Stronger Voices, Better Care

Serving the People of Nunavut

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21st-Century Engagement for a 21st-Century Health-Care Facility

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[1] See http://www.ottawahospital.on.ca/en/documents/2017/09/setting-stage-turning-page-21st-century-engagement-21st-century-health-care-facility.pdf

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Introduction

The Territory of Nunavut covers more than 2 million square kilometres. Although it includes 20% of Canada's landmass – the second biggest country in the world – it has less than 1% of its population. The climate is harsh. In winter, much of the land is dark, day and night, and the temperature can plummet to –40°C.

Nunavut is home to about 36,000 people, 85% of whom are Inuit. More than half reside in the eastern Qikiqtaaluk or Baffin region, with over 7700 of these in the capital city of Iqaluit. The population is young – remarkably young: the median age is 25 years, and 33% are under 15 years of age, with only 3.3% over 65.[2]

This unlikely mix of a tiny population and huge geography creates major challenges for the health-care system. For example, there are no oncologists in the territory, so cancer patients must travel thousands of kilometres to The Ottawa Hospital (TOH) for treatment. The same goes for other key services, such as complex obstetrical care and dialysis. There were 2,900 visits from Nunavut to TOH last year – about one for every 10 people in the territory.

Eventually, some of these medical services may be available in Nunavut. The territory is developing quickly, and new infrastructure is emerging. Qikiqtani General Hospital (QGH), for example, is a state-of-the-art 20-bed acute-care facility in Iqaluit. But at present, there are no plans for full tertiary level services.

Turnover of medical staff in Nunavut, especially of nurses, is very high. Travel is thus the only viable option for patients to receive some key services. This presents challenges of its own.

Life in Nunavut is very different from Ottawa. Many Inuit have never been outside the territory and being dispatched to Ottawa for treatment, without family and friends, can be very stressful. In addition to their illness, patients must deal with the anxiety and loneliness of separation. Language can also be a challenge for Inuit clients who do not speak or understand English.

In these circumstances, even small things can make a big difference. Caregivers report that decorating patients' rooms with colourful artifacts, such as banners, pictures, and Inuit wall-hangings, can significantly improve their mood and morale. Serving "country food," such as raw seal meat or arctic char, can make Ottawa feel more like home.

TOH recognizes the vital role morale plays in healing and is committed to improving conditions through new approaches to patient-centred care. The timing is no accident. Construction of TOH's new campus has recently been approved. It is one of the biggest infrastructure projects in Ottawa's history and will take 10 years to complete: five for planning and five for construction.

It also creates a unique opportunity for institutional learning and culture-change. Administrators plan to use this to make the hospital a leader in a new generation of health-care institutions that are highly engaged with their patients and fully integrated with the communities they serve.

[2] See http://www.statcan.gc.ca/pub/91-215-x/2012000/part-partie2-eng.htm

This not only means reaching out to the surrounding community in new ways, but also distinguishing between the different kinds of communities the hospital serves, and recognizing and responding appropriately to their special needs.

Stronger Voices, Better Care is part of this effort. Our task was to provide TOH with advice on the best ways to strengthen its relationship with the Inuit communities it serves in Nunavut. Over several months, we conducted meetings and interviews with members of the Inuit health-care community, including community spokespersons, health-care stakeholders of all sorts, and TOH officials. This included three days of interviews in Iqaluit.

Our participants had lots of views on how to improve patients' experience with the medical system in Ottawa, from raising cultural awareness among staff to training a new cohort of "system navigators." This report organizes their proposals under four main themes:

1. Recognizing the Past
2. Building Cultural Competence
3. Navigating the Ottawa Environment
4. Working Together

These themes are effectively strategic goals that support the vision of the new campus. **Their pursuit involves the creation of an informed, ongoing dialogue between TOH and the patients and communities of Nunavut**. Establishing such a dialogue is, we believe, a critical condition for strengthening the overall relationship in ways that will significantly improve the care and services for TOH's Inuit patients.

Where to Start

If Nunavut were a country, its cancer death rates would be the highest in the world. At 403.4 deaths per 100,000, these rates are nearly twice the national average and by far the highest in Canada.[3] Why?

Multiple factors are at work. Certainly, smoking is one contributor. Poor and overcrowded housing may be another. We also heard about the role of intergenerational trauma. But one story stood out from the others.

