in the colonial past and its major impact on the current intergenerational rupture.

> *"Myself what I went through growing up with my father and my mother, they use to fight and fight. This is painful for me, some days this is very bad for the mind. When you are small and you're watching them fighting it's very painful. "*
>
> *—Anonymous, Inukjuak*

The adults interviewed spoke of the impact of residential schools on their parents and on their experiences as children. According to the participants, substance abuse is the main consequence of these past trauma, and it therefore is one of the greatest obstacles to *Nunavimmiut* health today.

The impacts of residential schools were mentioned by many participants as having affected their own children, who now have very little access to elders' traditional knowledge and skills for living on the land, enjoying true peace of mind, the ability to plan, meeting one's family's needs, caring for loved ones by providing healthy food and safe spaces, and using the land to heal the mind. According to the participants' testimonies, the intergenerational ruptures led to people a distancing themselves from the land and being confined to the villages, greatly undermining their feelings of well-being today.

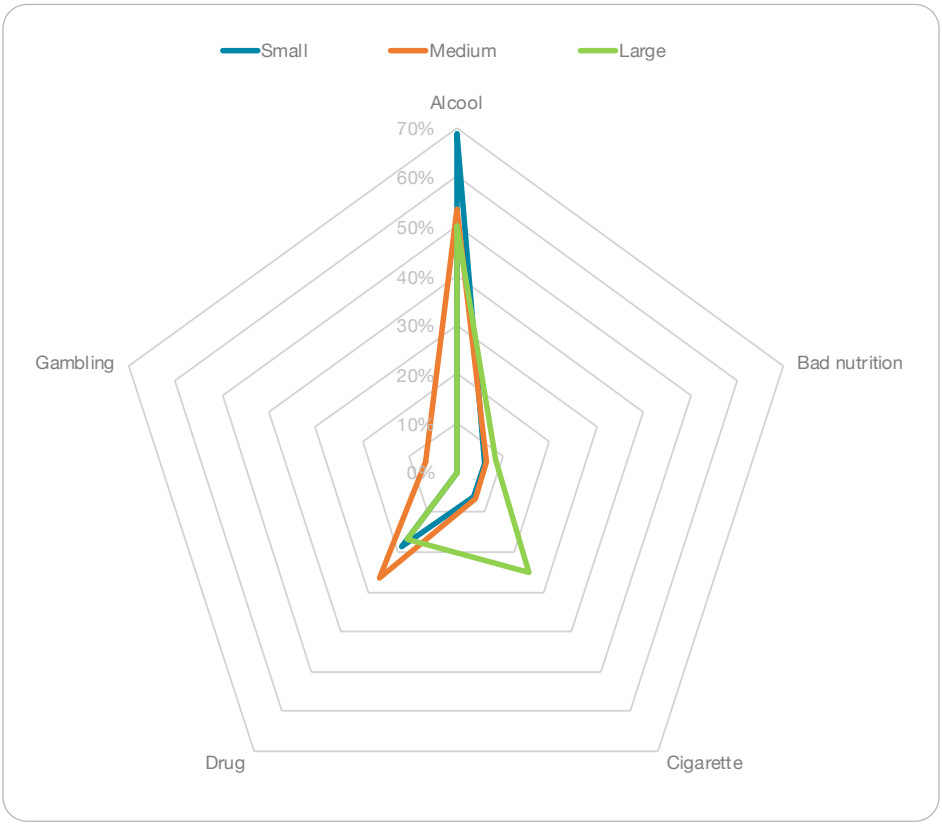

Figure 17: Substance Abuse

In fact, many expressed their concerns at the loss of value given in today's society to everything which used to contribute to Inuit population's health and well-being ; the vast majority of respondents also felt that a return to these traditional foundations would be useful.

> *"When I was growing up there were people gambling, drinking and playing bingo. These happened and this was something I was not comfortable with. And when I was a child we used to go out on the land as a family to be out for a long time and we do not do it anymore, so this is not comfortable for me because there's so many things that the world can offer: the internet gambling, also the children stopped following their parents and the grandparents so being out on the land with their family does not happen too often anymore just few people bring their family out on the land.*
>
> *—Lisa Elijasiapik, Inukjuak*

This overview of the challenges to maintaining health and well-being among *Nunavimmiut* provides a brief glimpse of the extent and complexity of the issues faced by many northern populations today. If the health system is to genuinely contribute to health in the Inuit population, it needs to tackle the root causes of these problems, by providing services to address substance abuse, support young parents, reduce violence, help people deal with past trauma and mental health difficulties.

Participants' perception of the Health and Social Services

The previous section emphasized the importance of the relational aspect of health for the population, as well as the impact of colonialist measures on the challenges that persist today within the communities. These issues will be raised again in the present section, from a slightly different angle, that is, the extent to which current services meet these needs. Will be covered here, the participants' points of view on the services currently available to them, including the aspects which appear to work well and those that may require improvement.

Elements of the Health System Perceived as Positive

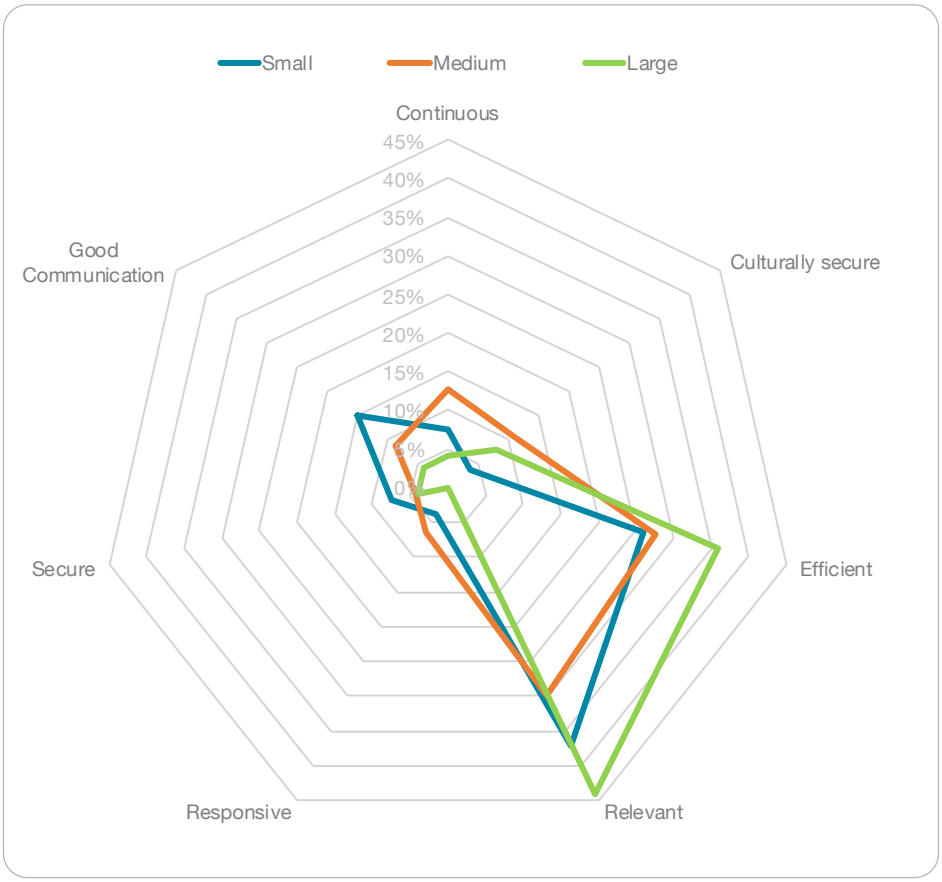

Figure 18: Elements of the health system described

Similarly to what was seen in the phase 1 survey results, respondents from all the communities tended to describe the current services as relevant and efficient. While a few users from smaller communities also mentioned appreciating the quality of caregiver-user communications, some from the medium-sized communities also qualified service continuity quite positively. The main advantage of qualitative interviews over quantitative survey results is the possibility of further exploring these findings.

As a matter of fact, for some participants, their experience with services is clearly positive: they considered the treatments received as effective and follow-up as adequate. The experience of care recounted here was thus perceived as relevant by the user, to the extent that it allowed the problem to be resolved definitively.

> *"When I was in Montreal, there was liquid inside my hand. It almost paralyzed me but they took very well care of it and it has healed and I had physio. I was in physio after they treated me for about a month and it has healed well. -Did someone follow you? —yes I had an escort"*
>
> *—Anonymous, Inukjuak*

In other cases, however, although the users were relatively satisfied with the treatment received, the absence of support services at the time of the visit gave rise to worries concerning safety. It therefore appears that support services that should be available for cases in Montréal are sometimes unavailable.

> ***"My treatment went very well, they took care of me well but I needed help after. There was lack of help especially after being tested for your eyes, because they would put different things in your eye and I would have blurry vision after the test. So I used to be afraid to go to my tests alone because I knew I've been going there for a while I knew what was going to happen to me. I was afraid from the time after my appointment to transit. It was okay if I had other people with me at the hospital but the people who are serving Inuit, I used to tell them: "I'm afraid to go alone." If they were able to come with me they would but they could not all the time.***
>
> *—Anonymous, Puvirnituq*

What Contributes to Health in the Current System

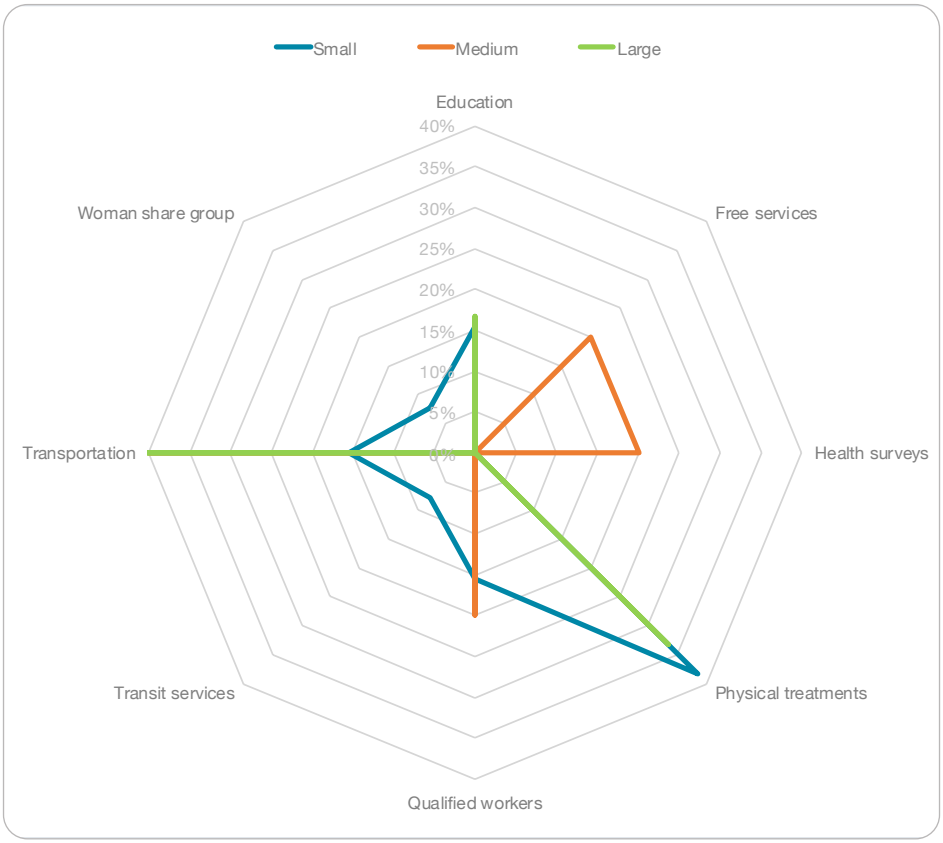

Figure 19: What contributes to health in the current system

When discussing the existing system of Nunavik, the respondents emphasized certain services and aspects particularly appreciated in the system, although these elements are not accessible in all the villages. In particular, having access to certain physical-health services (which was not always the case in Nunavik's history) was raised as a positive aspect of the current system. Access to qualified health personnel was also mentioned. Information services such as programs for newborn health as well as healthy lifestyles (including nutrition) were also mentioned as being particularly useful. Finally, service provision at no cost to the user, large-scale surveys on Inuit health (Qanuippitaa 2004 and Qanuilirpitaa 2017) and self-help groups for women, complement the list of the services most appreciated at present by the interviewees.

Elements of the Health System Perceived as Requiring Improvement

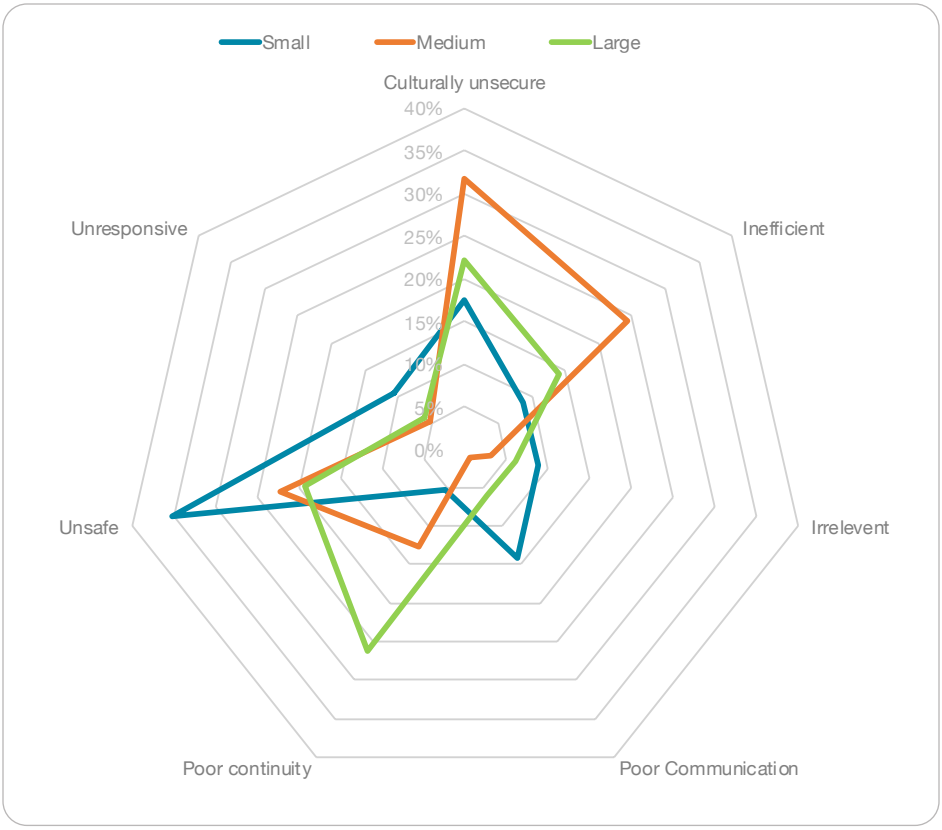

Figure 20: Elements identified as being of bad quality

Figure 20 shows the elements respondents consider to be of poor quality. It shows clear variations in the priorities mentioned by the participants, depending on the size of their community:

- Respondents from large communities first emphasized on the weaknesses in service continuity, followed by the services lack of cultural safety, lack of safety and inefficiency;
- Participants from the medium-sized communities first pointed out the services lack of cultural safety, followed by services inefficiency, lack of safety and poor service continuity;
- During the interviews in the smaller communities, lack of safety was most often mentioned, followed by weaknesses in cultural safety, poor caregiver-user communication and lack of service pertinence.

"If you have headache and they just give you Tylenol even if you have pain anywhere in the body they just give you Tylenol. It's also a problem because they're going to find out it's too late to treat them because the CLSC keep saying: "you're going to get better, you're going to get better." - So you you know of people who were diagnosed too late? - Yes a few of them. The patient went to go to CLSC for a long time before being treated and they tried to treat him too late."

—Eyuka Pinguatuk, Kangiqsujuaq

The impression that some caregivers wish to “get rid” of users by prescribing Tylenol, without trying to really understand the cause of their problem was widespread among the participants.

In fact, there seem to be an impression that the health care personnel are not truly concerned about the users nor their families, and that they do not seem to make efforts to find the true cause of the problems described to them. Elements which appear to corroborate this impression include, among others, the high staff turn over rate , the apparent over-prescription of Tylenol to users without proposing a clear treatment plan, as well as nurses denying patients access to physician, even in cases of symptoms persisting over weeks.

These situations appear to contribute to users’ perception of the services lack of safety , weak cultural safety and poor user-caregiver communication, which all add the users’ perception of treatment inefficiency. In fact, the lack of service continuity caused by the high staff turnover rate may actually be the source of many of these problems.

> *“My son was going through stress. He got seen by many different social workers because the social workers keep changing. So he had to talk about his issues (…) he really had no continuity of care. So this is what we’re going through here: you [have to] repeat and it’s not fun. And he’s not the only one.”*
>
> *—Anonymous, Puvirnituq*

> *« what can be improved I think is from Montreal general or maybe other hospitals, the link between them and the local hospital there is some breakage. The reason I say that because of my mother was supposedly scheduled to have knee replacement surgery years ago and when somebody finally found the file they said it’s too late because at her age she may develop complications that will not be good for her. So if they had followed up more quicker I mean if somebody is doing the administration, she should have had a lot less knee pain, now she’s barely moving. She’s too old now she can’t get it.*
>
> *—Anonymous, Kuujjuaq*

The lack of continuity in health care is often the result of inefficient communications between various caregivers. Whether the lack of communication occurs between caregivers working in the same community or between those working in the North and the specialists from the South, the participants' main perception remains the same: users' medical files do not appear to "follow the patients" efficiently. Undeniably, the high personnel turnover contributes at least in part to these difficulties in informational continuity, but shortcomings at the administrative level are likely also to blame.

> *"… someone should always be working on these daily records: the records that come from the South… you get the impression that they are simply not in the pile and they end up forgotten for a long time in the South." [Interviewer: Maybe there should be a system?] "I don't have an answer to that question because I have no experience with hospital administration. I guess it's like a garage: if there's a truck, it should have a work order, but if there's no work order you could end up doing anything... maybe it's got something to do with the high rotation too, I don't know."*
>
> *—Allen Gordon, Kuujjuaq*

According to many interviewees, these service continuity challenges are all the more harmful as they tend to fuel prejudices against the Inuit as "unable or unmotivated to take care of their health": a situation that clearly goes against the principles of cultural safety.

> ***« but when we finally get to our appointment, our doctor ask : " why did you take so long to be seen for your health problem?"… and we say we have Inuulitsivik, Tulatavik, they're the ones who takes care of all our papers. And they say: "this should have been done long time ago, I don't understand why you wait for a long time for your health issues!" Down south they ask questions and in the health system we have here they take a long time with paperwork just takes too long to get our appointment.***
>
> *—Phoebe Atagotalook, Inukjuak*

The Current System Needs to improve and support Inuit Health

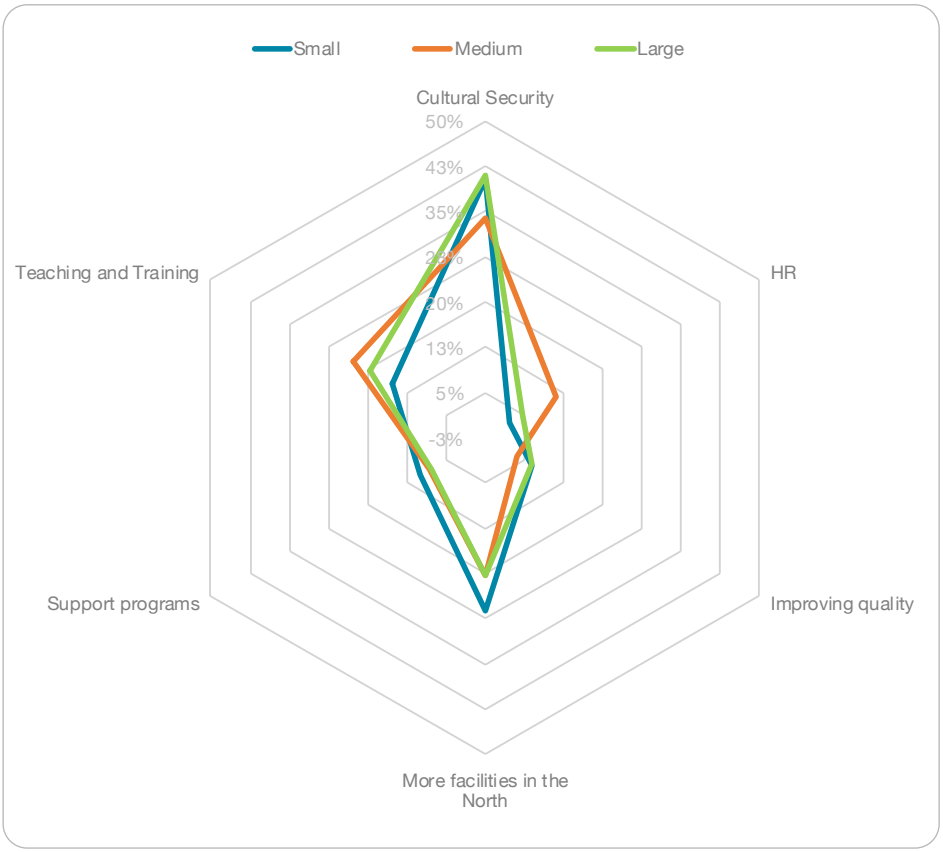

Figure 21: What the health system needs to improve Inuit health

When asked about the essential elements that the health system should have in order to better support the health and well-being of the Inuit population, respondents in all communities placed cultural safety at the top of their priorities, followed by the the urgent need for more infrastructure and services in the North. Third on the list was more training for both Inuit and non-Inuit workers. .

In addition, support programs, such as the Unaaq Men's Association in Inukjuak[32], were identified as the type of services which positively influence the health and well-being of Nunavik Inuit and, as such, similar programs should be expanded to other communities. Similarly, support programs for women, as well as the creation of spaces for psychosocial or holistic healing were mentioned by the participants as urgently needed. Finally, the need to improve the quality of health care by increasing our capacity to hire and retain competent workers were also mentioned. The next section will present more in-depth look at these issues.

32 This organization's mission is to support community youths by actively promoting Inuit culture and traditions in the community of Inukjuak as well as in Nunavik and Canada (https://www.facebook.com/pg/Unaaq-Mens-Association-of-Inukjuak-107534152705568/about/?ref=page_internal).

Needs in Terms of Education and Training

The participants pointed out several elements of training and education to be improved, namely public education, training for Inuit workers and training for *qallunaat* (non-Inuit) practicing in the region.
The types of training aimed at the Inuit population are listed below in order of importance:

1. train specialized Inuit personnel;
2. inform the population about mental health ;
3. inform the population about the available health resources and provide information on how to access them ;
4. train interpreters on medical terminology in Inuktitut.

« We need more services concerning mental health for our youth (…) maybe even trying to get Inuit to get the education so that they know how to deal with it. Because I've seen a lot of Inuit saying : "they're just looking for attention" for someone that's depressed and were having suicidal thoughts. And then a lot of Inuit youth don't want to go to a qallunaaq, they would rather go to another Inuit (…) so they would be to get more reliable people for our youth to go and talk to."

—Alan Palliser, Inukjuak

"Also we do not understand well in English, we really need good interpreters. So I want the medical interpreters to have classes, courses for terminology because the people who work in the justice system or any other thing have that. They are able to do translation but for medical interpreters, the body part names, the illnesses, it would be good if they would have a course on that. I think I would really like that."

—Tilly Alasuak, Puvirnituq

However, the need for training *qallunaat* workers was reported more often than training for the Inuit. The two needs primarily reported were:

1. The development of a mandatory pre-departure training that is more exhaustive than the current one, including solid cultural orientation in the communities before being authorized to work;
2. The training should also ensure a better understanding of Nunavik colonial history and its impacts, as well as to foster respect for Inuit history, culture, values, and way of life.

Needs in Terms of Cultural Safety

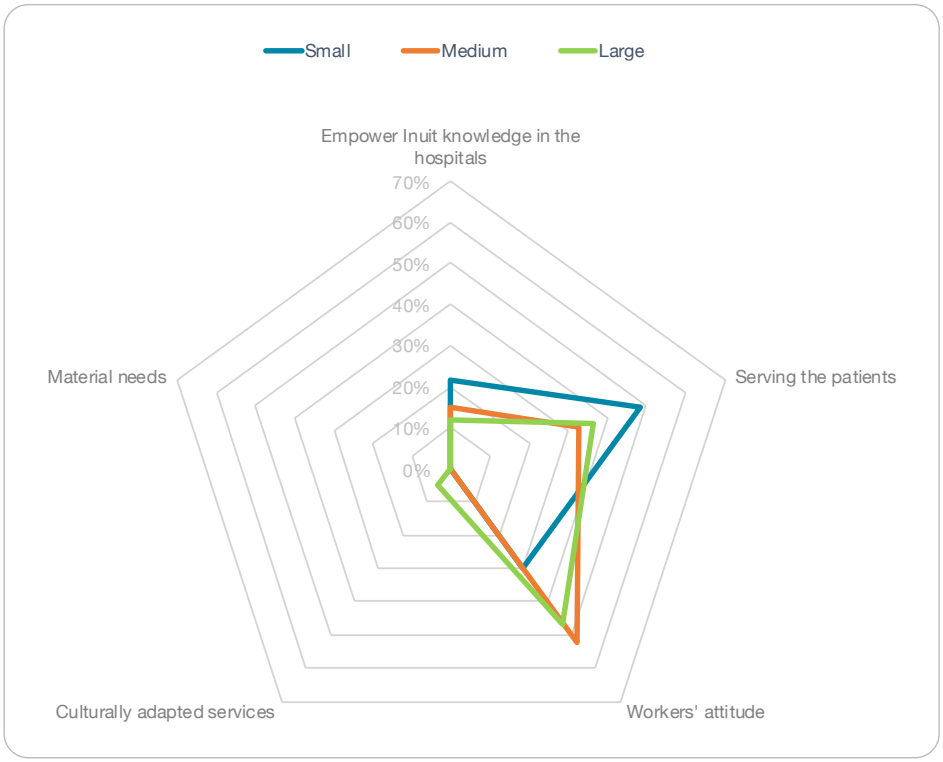

Figure 22: Cultural safety—what the health system needs to improve Inuit health

This section presents more detailed results under the topic of cultural safety. For the participants from the medium- and larger-sized communities, the element requiring the greatest improvement, in order to increase the level of cultural safety, is the caregivers' attitude. This notion was also mentioned in the smaller communities, but after the need to develop better patient services. Finally, the need to promote Inuit knowledge in the hospitals and CLSCs was also mentioned, and this regardless of community size.