Dr. Tim Asmis of The Ottawa Hospital Cancer Centre told us about a study he recently co-authored, which found that only 70% of Nunavut patients with cancer made it to Ottawa for treatment; 30% did not. The study was inconclusive about the reasons, but the fact that so many cancer patients didn't get treatment is striking – and a likely factor in the high mortality rates.[4]

Some participants suggested that trust plays an important role in this. During our interviews, they talked about Inuit distrust of the medical system and the reluctance of some patients to follow up on treatment because of this. It is hard to know how accurate these reports are. Or, if distrust does exist, how widespread it may be, what has caused it, or what it involves.

[3] See http://www.cancer.ca/en/cancer-information/cancer-101/canadian-cancer-statistics-publication/?region=on

[3] See http://www.cbc.ca/news/canada/north/some-inuit-may-be-refusing-cancer-treatment-study-indicates-1.3206509

Possibly, there are reverberations from the forced evacuation of Inuit in the 1950s, when many were diagnosed with tuberculosis and sent to sanatoriums in the south for treatment. This split families, sometimes for years. Some people died and were buried without their family's knowledge; others were sent from hospital to hospital without being tracked.

Participants also told us about early-stage cancer victims who arrive at nursing centres with pains, but then describe them in ways that mislead nurses or understate the gravity of the symptoms. While we don't know whether this is related to trust, as our participants suggested, or other factors, such as language, the result is the same: there are patients who need treatment but who fail to travel to Ottawa to get it.

This left us wondering about how to ensure open, informed dialogue between patients and their doctors and nurses and the role this might play in improving health outcomes in Nunavut and Ottawa. Dialogue is now widely recognized as a critical success factor in medical treatment of all kinds. According to Ontario's Ministry of Health and Long-Term Care, a so-called **patient-centred** or **patients first** approach puts people and patients at the centre of the system by putting their needs ahead of everything else.[5]

At the doctor-patient level, the approach is supported by an ongoing conversation in which the two parties work together to develop and execute a plan for managing the patient's health. Patients play a critical role here. They help the doctor form the plan and provide reports and updates on whether they are following it and how they are feeling. Establishing such a dialogue requires mutual trust and mutual understanding on both sides.

When we asked our participants to comment on this, they replied that if trust is a critical condition of patient-centred treatment, there is much work to be done in Nunavut. This, in turn, led us to ask some very basic questions about the relationship between these two communities. There was little disagreement on where to start.

Recognizing the Past

Most of our participants insisted on the need to educate health-care providers on the impact of "colonial government" on the people of the North. As with other Indigenous Peoples, the experience has been traumatic, including the sterilization of Inuit women, the forced relocation of whole communities, the slaughter of thousands of sled dogs, and the experience of residential schools.

These events are seared into the consciousness of Inuit, young and old. They are a defining presence in their relationship to government authority of all kinds, including the health system. Rebuilding trust and establishing an open dialogue starts with a clear understanding of the origins of the distrust many Inuit feel toward health institutions, professionals, and treatment.

Sensitivity training, we were told, is the first step. Our participants were especially clear that such training must come from Inuit who are experts in the field, not from southerners who have read about these events. To feel the emotional impact of the story, they said, it must be told by someone who has lived it. Health professionals need to see the past through the eyes of those who have experienced it.

[5] See http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/

Building Cultural Competence

Identifying Differences

At the start of each interview, we explained our goals of raising awareness and creating a conversation with Inuit patients and community leaders that would help TOH staff accommodate cultural differences. Ideally, we said, we'd like to create a kind of check-list that staff could use to anticipate where cultural perspectives might affect the doctor-patient relationship. People nodded approvingly.

Yet, when we asked them to identify such differences, the main reaction was silence – which was as likely with Inuit participants as others. Everyone, it seems, takes such differences for granted, but when asked to provide examples, many are at a loss.

Nevertheless, we persisted until we had some examples that our participants agreed on. Along the way, one person talked to us about similar research that is being done under the title of **cultural competence.** This work, he said, goes beyond traditional "awareness-raising." It starts by identifying cultural differences, then uses them to build new "navigational skills" that help practitioners provide services in ways that respect cultural differences.

This aligns well with our own approach. In conducting the interviews, we first tried to identify some of these cultural differences; then we asked people how this knowledge could be put to work. The idea of building new navigational skills of different sorts was a recurring theme in their responses. Before turning to it, let's consider the list of cultural differences that emerged from our interviews.