The two principal issues under this topic merit examination in greater detail. What, for the participants, represents a better attitude and better patient services?

Cultural Safety: Improving Workers' Attitude

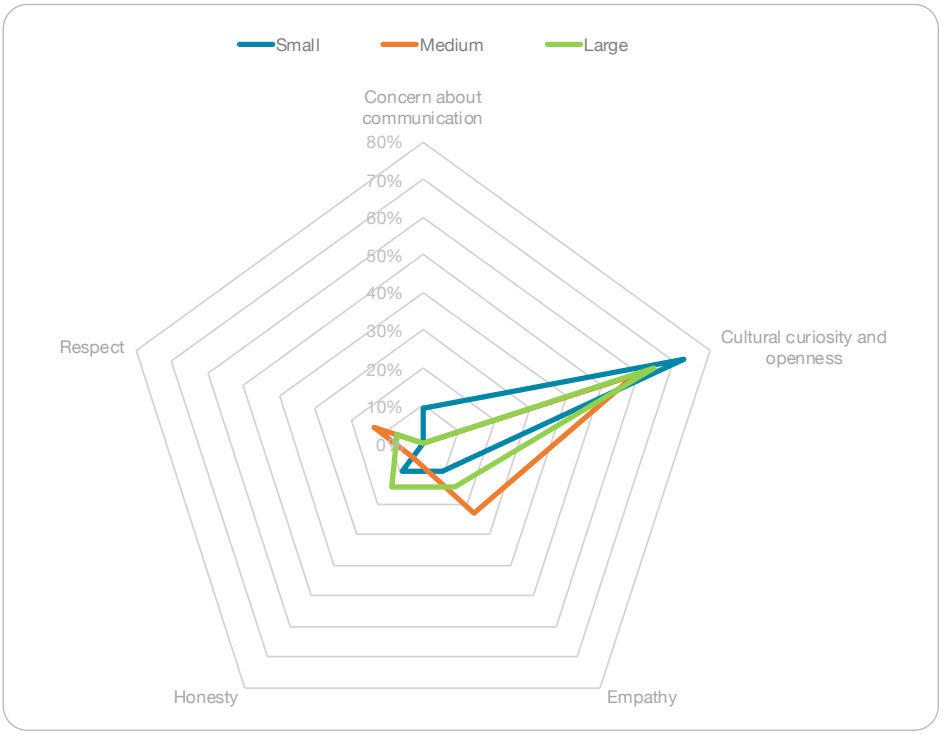

Figure 23: Cultural safety—improving workers' attitudes

The users demand more openness and curiosity regarding Inuit culture on the part of workers. Indeed, with the majority of workers being non-Inuit and often being very absorbed in their work, the population feels a distance, indeed, a lack of curiosity with regard to its way of life. The citations below illustrate this aspect.

> *" About us? So many things! The first one is just because you heard it about us Inuit don't just believe what they said but learn about us yourself. Because we all have different ways of thinking as Inuit: how we make decisions are all different. I think it would be good if they decide on their own to find out about us, get their own perspective because we're not all scary. Because they're in a hospital and they see things (…) so they they should look outside the hospital and figure out if they they could find something that they like and join the community (…) because the people who are in their own little world not welcoming are not as welcomed by others. They have to feel welcome and not look like they're scared and be part of the community because I see people when they make an effort to join the community: it's good to see their light!"*
>
> *—Mina Baulne, Puvirnituq*

"We're talking about new new staff coming up? It'd be great when they first arrive before they get to see all just the negative part, if there were workshops. Honestly, workshops on Inuit cultural orientations, on the land. At first. Not after. In the beginning it'd be good. And that's not just for the hospital also the police, everyone there with every organization (…) the nurses, they don't really have anybody to go out with so all they see is banged up people, people being brought in beaten up or suicidal… So we need them to experience... orientation : It gives you a different perspective."

—Allen Gordon, Kuujjuaq

"There's always good things that's happening in the community as well: fishing, going on the land is really refreshing for us. It's part of our healing. For a qallunaaq that comes to our North, comes to our community, they need to understand where we're coming from in order to work together. We don't like separating with qallunaat, we'd like to invite them and make them understand where we're coming from."

—Phoebe Atagotalook, Inukjuak

These interview excerpts highlight the importance of feeling welcome and accepted (*Tunngasuttita)* when consulting the services. Emphasis was also placed on the idea of meeting the other in person, not believing in the prejudices largely disseminated in the media and by other health care professionals already working in the region. In sum, respondents emphasized the importance for health workers to demonstrate openness and curiosity towards Inuit culture, qualities which, from the participants' point of view can contribute to improving the quality of the caregiver-user relationships.

Needs in Terms of Developing Patient Services

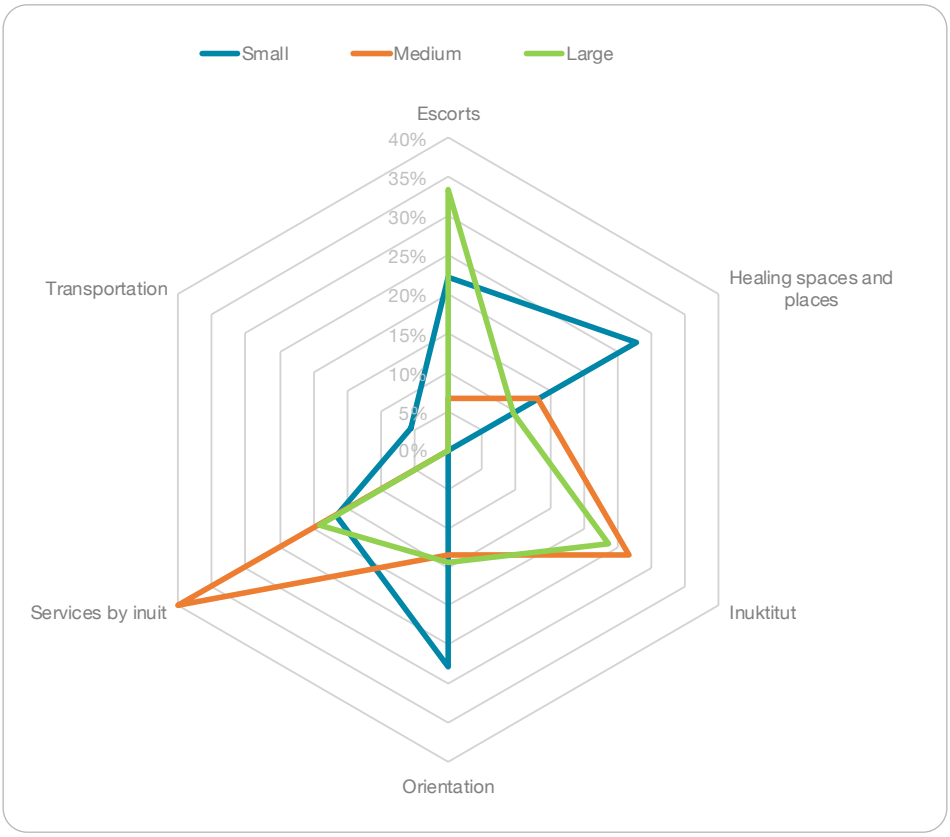

Figure 24: Cultural safety—improving patient services

The need to develop patient services is reflected here in different ways depending on community size. Among the respondents from the larger communities, patient services were particularly emphasized in relation to the problem of escorts and the need for services in Inuktitut as well as services provided by Inuit. For the respondents from the smaller communities, it is important to create open spaces in the physical locations where healing occurs. This means not only providing spaces for holistic healing sessions but especially to integrate elements of cultural safety into the services currently provided. Many persons pointed out that the fact of not being able to go out on the land or even simply outdoors because of their limited mobility greatly affects their well-being.

Initiatives creating opportunities for outings from the hospital (on the land or even in the community), eating traditional food and participating to community life were mentioned as very conducive to healing. By emphasizing the importance of making various locations for health and well-being accessible, Inuit are asking for a greater contribution to patient's mobility. Small actions such as systematically providing patients in the North with portable oxygen apparatus and wheelchairs better adapted to their needs so they can move about more easily in the community, would have a very large impact on users' well-being. This aspect concerns the elements of Pigunnasiarniq (being skilled, capable), Atuutiqatsianiq (being useful, occupied and active) and even Saimatsianiq (being at peace with oneself and others) of the IQI model, as being out on the land and being able to visit people are factors that contribute much to inner peace and well-being, according to the persons interviewed.

"For me as an example: I'm still able to walk but if I cannot walk anymore are they're just going to put me aside? Because there's roads that go far, there's vehicles… It would be good if they take us out (…) by boat or bring us across the river and take us out on the land not even for a full day even if it's just not full day it would be so big for us."

—Tilly Alasuak, Puvirnituq

The respondents from the medium-sized communities often pointed out the need to have access to services provided by Inuit workers, followed by the need for services provided in Inuktitut. The fact that traditional Inuit knowledge has practically no place in the current health-care system was pointed out by many respondents, concerning both physical and psychological health. The interviewees expressed the feeling that sometimes, their traditional knowledge could truly help more effectively than what is offered by modern medicine. Moreover, the fact that the health-care system shows very little openness toward such traditional knowledge leads to a sentiment of inferiority, which is evidently an obstacle to the users' acceptance of the health system.

"We are still being treated like second-class citizens or third world people by those supposed to be equal to us in Quebec. When my mom and dad were growing up they saw the nurses and doctors and lawyers as gods. They knew more about life than my mom and dad and my grandmother knew: "They're experienced, they're educated, so you have to listen to the educated people." I am educated. I don't have their diplomas on my wall but I'm educated, I'm experienced, I'm knowledgeable. (…) But those in charge those in power who are looking down at us Inuit (…) because nobody is giving the Inuit who has a knowledge and their wisdom and their life experiences to help other Inuit."

—Bernie Adams, Kangiqsujuaq

"We know people or have heard of people who know what to do, who can help, in terms of culture I mean, but where are they? So that's something I would like to see in the future. What we're living today and what we're going through, we try to see psychiatrists, but I think it would be more effective if we used our traditional knowledge to help. Communicating with the patient before the problem becomes too big, to treat him right away, if we could do it through culture, through what we know traditionally, if that could be made possible, I think it would be a good way of doing things."

—Alicia Ajagotaq, Kuujjuaq

In fact, the respondents who discussed this issue would like the natural helpers in the communities to be identified and be more clearly involved in the health-care system. This issue is linked to the following health conditions: Ilitarijautsianiq (being recognized for one's efforts and contributions), Pigunnasiarniq (being skilled, capable, in control of one's surroundings and life], Ippigusutsianiq (being aware, observing events, one's surroundings, environment, other persons, animals) and Atuutiqatsianiq (being useful, occupied and active; boredom is unhealthy, being active is productive). Including the Inuit as caregivers contributes much more than just users' health; it is also conducive to community health in general.

> *"I think it would be [better if we were] treated... less as a patient and more like a part of the community. This is not just that person's problem it's... we should all try to help one another and involve more people in the community to see what support is available. (...) you'd probably feel more welcomed wherever you were. You're not just a patient who's being treated, share a part of the support system in the Inuit way."*
>
> *—Chesley Mesher, Tasiujaq*

Facilities in Nunavik

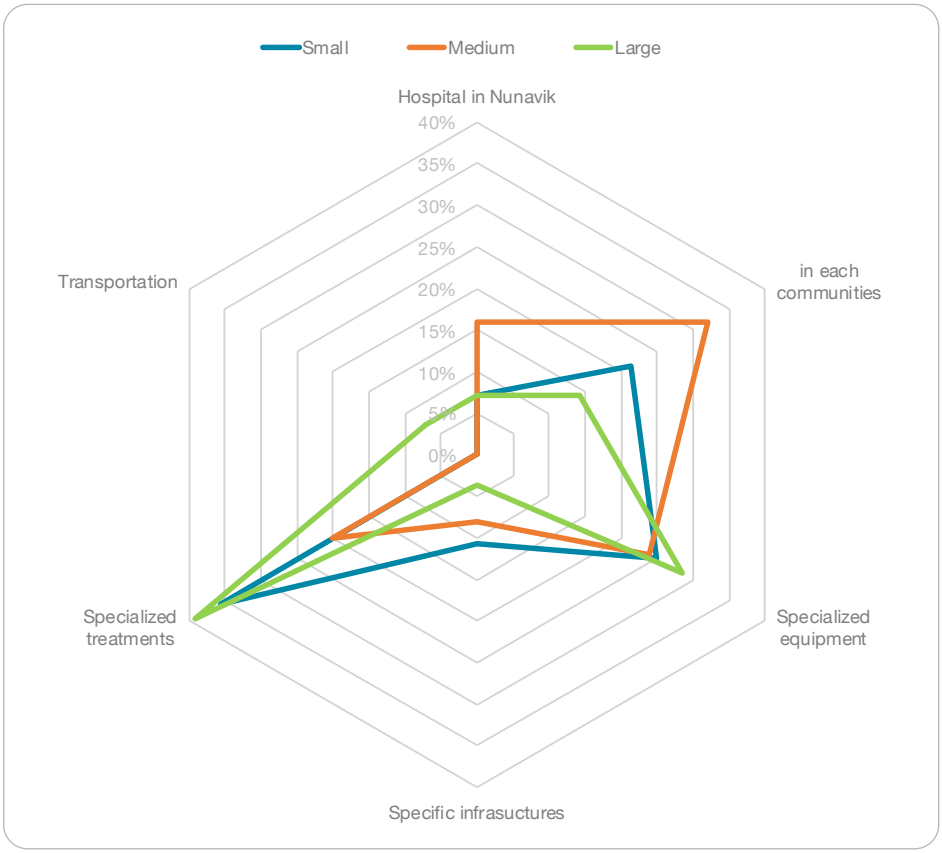

Figure 25: Infrastructures and services required in Nunavik

The figure above shows how development of specialized treatments in the North is a priority for the respondents of all the communities.

Any treatment that requires a prolonged stay during which the patient would normally be able to rely on assistance from family or other loved ones for recovery is the topic here. The population clearly expressed the desire for some minor surgery to be available in Nunavik. In particular, knee surgery and eye surgery were mentioned. Indeed, all operations or treatments that require recovery time and a stay of a certain duration in the South would be gratefully welcomed in the North by *Nunavimmiut*. Chemotherapy is also very demanding on patients who, for each treatment session, must travel by air and then be isolated from their families and support network, sometimes for long periods while they undergo treatments, and this in a state extremely difficult to deal with both physically and emotionally. One respondent recounted that her mother's final years were terrible because she was afraid of flying but had to travel regularly for chemotherapy in the South, whereas the poor prognosis had not been clearly announced. "If she had known, my mother probably would never have undertaken chemotherapy and would rather have spent her final moments more peacefully in Nunavik."

Other services are also in demand in Nunavik: MRI, CAT, not yet available in the northern villages, and not just in terms of X-ray equipment but also in terms of the technicians essential to the procedure. The persons interviewed gave the example of Inukjuak, which does have an X-ray machine but, for some time now, no technician to operate it, which in the end does not foster rapid and efficient diagnosis of the patients requiring X-rays.

The fact that certain services are available in some communities only was also raised by many respondents, who would like dentistry and midwifery services, for example, to be more accessible locally. Palliative care is also not always possible in the communities; the restriction in bringing family to Kuujjuaq or in the South limits the support of the dying to immediate family and is not aligned with Inuit traditions.

Results of Phase 3: Focus Groups

What were the main findings obtained from the focus groups?

- The development of mental health programs, healing programs, promotion of healthy lifestyles at an early age, improving worker attitudes, developing training programs, improving the quality of services, improving patient services, and attracting and retaining staff are the eight themes that emerged from these prioritization exercises.
- A number of solutions were proposed to address these issues, including improved family and culturally sensitive services, equity of access and continuity of care, actions to support families within communities, and improved quality and safety of services.
- The strategy to best address all of the identified priorities for action is to increase the number of Inuit staff as care providers.

Objectives of the Focus Groups

The objectives of the focus groups were to (1) validate and prioritize the issues raised during the Phase 2 individual interviews , and (2) propose potential solutions to address the prioritized issues.

Profile of the Participants

The following table shows the composition of each focus group in detail. Two participants were invited from each community and a minimum of four participants ensured that the planned activities could be carried out adequately. Each of the three groups therefore ended up with five or six participants.

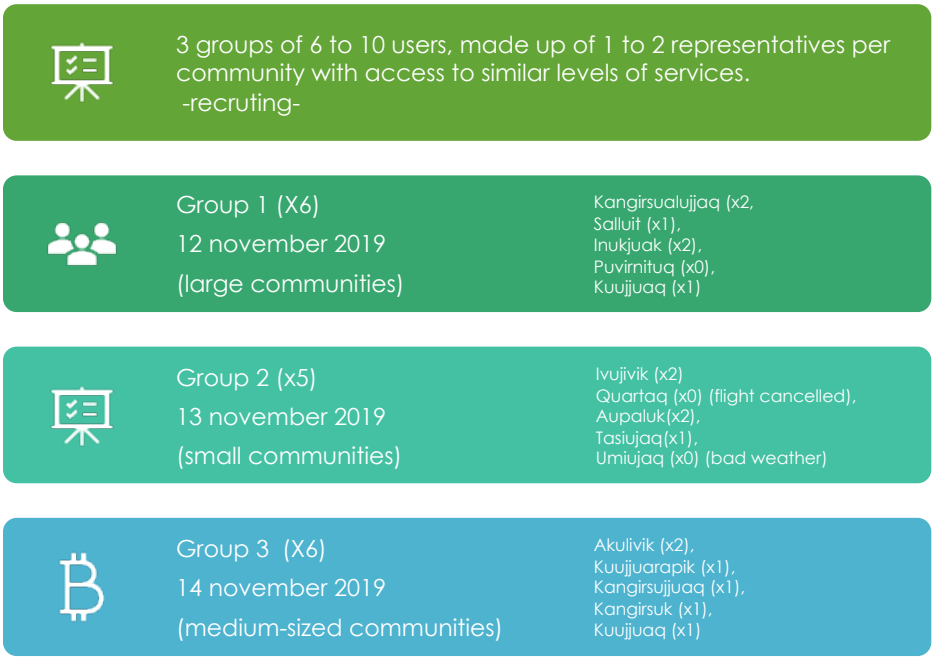

Figure 26 : Composition des groupes de discussion

Starting Data

Table 7: Topics and issues from the individual interviews

Topic	Priority issues			
Improve workers' attitudes	Curiosity and openness	Empathy	Honesty	Respect
Improve patient services	Services provided by Inuit	Orientation	Policies on escorts	
Develop training for Inuit	Promotion of existing resources	Train specialized Inuit personnel	More training on mental health	
Attract and retain personnel	Attraction and retention of specialized personnel	Experienced physicians and other personnel in each community		
Improve quality	Improvement of communications and follow-up between centres	Access to a second opinion	Improvement of transportation services	
Develop mental-health programs	More opportunities to speak out	Support for families	Support for and development of programs to help men	
Promote healthy lifestyles at an early age	Promotion of healthier drinking habits and information about consequences of alcohol abuse	Learning to prepare and cook food	Support for young parents	Development of parental skills
Develop healing programs	Learning how to forgive oneself	Healing sessions on anger management	Six-month rehabilitation programs	Learning to deal with past trauma

This table presents the various topics and issues on which the focus groups worked. The column on the left lists the eight principal topics raised by the participants during the individual interviews. Each line gives details on the issues linked to each topic. In preparation of the information, 26 main issues from the interviews were selected, based on frequency.

Validation of Priority Topics

Two methods were used to validate topics' importance for the focus groups' participants as well as organizing them by order of priority. Development of programs for healing, development of programs for mental health, promotion of healthy lifestyles at an early age, improvement of workers' attitudes, development of training programs, improvement of service quality, improvement of patient services, and attracting and retaining personnel thus make up the eight issues that came out of the process of establishing priorities.

As can be seen in the figure above, the ranking of these eight priorities tended to vary slightly according to community size.
For the smaller communities, the issue taking top priority was respect, followed by services provided by Inuit and access to experienced workers in all the communities.

For the participants from the larger communities, dealing with past trauma was the first priority, followed by acquisition of parental skills and specialized training for Inuit workers.

The participants from the medium communities placed priority on access to support groups for men, access to specialized and empathetic workers, and development of healing services aimed at anger management.

The issues were identified as being almost as important as those previously mentioned and should also be considered in the development of the service supply.

Figure 27: Priority of topics, direct method

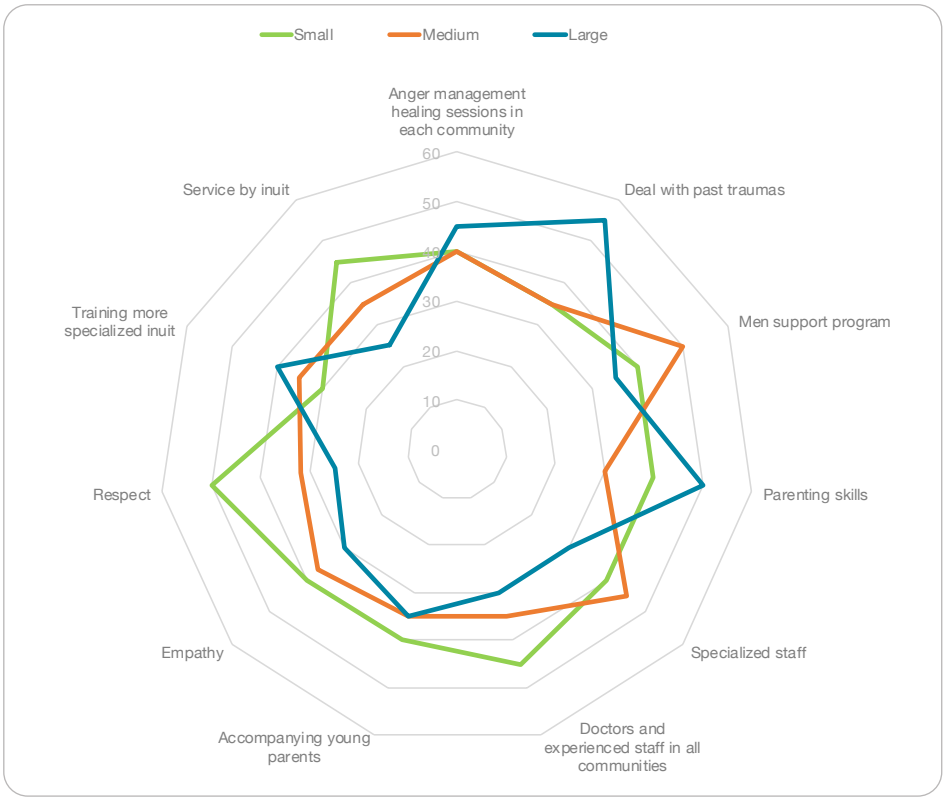

Figure 28: Priority issues, by community size

Potential Solutions According to Priority Topics

1. Improving Mental Health and Addictions Services

The urgent need for services in mental health prioritized by focus groups participants refer to many of the conditions deemed essential to Inuit health, including:

- Tungngasuttitaq: feeling welcome in one's surroundings (not feeling awkward or out of place, not feeling debased, pointed out or ashamed);
- Aaniagunnailuni: living without pain;
- Saimatsianiq: being at peace with oneself and with others;
- Atuutiqatsianiq: being useful, occupied and active;
- Pigunnasiarniq: being competent/capable (in control of one's world and life);
- Kamatsianiq: being prudent, aware of what one is doing, in order to think ahead, be prepared for the unexpected, think before acting;
- Ilitarijautsianiq: being recognized and rewarded for one's efforts and contributions.

Developing Healing Programs

The participants from larger communities proposed creating a support network for families to help them deal with major trauma, including trauma rooted in Nunavik's colonial history. Participants pointed out that it would be pertinent to train several Inuit local workers to respond to the large number of requests for healing and mental health support; they also emphasized the importance of organizing interventions to support these workers and prevent burnout. Indeed, the few Inuit who obtain diplomas as social workers are quickly overwhelmed by the high demand for their services.

Developing Mental Health Programs

Participants from medium-sized communities insisted on the urgency of providing better services for persons dealing with addictions and mental health problems. According to them, the current services in psychology or psychiatry is clearly insufficient on the territory to deal with the magnitude and severity of the crises in the communities.

One participant shared her personal story as an example, stating that when her child died accidentally, she only had access to two support sessions with the psychologist: one after the accident and the other three months later. In her opinion, that was far from sufficient to help her adequately get through the trauma of such a tragic event.

The following are some of the suggested programs and services by the focus groups participants:

- Psychological support services available in all communities at all times;
- Services for screening and supporting people suffering from post-traumatic stress disorder;
- Longer programs for dealing with addiction, including detox and anger management;
- More men's support groups following the *Unaaq* model developed in Inukjuak, as well as more services for women victims of violence.

During the interviews it was mentioned that many people in distress turn to the church but that this is not necessarily appropriate for everyone and that it would be essential to develop other support options within the health system for Inuit wishing to regain some

emotional and psychological well-being. The interviewees felt that it would be important to educate the population to stop stigmatizing people with mental health problems who need psychological support.

According to the participants, mental health services should also be able to promote the autonomy of people with chronic and persistent problems. The lack of specialized centers in Nunavik for people with mental health problems would cause great hardship for families, who are often forced to send their loved ones out of the community.

Training Inuit Workers in Providing Mental Health Support

The participants from the larger communities emphasized that it would be essential to train Inuit as mental-health workers. That would ensure a more stable coverage in terms of mental-health services, besides providing more culturally safe intervention in the users' own language. Indeed, many respondents affirmed that they are generally more comfortable expressing their frailties to another Inuk and in Inuktitut. These workers could also create support groups and enable better detection of post-traumatic stress disorder that, in their opinion, is very likely widespread among the population.

Provide Information on Responsible Alcohol Consumption

The participants from the medium- and larger-sized communities discussed the importance of organizing more awareness activities for the general population concerning scientific knowledge on alcohol consumption and its consequences, in order to foster responsible drinking. The participants reiterated that such information is rare in the villages and even in the communities where alcohol sales are permitted. According to these participants, accurate information on the consequences of alcohol abuse should be widely circulated among the public, particularly the impact on risks of accidental death, homicide, suicide and child neglect.

During the interviews, the respondents also mentioned that information is not readily available or tends to be unreliable. One person compared the situation to the moment in the past when the first cigarettes were sold: no one knew they caused cancer, and the consequences became evident only much later.

Finally, these participants also pointed out the importance of choosing the right communication channels to reach *Nunavimmiut*, as they can be quite different from those used to reach the populations of urban centres in the rest of Quebec.