Family

Family, we were told, is the cornerstone of Inuit society. Families usually include lots of extended relatives and even friends. These connections are nurtured and maintained through frequent gatherings, from community events and feasts to hunting and fishing trips. Family gatherings can occur in all kinds of places, public and private, and often spontaneously – especially in times of stress or difficulty, such as illness**.** Thus, the hospital room of a sick child or elder may attract a small crowd, which may even spill over into the hallways.

Traveling south for treatment cuts people off from these gatherings and can leave them feeling like their social foundations have collapsed. The effects can be debilitating, and our participants urged that more be done to help patients adjust to this loss when they come to Ottawa for treatment.

Decision-Making

Inuit tend to make decisions in a more communal way than many other Canadians. Consultation with family members is integral to the process. When there is an issue to be solved, they will gather to share information and discuss. This kind of reliance on family and friends, we were told, is basic to the culture. It can also make medical treatment confusing and stressful for patients. Doctors may ask a litany of questions regarding medical tests, procedures, and treatments. Where decisions are required, the patient may be at a loss to respond. He or she

may feel the need to connect with family members to seek their advice and support, yet the situation forces them to act alone. This not only conflicts with their lived experience, but it also could compromise their capacity to provide informed consent.

Time

Traditional lifestyles take Inuit onto the land where daily rhythms are very different. Unsurprisingly, their sense of time, we were told, is also different. This, in turn, can complicate medical treatment. Telehealth Ontario was discussed often in this context. It requires tight scheduling, but some service providers found this difficult in the North, especially with older people. They view time differently, we were told, and are often unresponsive to schedules. Not that anyone thought Inuit are indifferent to time or disrespectful of others' time. Rather, their experience of time has been shaped by natural events, from the migration of animal herds to changes in the weather. Their temporal markers and/or priorities are therefore different, which can be a challenge for a medical system that runs by the clock.

Storytelling and Narrative

Southerners often say they find it difficult to follow Inuit thinking. Inuit elders, they say, can take a long time to make a point – or perhaps they give a response that doesn't seem to answer the question. Our participants treated this view as a failure to understand Inuit culture. Inuit are part of an oral tradition where storytelling is used to convey information in ways that connect it to their values, customs, and beliefs. The bullet-style list of facts, so typical of southern thinking, is foreign to Inuit and they aren't likely to answer questions this way. Indeed, stripping stories down to facts, we were told, can make them uneasy. They are inclined to answer a question with a story because it shows how the speaker feels about the information and why it may or may not be important. If this seems beside the point to a southerner, said one, perhaps they need to learn to listen differently.

Hierarchy and Deference in Conversation

Given what has been said so far, the issues with doctor-patient communications shouldn't be surprising. A range of factors can affect the exchange, from the storytelling style of Inuit conversation to traumatic memories of residential schools. Cultural protocols around hierarchy and deference, we were told, add yet another layer of complexity.

For example, the person who answers a question is not always the person to whom it was asked. The responder may be an uncle, a mayor, an elder, or someone else. This deference to such a person is usually a sign of respect – though not always.

The important lesson here is that hierarchy and deference play a significant, but subtle role in Inuit conversation. While Inuit make decisions together, they don't all have the same voice. Hierarchies in families and communities are strong, but we must be careful when discerning how they work.

Food

There was scarcely an interview where food was not discussed. Traditional food is at the centre of Inuit social life and culture. Sharing food is a seminal way of connecting with one another. Being deprived of country food when in Ottawa is more than an inconvenience or an interruption of their normal patterns. It is a constant reminder of the loss of their social connectedness and their way of life. Many of our participants called on TOH to ensure a supply of country food is available in an accessible location – ideally, a spot where members of the Inuit community can gather to share a meal.

The Language

Finally, there is the language. Some 70% of Nunavummiut identify Inuktitut as their mother tongue. The language is, we were told, the cultural soil in which these other practices are rooted. While our participants recognized that many young people today grow up bilingual – more on this in a moment – they agreed that speaking Inuktitut is a fundamental condition for the experience of being Inuit and that the vibrancy and health of Inuit cultural practices, from storytelling to decision-making, rests on the use and mastery of the language.

Generational Change

If participants agreed with our list of cultural differences, they also agreed that rapid cultural change is underway among youth. Exposure to southern television, movies, music, social media, and so on means most young people are as steeped in the values and trends of the South as the North. Nunavummiut describe these young people as **bicultural**.