2. Improve Cultural Safety

Improving cultural safety is directly linked to several components of the relational aspect which is central to the IQI health model , including Ippigusutsianiq (being aware and observant of surrounding events, environment and others), Tungngasuttitaq (feeling welcome in one's surroundings), Aaniagunnailuni (living without pain), Pigunnasiarniq (being competent/capable), Saimatsianiq (being at peace with oneself and with others), Kamatsianiq (being prudent, aware of what one is doing) and Ilitarijautsianiq (being recognized and rewarded for one's efforts and contributions).

Adopting an Attitude That Demonstrates Empathy

As mentioned, focus groups identified workers' attitude ranked second among the list of priorities for improvement of the Nunavik health system. As a matter of fact, interviews confirmed the survey results indicating that the communication between caregivers and users more or less met the participants' expectations, as long as it related to facts such as explaining medical conditions, or treatment steps; many interviewees, however, suggested that caregivers' communication would benefit greatly from adopting a more empathic and sensitive approach as well as an attitude of greater curiosity and openness toward Inuit culture .

Indeed, according to the people interviewed, negative prejudices against the Inuit still exist among some of the workers, thus further harm the already fragile trust that the Inuit have in the current health care system. Honesty, respect and empathy on the workers' part are attitudes that should be encouraged and developed through proper training.

Interviews often focussed on the participants' impression that many workers from the South come to practise in the North primarily for the salary and benefits it provides, without demonstrating true concern for their patients' well-being; participants admitted at times feeling that health care professionals were not sufficiently interested in understanding the patients realities to provide treatment options adapted to their situation.

One respondent said she had the impression that diagnosis is often made with a certain urgency, without taking the time to ensure it is accurate. She recounted that she had been visiting the CLSC for several months because she had been experiencing pain, but the regular personnel always gave her Tylenol without seeming to want to explore the cause further. Seeing that a replacement physician was present, her husband managed to arrange an appointment for her. The physician, who finally truly showed interest in her case, she ended up with a cancer diagnosis. From that experience, she concluded that love and compassion are lacking in health care, and she would like the personnel to treat users with the same interest and the same motivation to help as if they were members of their own families.

Furthermore, focus groups participants indicated their wish for organizations managers to be honest and transparent, in both their professional and personal lives. Indeed, they felt, workers who adopt the behaviours that they promote are always more credible and trustworthy in the eyes of the population, then those who don't.

More Services Provided by Inuit Workers

The participants from the medium-sized communities also expressed the desire to hire more Inuit in the health system to provide services. They noted, among other things, that some Inuit are already helping their fellow Inuit as natural helpers and they should be recognized and be part of the health care system in Nunavik. Respondents also expressed a certain frustration with the current system, which considers only diplomas and places no value on life experience and cultural competency, recalling that before the arrival of government services, the Inuit learned primarily by watching and listening. According to them, the added value of Inuit employees is based on their profound concern for helping their loved ones and contributing to the community.

In fact, Inuit workers have a greater tendency to remain in place once they have acquired skills and experience; thus, hiring more Inuit would also reduce problems linked to personnel turnover and the communication difficulties linked to use of several languages and recourse to interpretation.

Moreover, the participants suggested that training in health-related fields, such as for first responders or nurses, be given in the schools of Nunavik (for example, Pigiursavik adult education in Inukjuak). It could also be a good idea to improve efforts at promoting health-sector jobs among Inuit youths, for example by organizing a career week with activities showcasing possible health-sector careers in Nunavik.

By opening up possibilities for specialized training for the population and by inviting people to engage actively in jobs recognized by the health system, the impact would be felt in the aspects of Ilitarijautsianiq (being recognized and rewarded for one's efforts and contributions), Atuutiqatsianiq (being useful, occupied and active), Kamatsianiq (being prudent, aware of what one is doing, in order to think ahead, be prepared for the unexpected, think before acting) and Pigunnasiarniq (being competent/capable).

This would enable not only serving patients more effectively and in a culturally safe manner but also creating a profound sense of contribution and empowerment among the Nunavik population.

3. Improving Equity in Access and Continuity of Care

The third element raised during the focus groups was the need for access to more services in the North. Nunavik being an isolated region accessible only by air[33], access to health services is understandably limited, Although focus groups participants stated appreciating having access to specialized services, lodging and transportation at no cost to the user, they would nevertheless welcome the possibility of having more service infrastructure in Nunavik.

In some cases, services, they suggested, should be extended to all the communities (such as dentistry, midwifery, and X-rays), whereas others need to be urgently developed, in mental health particularly.

Recruitment and Retention of Specialized Workers

During the focus group, participants from smaller communities clearly expressed their wish for more specialized services in Nunavik, especially general surgical and pediatric services. Participants from larger communities added that more pediatric services would be welcome, given Nunavik's high birth rate. During the interviews, many expressed just how burdensome the procedures to arrange minor surgery in the South can be; some of surgery requiring days, weeks, or sometimes months of follow ups, hence causing significant disruptions to family life, prolonged absences from work and, once again, being isolated from one's support network.

Accompaniment during Travel to the South

Phase 2 interviews revealed that escorts must be provided for all users being transferred to Montreal who do not speak English regardless of age. Young adults do not always speak French or English well enough to consult health care professionals. This point is related to the previous one of communication but especially involves referrals, because once they are alone, they sometimes have difficulty understanding where they should go, at what time, by what means and even for what procedure. Participants from larger communities also proposed that escort services be recognized and that positions be created for them in the health care system.
At the same time this would allow to provide them with basics training such as cardiopulmonary resuscitation and first aid skills.

In other words, participants to both the interviews and the focus groups' confirmed the importance of providing escort services in Inuktitut by qualified Inuit workers so that Inuit users can better understand what is happening (Pigunnasiarniq: being competent/capable [in control of one's world and life]), as well as contribute to their peace of mind (Saimatsianiq: being at peace with oneself and with others).

In actual fact, Inuit escorts act as much more than interpreters; they help clarify situations for both caregivers and users, thus enabling users to make informed decisions regarding their own health (Kamatsianiq: being prudent, aware of what one is doing, in order to think ahead, be prepared for the unexpected, think before acting). Further, being escorted can help users avoid uncomfortable situations, or suffering for hours or days, simply because they are not familiar with the hospital environment (Aanniagunnailuniq: living without pain). Finally, having an escort serving as mediator aligns with Ippigusutsianiq (being aware and observant of surrounding events, environment, and others).

33 Maritime transport is possible in the summer months, but only for cargo, not passengers.

4. Developing Support Services in the Community

Support Groups for Persons with Cancer

Although this subject was not among the issues prioritized, the focus group participants from larger communities spontaneously suggested that it would be useful to set up support groups for people with cancer and their loved ones. Such groups could, among other things, offer activities enabling participants to become more aware of their strengths and weaknesses in their management of the disease and its treatments; indeed, many explained how cancer treatments affect patients because they are required to travel to South where they tend to feel isolated from the social support network they need.

Support Programs for Families

The need for other types of community-based support programs was also discussed during focus groups in all the communities, namely those aimed at supporting young families. Participants emphasized the impact of the intergenerational gap on many young parents' parental skills, and that it would be useful for them to have access to support resources. They added that having Inuit elders hold workshops targeting young parents could help bridging this gap in the transmission of Inuit knowledge and traditions.

The type of activity proposed varied according to the size of the participants' communities:

- Those from smaller communities proposed designating an Inuit elder in each community to teach young parents and help restore traditional parental skills;
- Those from medium-sized communities, on the other hand, proposed using the course on parental skills which has been developed by KI (kativik Ilisarniliriniq), to which more cultural elements could be added;
- And finally, those from larger communities proposed teaching parental skills in school, with the help of elders as a sources of Inuit knowledge on the subject.

Other structures to support families which were brought up by participants from all the communities include specific infrastructure to facilitate the mobility of people with disabilities, as well as elders living in the community. It was also mentioned the need for more gathering spaces within the communities for holding workshops and training.

5. Ensuring Health Care Services Quality and Safety

During the interviews, the participants pointed out that availability of physical-health services and the presence of qualified workers are seen as effective elements of the system. On the other hand, improvement of service quality was seen as a priority issue in the focus groups, thus confirming the survey results of Phase 1, in which effectiveness was one of the topics that least meet the users' expectations. Moreover, inefficiency and poor continuity between points of service were reported as causes for users' impressions of lack of safety.

The Role of Inuit Workers in Service Quality and Safety

Being served in Inuktitut by Inuit personnel was reported by many participants as essential to improving the efficiency of the current healthcare system. According to these participants, hiring more Inuit as caregivers would greatly enhance service efficiency by eliminating the cultural and language barriers which affect the quality of interactions in the health care system at the present; indeed, having to rely on interpreters hampers the consultation process and increases the risk of misunderstanding, which in turn contributes to the users' perception of the services inefficient, and unsafe.

Both focus groups and interview participants would like the interpreters to have access to specialized training on medical terminology in Inuktitut as well as to gain a better understanding of the medical approach in order to provide better support for patients. Moreover, many affirmed not being comfortable speaking about their problems with non-Inuit care providers; here again, results seem to reiterate the considerable impacts that the current lack of Inuit staff has on the participants' overall impression of service inefficiency and lack of safety. Hiring more Inuit in the health-care system and training them for professional positions would have a true and positive impact on the Inuit communities.

Providing Access to a Second Opinion

Participants from both large and small communities stressed the importance of allowing users to have access to a second opinion, when they feel their situation is not properly cared for. This is in fact currently practically impossible, since once the village nurse judges that users' conditions do not require that they'd be seen by the physician, users have no other options than to try going through triage again later, only to be assessed by the same nurse and thus again denied access to the physician. This situation leads to users' inability to have access to a second opinion, even when their symptoms persists.

One participant also reported how the CLSC physicians in her village once believed she had become addicted to the medication she was taking for chronic pain and thus began refusing to renew her prescription. In great pain, she tried to arrange an appointment with a chronic pain specialist on her own, but was told she needed a medical referral; as her CLSC's health care personnel persisted in denying she was truly in pain, her situation quickly became hopeless. In doubt, she should have had help to get off the pain medication.

Thus, if a user expresses doubts about an evaluation by the physician on site, he will simply not be able to consult another physician. According to many participants, such situations have already caused major delays in diagnosis. In Nunavik, the physicians making the rounds of the smaller villages are often the same. Although that may be a positive factor for continuity, it can be a problem if a user has not established a relationship of trust with a given physician.

To resolve the difficulty of access to a second opinion, the participants proposed using more technologies such as telemedicine or teleconsultations. Keep in mind that in Nunavik, info-health is not available, and thus the only way to obtain advice by telephone is to call the CLSC and speak to the same person consulted on site.

Experienced Physicians and Workers in All the Communities

In the focus groups as well as in several interviews, participants from smaller communities pointed out that it is not rare for health-care personnel practicing in the North to be young and relatively inexperienced. The personnel's lack of experience, they said, along with the multiple challenges of the practice in the North, can sometimes have serious negative effects on the quality of the care provided.

Some admitted being quite shocked to see young new graduates with very little life experience and who are not parents themselves, make critical life-changing decisions such as removing children from their family. These participants hence would like to see measures in place to ensure that the personnel hired in all communities have sufficient professional experience to be able to handle the complexities of the practice in Nunavik.

Overall Findings and Recommendations

The project's overall objective consisted of integrating the users' perspective into the process of the Nunavik Regional Clinical Plan aimed at developing a regional service supply that better responds to the expectations of Nunavik community members. The principal interest of this three-phase consultation was the possibility of combining the results of the information-gathering methods:

- Quantitative data from Phase 1 on the perception of the quality, accessibility and cultural safety of the health services currently provided in Nunavik;
- Qualitative information gleaned from the individual and group interviews of Phases 2 and 3, further exploring the users' perspective on health, its challenges and their experiences with the services.

The cross analysis combining all results draws up a rich, in-depth profile of the users' perceptions of the health services available to them and highlights the aspects of the health system requiring the most urgent and profound changes.

Foster Healing and Mental Health

The establishment of priorities in Phase 3 showed clear consensus for the development of services fostering mental health and emotional well-being and the need for mental-health services (larger villages) and spaces for healing (smaller villages). This corroborates several of the results presented in the preceding steps, in particular:

- The intergenerational impacts of colonialist measures on the Nunavik population's health, which are still felt today;
- The numerous weak points of current services in responding to the needs of persons suffering psychological distress or mental-health problems;
- The need for a full continuum of services in the region, fostering sound mental health, including spaces for holistic healing, as well as prevention and promotion programs in the areas of addictions and early childhood.

Intergenerational Impacts of Colonialism

The Phase 2 interviews definitely revealed the importance placed on the relational aspects of health and well-being (Inuuqatigiitsianiq). It thus comes to no surprise that all governmental measures forcing settlement and a sedentary lifestyle, as well as cultural assimilation of populations through measures marked by great violence, such as the slaughter of sled dogs, deportations to the High Arctic and removal of children from their families, are among the most important sources of the health problems that persist to the present day.

The intergenerational effects of those measures take many forms, which all in a way or another affect the population capacity in reaching the conditions they identified as essential to attaining collective health and well-being. The rupture in the intergenerational transfer of traditional knowledge impacted parental skills, the loss of connexion to the land affected their lifestyles and economic self-sufficiency, which all contributed to the loss of meaning, identity and ability to be useful to the well-being of loved ones. The accumulation of these collective losses over a mere generation or two manifests among the population through various forms of stress-induced behaviour, including abusive alcohol consumption and family and sexual violence.