The speed and depth of this change varies between communities. Iqaluit, for example, seems to be changing faster than Pond Inlet. Still, our participants felt the trend is advancing everywhere and that the next generation of adults will be very different from their parents and grandparents.

For example, most felt that language would be less of a barrier, as many young people today speak English fluently. In the short-term, people from smaller communities may continue to need translation, but that will diminish.

There was less clarity on what this shift means for traditional Inuit values and culture. One view was that belief systems are highly resilient and don't change quickly, even though circumstances may. In this case, the underlying values around families and shared decision-making are likely to persist.

Others felt the changes are profound enough that the next generation will be much less concerned with culture and more focused on issues arising from their environment: the landscape, climate change, the remoteness of their communities, the size of their population, the issues with a resource-based economy, and so on.

Some participants reminded us of the distrust arising from intergenerational trauma and insisted that, whatever changes may unfold, this will not disappear in a generation or two. The sense of trauma is very real in some youth – the rates of suicide, drug use, and unemployment, said one, are evidence. While not all young people are traumatized, this needs to be recognized and acknowledged.

Others agreed that times are changing, but pointed to the efforts by youth to reinvigorate the language and culture. If it is true that young people will be more influenced by trends from the South, they said, youth also want to keep their language and cultural practices. This is likely to intensify.

If there was a considered view, it seemed to be that key cultural traits will remain intact into the future, from deep values about family and shared decision-making to the sense of cultural membership that comes from sharing traditional food or telling stories. The use of Inuktitut may or may not diminish, but the use of English will grow. And the people of Nunavut will continue to rely on TOH for some of their key medical services.

Training Youth as Cultural Navigators

While the future is hard to predict at the best of times, two things seem likely here. First, generational change is real. Second, the fact that 31.7% of Nunavummiut are under 15 years of age and a mere 3.3% are over 65 suggests that generational change is the most important cultural issue on the horizon – and that TOH's plan to establish a long-term conversation with the people of Nunavut should reflect this.

If so, a principal finding from this study is something we barely sensed at the outset: **Young people have a natural endowment – a skillset – that could play a key role in helping TOH lead the next generation of health-care institutions.** If the 21st century calls for hospitals that are highly engaged with their patients and fully integrated with the communities they serve, these young people are a stepping stone. They are extremely well-positioned to help TOH respond effectively to the cultural needs of the older generation of Inuit.

Our participants shared this view. They told us that youth could and should serve as intermediaries or "cultural navigators" for their elders and several called on TOH to work with the Government of Nunavut to develop a plan or strategy to engage and train youth for this mission.

Such training, they said, could be achieved in a variety of ways, including courses at Arctic College or new "apprenticeship" or "mentorship" programs in organizations like the Ottawa Health Services Network Inc. (OHSNI) or Akausivik Inuit Family Health Team (AIFHT) (see below). One participant told us of a plan to build a home for elders in Iqaluit. The facility, she said, will require 80 to 100 culturally aware care workers. Why not hire and train young, bicultural Nunavummiut to fill these jobs, she asked? They would bring their skills to the job in a way that would quickly institutionalize their cultural competence. At the same time, they would be preparing the way for a much richer conversation between themselves and TOH – they would be redefining the doctor-patient relationship for the future.

Nunavut Arctic College offers courses for the interpretation of medical terms as part of its Interpreter-Translator Program. These courses are available to all staff in the Department of Health staff, regardless of their employment status (i.e. casual, indeterminate, etc.).

Navigating the Ottawa Environment

A patient's stay in Ottawa may be as short as a few days or it may last months, depending on the treatment. The Ottawa Health Services Network Inc. (OHSNI) is the main agent for planning patient visits to Ottawa. It provides case management, medical interpretation, and coordination of specialty health-care services to Inuit patients. It also makes their appointments and provides them with interpretation services.

The OHSNI is the principal contact for patients from Nunavut, but it is not the only one. In fact, Ottawa is home to the largest Inuit population south of the Arctic. About 3,700 Inuit now live here – possibly many more.[6] They are part of an increasingly well-organized and vibrant community, which also serves as a support system for patients from Nunavut and their families.

For example, the Akausivik Inuit Family Health Team (AIFHT) is the only existing Inuit family health centre. Along with the special services it offers the Ottawa community, the clinic provides counseling to patients from Nunavut. It provides a comfortable space where they can discuss their illnesses and treatment in Inuktitut, at their own speed, and in their own way.