Poor Access to Services

The results of Phases 1 and 2 confirm that the current services do not meet the population's pressing needs for psychosocial and emotional support. On one hand, conventional services in psychology and psychiatry are not regularly available in all the villages, a situation which probably contributes much to the low scores for access equity and service efficiency observed in Phase 1.

On the other hand, the system's lack of recognition of natural helpers' expertise and absence of spaces reserved for healing considerably limits users access to stable and efficient support. Participants emphasized the need for mental health support provided in their own language, by members of their community, using an approach anchored in Inuit values and practices. Moreover, these issues were strongly corroborated with Phases 2 and 3 identification of cultural safety, , and Inuit caregivers as important priorities for improving the current system.

Developing a Full Continuum of Mental-Health Services

There were multiple potential solutions mentioned by the participants in Phases 2 and 3 in terms of the required mental health services, particularly:

- **Services for health promotion and prevention** outside of institutions (in community settings, or on the land, for example):
  - Making traditional activities on the land accessible to all, including to community members with limited mobility;
  - Creating community spaces for activities fostering healing, collective well-being and resilience;
  - Developing support programs for young families, promoting of healthy behaviour (such as nutrition) and Inuit parental skills;
  - Expanding current support programs for men and women in difficulty;
  - Creating awareness activities for the general public to encourage responsible alcohol consumption.
- **clinical services in the North** (ideally in all the communities or at least regionally) providing, among other things:
  - Prompt access to psychosocial support in Inuktitut by Inuit workers trained for that purpose; these workers should include local natural helpers, paraprofessionals and social workers, the providers of such services should also have access to emotional support to avoid burnout;
  - Services for detection, diagnosis and appropriate treatment for people suffering from post-traumatic stress disorder;
  - Longer-term addiction treatment, including healing services, support for family members, and harm reduction interventions.
- **Specific accommodation and support services** to avoid transfer to institutions in the South for clients with chronic diseases:
  - People suffering from chronic mental-health disorders;
  - People with physical or intellectual disabilities;
  - People needing end of life support (palliative care).

Reinforcing Cultural Safety of Services

While the need to reinforce services' cultural safety ranked second among the priorities identified by Phase 3 focus groups, it was identified as the top priority for health care system improvement in Phase 2 interviews. In fact, multiple aspects of the cultural safety concept were raised across the three phases of the project:

1. The importance of developing trust at the core of the caregiver-user relationship;
2. The need for change in non-Inuit workers' attitude and how this affects users' perception of the quality of the services received;
3. The need to improve cultural safety of services as an important, multicomponent organizational change.

Trust at the Core of the User-Caregiver Relationship

Cultural safety is an increasingly widespread principle in the evaluation of health systems' capacity to respond to the needs of the Indigenous populations they serve. It is now recognized as going well beyond conventional intercultural approaches, emphasizing that true quality of care can only be achieved when users feel perfectly safe throughout the health care trajectory; Therefore only the users can define whether a service received is culturally safe and untainted by discrimination.

The interviews in Phase 2 demonstrated that the relational aspect central to Inuit health and well-being extends to the quality of the user-caregiver relationship. Thus, health care providers can contribute to Inuit users' health and well-being only if they succeed in making them feel heard, comfortable, and at peace, as well as show profound respect for users' integrity, priorities and perspectives.

In fact, the quality of the user-caregiver communications is at the core of the relationship of trust which can only be established, when health care providers demonstrate genuine openness and sensitivity to the users' experience. The importance of establishing this relationship of trust between non-Inuit caregivers and Inuit users simply cannot be understated, given the wounds of Nunavik not so distant colonial history. Indeed, a majority of non-Inuit professionals working in a context which tends to leave little room for Inuit knowledge and practices can be seen as a form of present-day colonialism, that could occasionally revive some of the users' past trauma. If one adds to this already complex picture the inevitable communication problems which tend to arise when care providers and users are from different cultures and speak different languages, it becomes easy to understand why the users' impression of cultural safety is so weak.

Attitudes Sought in Professionals from outside the Region

These findings explain the emphasis that the participants in Phases 2 and 3 placed on improving the attitude of professionals. They said that prejudices against Inuit are still present , in the attitude of some professionals, further undermining the users' trust in the health care system. Honesty, respect, and empathy are thus the attitudes Inuit look for, along with greater openness to participation in community life, curiosity towards Inuit practices and culture, and the desire to stay on the territory long enough to truly understand local realities.

These findings may appear contradictory to those found in Phase 1, where communication, cultural safety and safety of services were reported as the aspects of the services which best met the users' expectations. A closer examination of these results, however, reveals that, while the most appreciated aspects of communication primarily involved transmission of practical information (explanation of the diagnosis, steps in treatment,

etc.), the empathy and sensitivity items appeared not to score very high on the users' expectations scale. Indeed, service reactivity to users' needs was in actual fact among the topics with the lowest scores, thus corroborating the broad consensus on the urgency of improving the cultural safety of services.

Cultural Safety of Services in Nunavik: the need for a Multi-Facetted Strategy

The participants of Phases 2 and 3 appeared to favour educational approaches to improving the cultural safety of services, by recommending training non-Inuit workers on the principles of cultural safety, but also training more Inuit as caregivers. Increasing the number of health workers recruited from within the communities is the primary means for establishing the conditions that foster the users' trust in the services: better communication, greater stability among workers and, finally, greater effectiveness of health care.

Training more qualified Inuit workers will, however, require a global approach applied in the long term, including:

- Promotion of health care professions and the diversification of the technical training programs available in the region;
- Promotion of the key role played by cultural interpreters and other paraprofessionals in supporting users;
- Creation and recognition of new roles for natural helpers and other interveners who, without having undergone technical training, possess key traditional knowledge that responds to the users' needs better than modern medicine (particularly in the areas of mental health and traditional healing).

The need for health professionals from outside the region will remain, in the short term, especially for the provision of the more specialized services. Training for these workers will therefore require to be strengthened, particularly by the incorporation of a experiential learning approach (cultural orientation and immersion programs) into the pre-departure training already available. Such training should also be made mandatory and continuous for all health care professionals, as well as put more emphasis on Nunavik colonial history and its consequences on Inuit health.

Develop a More Complete Service Supply in Nunavik

That said, the persons consulted mentioned their desire for a certain expansion of the service supply in the communities in order to limit transfers to the South for health reasons as much as possible. The elements attaining the greatest consensus among the participants consulted were the following:

1. importance of limiting the frequency of travel to the South;
2. lack of service continuity has sometimes very serious consequences;
3. expansion of the service supply in Nunavik.

Reduce the Need for Travel to the South

One of the main problem raised by the Phase 1 survey results was the lack of access equity in the region. As a matter of fact, users must often leave their community to obtain services that are available in most of the province's other regions. Hence many confirmed their wish to have access to the same level of front-line services which are available elsewhere in Quebec. Such demands seem to be consistent with the increasing prevalence of health problems which require specialized services, including mental health and addictions problems, as well as chronic diseases such as cancer, osteoarthritis, and cardiovascular diseases. The recent years' marked increase in transfers to

the South at the expanse of the person, and of high financial costs are unlikely to be sustainable in the long term.

This problem also brings up issues that are particularly central to the way health and well-being are perceived in Nunavik. Indeed, the relational aspect of health appears to be particularly challenged by the very services whose goal are to improve patients' health. In addition, long-term separation from loved ones during transfers to the South cannot help but bring to mind sad memories from the tuberculosis epidemics of the past. Hence, issues of access equity are profoundly interrelated with those of cultural safety, as well as with those of overall service pertinence and efficiency.

Reinforcing Continuity of Care in Nunavik

Aside from the users' frequent travel outside their communities, the participants also often mentioned that many other aspects of the current health system create a major rupture in the continuity of care, particularly:

- The high **personnel-turnover rate**, which results in difficulties with follow-ups, not only with the services provided in the South but also for those provided locally:
  - Gaps in patient follow-ups can create delays in diagnostics and treatments which could have serious consequences on service efficiency and thus on the users' recovery;
- Although the survey respondents indicated that current referral services meet their expectations well enough, the discussions often raised certain problems linked to **unmet needs for accompaniment**, both in the North and during travel to the South:
  - Many reiterated their need for accompaniment by an Inuktitut speaker, in order to properly understand the (often complex) information provided by non-Inuit interveners, as well as to properly navigate their way through the health system (obtaining appointments, getting around, etc.);
- Further, transportation services are greatly appreciated when provided and functional, both during stays in Montreal and for appointments at the local clinic; in fact, although the villages are small compared to the large urban centres, users are rarely able to get around without the assistance of a loved one to transport them, which can be a serious obstacle to access to services (even when available locally).

To respond to the needs expressed by the participants of improving the service supply and the continuity and effectiveness of care, the participants of Phases 2 and 3 suggested the following strategies:

- **Expanding the regional service offer,** in order to reduce the need for users' to travel outside their communities ;
- **Enhancement of the system for user follow-up** throughout their trajectory in the system, and this both in the North and during transfers to the South.

Expanding the Regional Service offer

The services which were suggested should include a complete range of front-line services in all the communities:

- Access to primairy care services in dentistry, maternity health and radiology in all the villages;
- Prompt access to a physician when a user requests:
  - especially when symptoms persist in spite of the interventions by the nurses on site;
  - recourse to telephone consultations (or by teleconference when possible) could make this service accessible, even in the smallest villages;
- access to psychosocial support services at all times in the communities this could be made possible through training local workers, who can be supported by professionals (psychologists, psychiatrists, etc. even remotely) when the latter are not visiting the communities.
- **Specialized services** in the region:
  - Although it may not always be possible to provide services requiring highly specialized equipment in the region, some second line services could be made accessible through specialist visits and telemedicine;
  - The services most often mentioned include common orthopedic surgeries, pediatrics, oncology, and palliative care.

Enhancement of the System for User Follow-Up

- Establish **referral** services (info-health model) to inform the general public about the services available in Nunavik and the procedures to access them.
- Establish services by Inuit **patient navigators** in all communities to support users through the trajectory of care (cultural mediation between professionals and users, transportation, etc.):
  - locally, these services should help ensure continuity of information between caregivers;
  - these services should work in conjunction with the Ullivik Centre's support services when users are required to travel to Montreal.
- Establish **community-based support** services for persons with chronic diseases and their loved ones:
  - this need was mentioned for cancer patients, those with a physical or intellectual impairment, and those with serious and persistent mental-health problems.

Conditions Necessary for action on these Recommendations

While some of the solutions proposed above are in fact already being implemented, others have yet to be developed. The very first step to their realization will therefore be the validation by the NRBHSS so that they can be integrated into the appropriate level in the regional planning process.

Key Components of the Nunavik Cultural Safety Strategic Plan :

The figure below illustrates the four main health care system's components which should be involved in the implementation of all the above recommendations; indeed, these can all be integrated under the umbrella of a global regional strategic plan for culturally safe services for all users in Nunavik. Much more than a mere case of adapting services, the NRBHSS is aiming for a true transformation of its internal operation, in accordance with the principles of User's partnership, decolonization of health institutions, and respect for Inuit knowledge, values and practices.

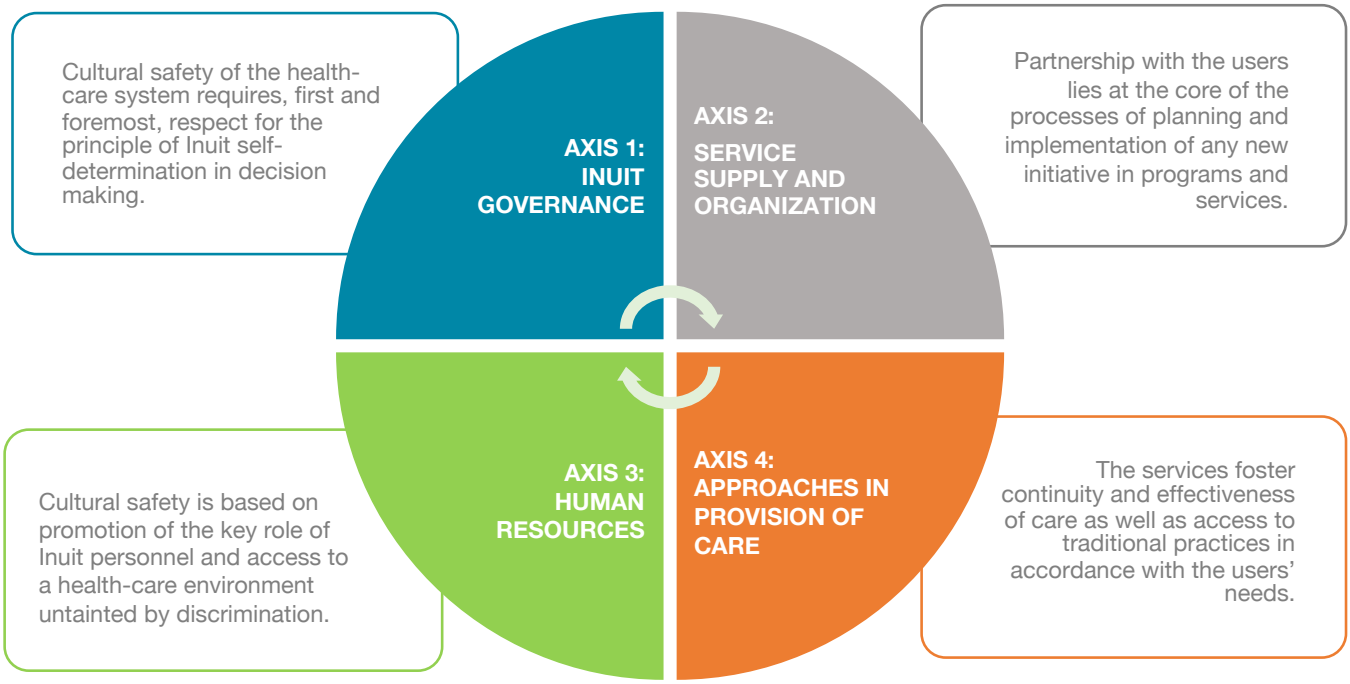

Figure 29 : Quatres axes structurant de la sécurisation culturelle de l'offre de services

For each of the components illustrated above, there are initiatives already underway within the organization. For example, for Axis 3 (human resources), the NRBHSS already has trainings on cultural safety aimed at non-Inuit health care professionals. The NRBHSS also offers a certain number of professional trainings for Inuit workers.[34] These strategies, however, could be further improved using the recommendations formulated in the present report.

34 For example, efforts are under way for application of Bill 21, Act to amend the Professional Code and other legislative provisions in the field of mental health and human relations. From a perspective of service quality and safety, Bill 21 limits the right to perform certain activities to professionals who are members of an order. Whereas the various legislative frameworks define the provision of services equivalent in quantity and quality in the Inuit communities, the application of Bill 21 would result in ruptures in services and would impose obstacles to the quality and cultural safety of the services received: the services, for the most part, are provided by non-Inuit who possess little training in intervention in Inuit cultural settings and no knowledge of Inuktitut (from An Integrated Vision of Cultural Safety in the Nunavik Health and Social Services Network, paper presented by the NRBHSS at the Viens Commission, February 12, 2018).

That said, some components are rather recent in the organization's operations and, for the moment, are in the preparatory or pilot phase. For example, Axis 2 is currently being implemented by the team responsible for partnership with the users.

> *"In the context of health care and services, (…) user partnership ensures that the experience of the users and their loved ones corresponds to their expectations, needs and life projects, as well as fosters their self-determination. More broadly, that is, in a context of organization of health care and services as well as governance, the users and their loved ones, through their knowledge and as partners throughout the process, contribute to the improvement of the quality, pertinence and safety of health care and services and to the improvement of the health and social services system."*[35]

Although partnership with the users was not mentioned directly by the respondents, the three steps of the process presented here revealed the population's keen interest in being involved in the improvement of the health and social services supply.

Follow-up to the various recommendations will fall under Axis 1, via an advisory committee on cultural safety which is also currently in the preparatory phase. The NRBHSS has to be reactive to the proposed solutions by quickly applying those that are readily feasible in the short term and working constantly on developing solutions for the longer term.

35 Reference framework on the partnership approach between users, their loved ones and providers of health care and social services. Ministère de la Santé et des Services sociaux. 2018.

Major Organizational Changes

Thus, for the NRBHSS, development of a culturally safe health and social services supply necessarily goes through a substantial organizational change that particularly involves "changes in practice, development of adapted tools, personnel training, evaluation of implemented initiatives, and respect for standards of safety and quality."[36]

As with any organizational change of this scope, successful follow-up to the recommendations formulated in the present report will require a gradual approach, one that is well thought out and based on a common vision of the objectives pursued. This approach should also be reactive and adapted to the sometimes changing realities of the NRBHSS' organizational context.

The experience with similar initiatives carried out in other jurisdictions in Canada and elsewhere shows the importance of demonstrating the benefits (even in the very short term) of approaches centred on the clientele's needs, in terms of both the users' experience and their use of services, as well as on the caregivers' and their managers' satisfaction in the workplace.[37] Such demonstration will therefore require rigorous follow-up that will lead to learning and adjustments for all stakeholders.

On the other hand, the management of organizational change is also facilitated by the mobilization of people with both formal and informal leadership within organizations, as well as by paying particular attention to the needs of those responsible for making changes within their field of expertise. This will be a long-term process requiring the contribution of all, but the benefits in terms of health equity will be invaluable for the Inuit population of Nunavik.

Finally, the establishment of a framework and an ongoing evaluation process for cultural safety, allowing for the monitoring of developments in each of the areas presented, will be essential in order to measure the extent of these organizational changes.

36 An Integrated Vision of Cultural Safety in the Nunavik Health and Social Services Network, paper presented by the NRBHSS at the Viens Commission, February 12, 2018.
37 https://www.un.org/en/chronicle/article/primary-health-care-now-more-ever.

Conclusion

We hope we have succeeded in adequately illustrating the challenges raised by users of the health and social services in Nunavik, as well as the direct impacts of the obstacles they encounter in the current health care system. We also hope that the issues raised in the present report will be heard and addressed with all the seriousness and urgency they call for. Indeed, as stated in the Viens Commission report, numerous studies have been conducted in the past and numerous reports have remained on the shelves.[38]

Users are valuable witnesses to what occurs in the field. Their statements allow an assessment of the true impacts of their experience within the health care system on their health and other aspects of their lives. Increasing close collaboration with the users and communities in Nunavik, as was done in the current evaluation, will certainly contribute to the development of services that better address Inuit priorities, needs and vision of health. This process could help create relationships of trust between users and caregivers, thus contributing significantly to the improvement of the Nunavik population's health and the cultural safety of the health-care system.

This three-phase evaluation project compiled a considerable amount aof information on the users' point of view relative to the health and social services currently provided in Nunavik. The data-collection tools developed during this project will be used to conduct periodic assessment of the desired changes over the coming years.

38 Public Inquiry Commission on relations between Indigenous Peoples and certain public services in Québec: listening, reconciliation and progress. Final report, 2019, p. 496.

Methodological Considerations

The approach used in the present report ensured greater reliability of the results. In fact, the combination of quantitative and qualitative approaches at various phases and in this sequence allowed interviewing the users on certain results that required in-depth explanation and thus confirming the results obtained at the previous step.

Considerations in Phase 1: Survey on Users' Experience

The exploratory goal of this survey on the users' experience did not require an inferential statistical framework with a significance test.

Non-random sample

The survey, both online and on paper, was open to everyone in all the communities. No sampling method was established and everyone was free to participate. Moreover, a cluster of responses was expected around a given household (responses possibly being similar among individuals from the same household). No corrective measures were used to counter that effect. Simplicity in access to the survey was privileged.

Countermeasure

Evaluation of representativeness: Weekly analysis was performed while the survey was online to evaluate the respondents' representativeness of the Nunavik population's profile. Four variables were monitored: age group, sex, community and status (beneficiary or not). The results were deemed satisfactory.

Social desirability

The effect of social desirability comes into play when the respondents tend to reply according to what they believe is expected rather than that they truly think.

Countermeasure

Although this effect is always possible in any survey, the fact of not having performed sampling, which would imply the participants' engagement in the study without having been asked, likely enabled a reduction of this bias. The respondents all participated voluntarily because they had something to say.

Distribution of results

In spite of all the countermeasures applied, the results may nevertheless be too heterogeneous and lack a clear direction.

Countermeasure

To establish a clearer focus among the findings, the 75th percentile was used to arrive at the minimum score obtained for 75% of the participants. The findings thus represent what the majority of the respondents mentioned.

Considerations in Phase 2: Interviews

The interview phase was also subject to certain methodological biases.

Non-random sample

Like in Phase 1, recruitment for this phase was on a voluntary basis after open invitations were made. The users who accepted the invitation thus assuredly had less neutral experiences that do not necessarily represent those of most Nunavimmiut.

Moreover, the communities visited were not selected at random. Two factors (size and coast) were used in the selection.

Countermeasure

None. On the other hand, a degree of validation was made regarding the topics and replies in the first phase, which involved a larger portion of the population. That validation was deemed relevant.

Consideration in Phase 3: Focus groups

Non-random sample

Like in the other two phases, the participants were involved on a voluntary basis and their profile might be somewhat specific and unrepresentative of the general population in this phase.

Countermeasure

None. However, two validation methods were used (direct and indirect) in this phase to ensure consistency between the two phases. The direct method allowed placing priority directly on the topics covered in Phase 2, whereas the indirect method described those topics through an intermediate classification. The entire process enabled validation of the foundation of the work and the conclusions drawn from the previous interview phase.

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Appendices

Appendix 1: Service Trajectory

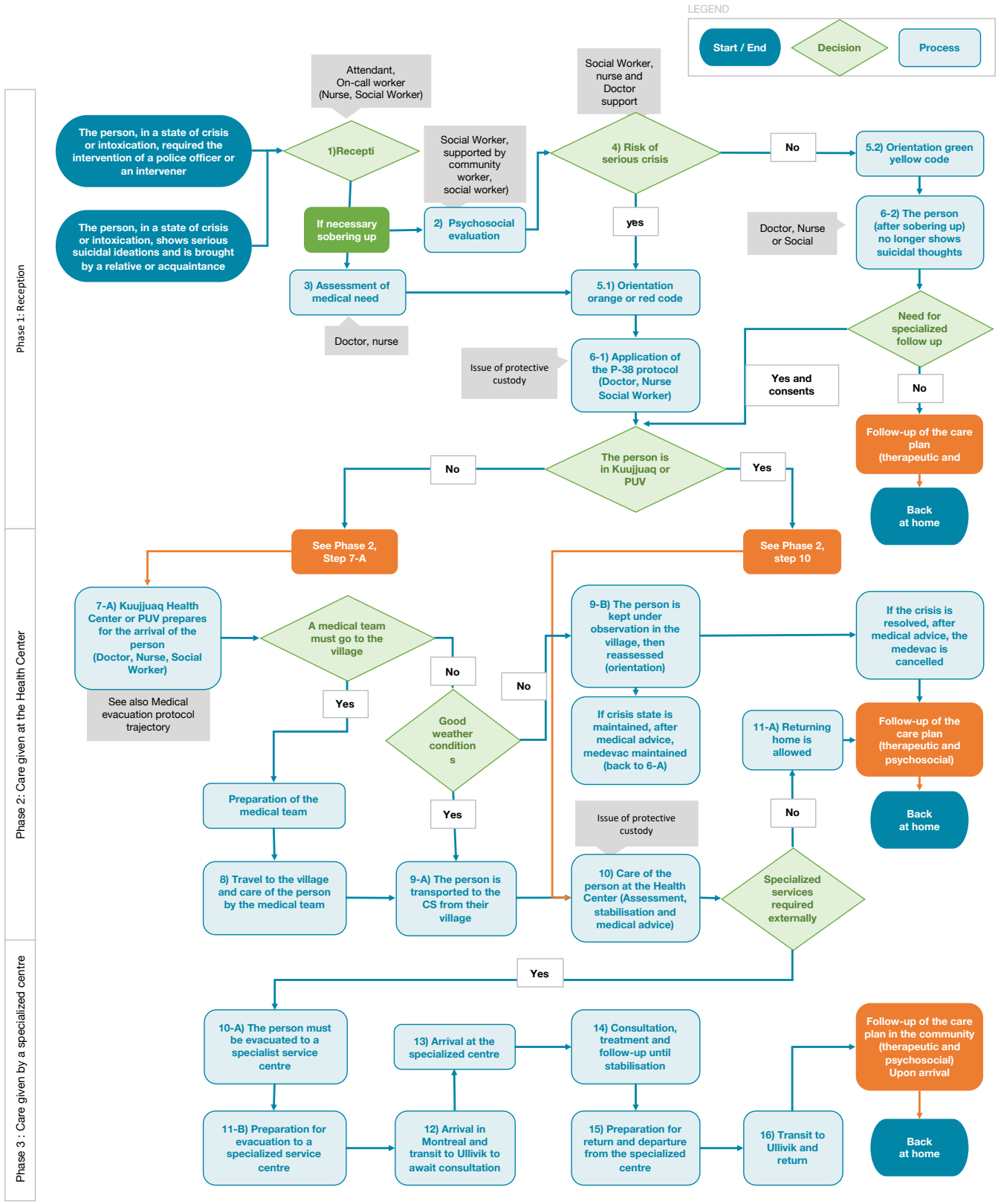


Figure 30: Service trajectory for mental health (from the Nunavik Regional Clinical Plan)

Appendix 2: Population Survey

The survey was conducted in June 2018; the full report was released online in June 2019 (https://nrbhss.ca/sites/default/files/health_services_clinical_plan_report_fr.pdf).

Objectives of the Population Surveys

The surveys were distributed among the entire population of Nunavik. They were available for a certain time, on paper at the various points of service and online at the regional board's Web site. The aim at this stage was quantification: gathering information on the patients' experience and thus assessing the gap between their expectations and the organization's standards.

Methodology

Questionnaire Design

To document the users' experiences with the Nunavik health network, a specific questionnaire was designed. The quality, accessibility and cultural safety of the services were assessed from the perspective of six topics drawn from the ministerial reference framework for evaluation of the performance of the health system[39] with the addition of the aspect of cultural safety:

- Service accessibility
  - Accessibility: Are they aware of the service offered, do they know what should be available to them and do they effectively have access to the service?
  - Equity in access: Do they consider that access is equitable between communities and with the rest of Québec?
- Service quality
  - Effectiveness: Do they consider the service to be effective? Or do they find it ineffective and, consequently, the service is not available?
  - Safety: From their point of view, is there a risk for them in seeking assistance?
  - Reactivity: When nurses and physicians join the network, do they adapt easily to the reality in Nunavik?
  - Continuity: Is the trajectory simple?
- Cultural safety: Do they feel they can trust their caregivers because of the latter's efforts at competency?
  - Communication: Did they understand what was explained to them? Did they get a chance to ask all their questions in order to make an informed decision concerning their state of health?
  - Pertinence: Was the service pertinent to their overall situation and their values?

39 Ministerial reference framework for evaluation of the performance of the public health and social services system, ratified by the steering committee on January 31, 2012.

The questionnaire included 43 questions based on other methodologies specific to the user's experience and adapted to the northern experience. Given the questionnaire's context of cultural safety, it was deemed essential, before distribution among the population, to ensure its face validity. This notion refers to the participants' subjective view of the questionnaire as such and enables validation of its transparency and its pertinence in the eyes of the participants relative to the research objectives.

Thus, revision of the questionnaire, with the help of Inuit collaborators working in the field of health, enabled ensuring not only the clarity and pertinence of the questions but also the most complete possible coverage of the Inuit experience with health care. Finally, five test respondents filled out the questionnaire and some adjustments were made according to their comments in terms of the level of language used, in order to avoid redundancy and thus maintain the respondents' interest as much as possible through the entire questionnaire. The time required to complete the questionnaire was also assessed to make sure it took less than five minutes, and this in all three languages in which it was available (Inuktitut, English and French), to minimize discouragement and thus abandonment of the questionnaire.

Analysis

The detailed quantitative analysis is presented in the full report, available online (https://nrbhss.ca/sites/default/files/health_services_clinical_plan_report_en.pdf).

Appendix 3: Individual Interviews

Objectives of the Individual Interviews

Several prior research projects in the field of health care have demonstrated that the participation of users from remote regions in the evaluation of the health system contributes significantly to improving the service supply's consistency with the users' expectations and thus increases their satisfaction, besides improving their rate of compliance with treatment and the feeling of having access to a better quality of life.

More specifically, the objectives of the individual interviews conducted for this project were to:

1. gather data on the Inuit vision of health;
2. gather data on the problems related to health from the users' point of view;
3. enable users to express their needs as well as the issues, challenges and their preoccupations with the various sectors of the service supply;
4. enable users to propose potential solutions to the issues and challenges they have faced in their experiences with health care.

Methodology of Phase 2: Individual Interviews

Choice of Communities Visited during Phase 2: Interviews

Six of the fourteen Nunavik communities were visited for this project and were selected according to location—Hudson Bay or Ungava Bay—and their size, two criteria that affect service trajectory and thus the users' experience.

All other things equal, the service trajectories in the various communities are in fact similar. As the population's expectations are largely influenced by its experiences with the health and social services system, users from communities with comparable service levels would generally have similar service trajectories and therefore similar experiences and expectations.

Further, it was necessary to take into account the fact that the region is divided into two subregions—Hudson and Ungava—each served by the territory's two health centres, the Inuulitsivik Health Centre and the Ungava Tulattavik Health Centre.

These criteria determined the choice of the communities to be visited, the point being to ensure accurate representativeness. Thus, three communities on each coast were selected: Inukjuak, Puvirnituq, Ivujivik, Kangiqsujuaq, Tasiujaq and Kuujjuaq.

Kuujjuaq and Puvirnituq are comparable because they each have an acute-care hospital. They enabled determining whether or not distance influences the users' experience with and assessment of the health system. Then, for each coast, one smaller-sized community with the *basic* service level and one medium-sized community with a service level of *600+* or *900+* were selected. The difference between 600+ and 900+ is often the number

of permanent physicians on site (only one compared to two) whereas a *basic* service level indicates no permanent physician, with a physician visiting only every six weeks, and presence of one or more nurses.

Table 8: Final choice of communities visited for individual interviews, according to population size and level of services available

HUDSON	Population	Service level	UNGAVA	Population	Service level
Ivujivik*	393	Basic	Kangiqsujuaq*	807	600+
Puvirnituq*	1983	1800+	Tasiujaq*	376	Basic
Inukjuak*	1799	900+	Kuujjuaq*	2682	1800+

The final choice for the communities was also influenced by pre-departure contacts, which facilitated recruitment of participants by the interviewers, who had only a very brief period of time (one week per community). The final choice was submitted for approval to the regional executive committee, which consisted of the executive committees of the NRBHSS, the UTHC and the IHC.

Recruitment of Participants for Individual Interviews

Various recruitment methods were established to ensure a varied sampling in each community visited. For each community, a basic list from the population survey was available as some of the respondents had agreed to be contacted afterward for participation in an individual interview. Upon the interviewers' arrival in each community, the project was announced over community radio and the participants were invited to meet them in a neutral space or at their homes. This allowed opening the invitation to the entire population of the community, as radio is a very important local source of information.

Moreover, the interviewers made sure of their visibility in the communities by visiting public places (COOP, Northern, mayor's office, airport), greeting people, explaining the aim of their visit and inviting people to participate in the project. Other means—word of mouth, request for references from health workers, personal contacts or the mayors, and recruitment of key informants—were also used for recruitment purposes.

Some interviews were conducted with *key informants*. Key informants are individuals who, due to their position in society or their particular skills, can provide more information and have a more profound view of the issues of their society.[40] Marc-Adélard Tremblay emphasizes five important criteria for selecting a key informant: Her role in the community, her possession of information, her will to communicate, her capacity to make her vision understood by another and her impartiality (or transparency relative to her own biases).[41] Here, the key informants were the mayors and Inuit health workers.

Ultimately, the recruitment process therefore approached the method of convenience sampling, given that the persons recruited had to be accessible, available and interested, and this in a rather limited space-time. Nevertheless, the various sources of recruitment enabled limiting the potential biases linked to this type of sampling.

Interview Process

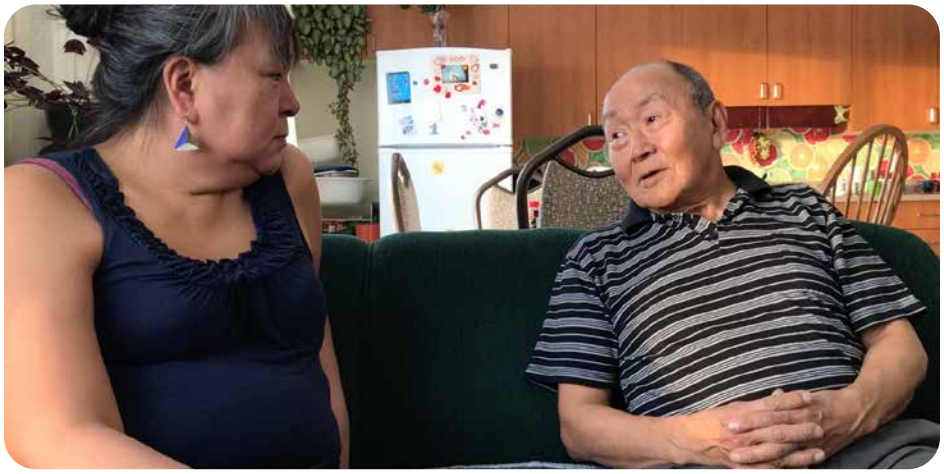
The semi-directed interviews, lasting a maximum of 50 minutes, were conducted entirely in Inuktitut. With the participants' consent, a video or audio recording was made in order to conserve the original sources and subsequently systematize the analysis.

40 Marshall, NM. "The Key Informant Technique." From Family Practice. Oxford University Press, 1996, p 92.
41 Burgess RG (Ed.). Field research: a sourcebook and manual. London and New York: Routledge, 1989.

Questionnaire Design

The interviews were based on a simple guide that allowed coverage of three broad subjects:

1. the Inuit conception of health and well-being;
2. the respondents' experience with the health and social services system;
3. the improvements sought for the system for better compliance with the Inuit vision of health and Inuit values.



Analysis

Content analysis is the method that seeks to document what interviewees state as objectively and accurately as possible. Berelson (1952), the father of content analysis, defined it as "a research technique for the objective, systematic and quantitative description of the manifest content of communication."

In the context of the interviews, it was first necessary to proceed with simultaneous translation of the interviews and then, using the *N'Vivo* software, proceed with coding. Analysis of the frequency of words, topics and word roots was carried out, with community size a constant comparative unit.

Exhaustive coding of each of the interviews enabled quantitative analysis of qualitative content. Two coding methods were combined:

- open coding: based on data (generalization process), sets were created and compared. Here, coding of the principal dimensions of the discussions as well as selective coding of central and repeated ideas were carried out. There were no pre-established codes;
- closed coding: based on the research topics (translation process), pre-established variables were examined. This coding is performed on research indicators. In the present case, the concepts used were parsed according to all the components of the IQI model for health; the related conditions for well-being and health, as well as all the components of the ministerial reference framework for evaluation of the performance of the public health and social services system, ratified by the steering committee on January 31, 2021, were used.

Appendix 4: Focus Groups

Objectives of the Focus Groups

Based on the results of the preceding surveys and interviews, the focus groups aimed principally at more in-depth reflection on the cultural safety of the service supply and development of ideas to improve this aspect in various service sectors.[42] The specific objectives of these focus groups are to:

1 document the participants' points of view on the objectives to receive priority in the short, medium and long term concerning the development of health services culturally adapted to Nunavik;

2. compile potential solutions and concrete actions responding to the problems raised by the Nunavik population;

3. validate the process and then recommend guidelines for the board of directors;

4. inform the participants of the partnership with users which the NRBHSS wants to establish as organizational culture.

Methodology of the Focus Groups

Recruitment of Respondents

The first recruitment attempt was through the community liaison wellness workers (CLWWs), to identify users who might be seriously interested in the process and who would respond to the profile sought. That profile matched the one proposed in the efforts toward a partnership with users: persons with experience with the health-care system and interested in constructively participating in discussions on concrete improvements for the future. Although some names had been recruited through the CLWWs, many more were needed and it proved necessary to go back to the lists of survey and interview participants as well as rely on word of mouth to complete the recruitment process. In the end, three groups of 6 to 10 users, with one or two representatives for each community with access to similar service levels, were set up.

Daily Process

Each focus group was scheduled for one day in total and all the groups were organized in Kuujjuaq during the same week. The sessions were held in Inuktitut and facilitated by co-researcher Annie Baron. Simultaneous interpretation in English enabled the team to follow the discussions and intervene as needed. Each day was divided into two parts: establishing priorities among the issues raised in the surveys and interviews, followed by proposing potential solutions to those issues.

Methodology

The participants of the focus groups therefore first worked individually at establishing priorities among the topics. Then, in groups of two or three, they established priorities among the issues (without knowing the topics to which the issues referred).

42 As time and resources were limited, the process will go according to groups of service sectors. The discussion will be general in tone but open to specifics according to the respondent and his experience.

The results of classification of the topics were analyzed according to two methodologies. The first—direct—dealt directly with the first individual classification exercise according to which each of the participants individually classified the topics by order of priority. The second method—indirect—involved classification of the issues established during the second exercise. Thus, by linking the issues to their topics, it was possible to validate the results obtained through the direct method.

For both methodologies, a relative score was derived according to the number of points assigned by the participants or groups. These topics were then broken down by community size. In the table below, the two methodologies are compared. Certain variations appear in the relative order of the topics, which may be due to various factors, such as the individuals' influence on their subgroups during the group discussion of the second exercise. Thus, the results of the exercise involving the issues represent a classification of the topics resulting from pooling, a group choice, whereas the direct results stem from a compilation of the individual results. The two figures below the table help visualize the results.

Topics Chosen for Work on Potential Solutions

After establishing priorities among the topics and issues, the participants selected, from among the issues, those they wished to work on for the purpose of identifying potential solutions. The issues chosen do not necessarily correspond to the priority topics or the priority issues. In fact, most of the time the participants felt more comfortable finding potential solutions to issues they did not necessarily tag as priorities but with which they had had a direct experience and thus in which they developed a certain expertise (if we think in terms of the partnership with users). Below is the list of issues on which each group decided to work.

Larger communities

- Improve patient services:
  - escort policies
  - support group for persons with cancer and their loved ones
- Design an education and training program for the Inuit and the personnel:
  - more specialized training for Inuit
  - responsible alcohol consumption and consequences of alcohol abuse
  - trained mental-health caregivers
- Attract and retain personnel:
  - specialized personnel
- Improve quality:
  - access to a second opinion
- Promote healthy lifestyles starting at a young age:
  - parental skills
  - treatment for past trauma

Medium-sized communities

- Improve workers' attitude:
  - honesty
- Improve the way patients are served:
  - orientation
  - services provided by Inuit
- Design an education and training program for the Inuit and the personnel:
  - responsible alcohol consumption and consequences of alcohol abuse
- Design mental-health programs:
  - more opportunities to speak out
- Promote healthy lifestyles starting at a young age:
  - support for families
  - parental skills

Smaller communities

- Attract and retain personnel:
  - specialized personnel
  - experienced physicians and health personnel in all communities
- Improve quality:
  - access to a second opinion
- Promote healthy lifestyles starting at a young age:
  - parental skills
- Design healing programs
  - learning to forgive oneself

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RÉGIE RÉGIONALE DE LA SANTÉ ET DES SERVICES SOCIAUX DU NUNAVIK

NUNAVIK REGIONAL BOARD OF HEALTH AND SOCIAL SERVICES