Larga House Baffin is a boarding facility that provides meals and accommodation for patients during their stay in Ottawa, as well as transportation to and from appointments.

The Ottawa Inuit Children's Centre runs Ontario's only Inuit kindergarten, where children play games with seal bones and caribou legs and are taught in Inuktitut.

Tungasuvvingat Inuit, Ottawa's Inuit social and community organization, sponsors an array of programs, including food banks, addictions treatment, church services in Inuktitut, regular community feasts, and field trips to pick apples and berries.

TOH recognizes the huge value of this community for visitors from Nunavut. A staff member has recently been designated to help Indigenous Peoples navigate the medical system. Part of her work is to establish a trusting relationship with patients and their escort/family members from the North. This is achieved by acknowledging the separation between the patient and their community/culture and providing experiences that are unique to Ottawa that supports their connection with land and community. Still, as she was quick to note, much more needs to be done.

Our participants agreed. They suggested various ways to expand and develop this navigational role to help Inuit patients and their families while in Ottawa. We've consolidated their proposals under **four navigational principles** that we think should guide service providers at all levels.

Four Principles to Guide Inuit Navigators

1. Acknowledge Cultural Differences

The new campus creates a unique opportunity to recognize and celebrate TOH's relationship with the Indigenous Peoples it serves:

[6] See http://www.cbc.ca/news/canada/ottawa/woefully-inaccurate-inuit-population-ottawa-1.4391742

- The new building will stand on unceded Algonquin lands. Several people thought the main entrance should clearly recognize this.

- In addition, participants said the main foyer should somehow express TOH's commitment to respect Indigenous Peoples' unique cultural and linguistic heritage – perhaps even the cultural differences of peoples around the world.

- An Inuit carver or sculptor could be engaged to create a welcoming piece for the hospital grounds, which might be placed near the main entrance, possibly with a seating area nearby for patients.

- An outside park or healing space could be designed to symbolize the close relationship between Nunavut and TOH and to show that TOH's doors are always open to the Inuit community.

- Nunavut dignitaries and traditional singers could be invited to participate in an inauguration ceremony to dedicate the sculpture and space as symbols of the importance of the relationship.

- Plans like these must be made in close consultation with the Inuit and other communities they depict. If these gestures are to feel authentic, they must embody the spirit of partnership and service that underwrites TOH's vision of a 21st-century health facility.

2. Help Inuit Find Their Way Around Ottawa

Much in Ottawa and TOH will be unfamiliar and even intimidating to first-time visitors from Nunavut, from the Light Rail Transit system to the network of passageways that will connect the campus. Patients and their families need help finding their way around.

- Accessible brochures or information packages should be available to inform visitors about the facility and the city around it. Ideally, the material would be highly visual and/or available in Inuktitut.

- Signs in the hospital should be accessible to Inuit. If signs cannot be in Inuktitut, perhaps universal symbols or appropriate pictographs could be used.

- An information centre at TOH might allow Inuit patients to post their names and some contact information so they can connect with one another during their stay.

- More resources should be dedicated to training system navigators who can introduce patients and their families to the special features of the hospital, and provide advice, help and contacts in the Ottawa community to make their stay easier. This is a natural role for bicultural youth from Ottawa and Nunavut.

3. Make Inuit Feel at Home in Ottawa

Larga Baffin has shown how a few simple adornments in a room can help normalize patients' moods and increase their comfort during their stay. TOH should develop a "**home away from home" program** to help patients feel at home through initiatives like these:

- Decorate patients' rooms with Inuit art and other culturally familiar articles.
- Install a fridge for country food in the hospital, create a gathering space around it and organize meals where patients from the North can gather and socialize.
- Qikiqtani General Hospital allows the use of Inuit knives for food preparation. Perhaps TOH could provide disposable cutting boards and access to sharp knives for preparing country food.
- TOH has very few Inuit working as cooks, cleaners, orderlies, and so on – especially given the size of Ottawa's Inuit community. Greater effort should be made to recruit Inuit staff – especially bicultural youth – to help create a more welcoming environment.
- More spaces like the Windocage Community Room could be created and dedicated to special purposes, such as carving and crafts or preparing country food.
- Child-friendly areas should be designed for different cultural communities and family sizes.
- Fresh air and good air quality are very important to Inuit, especially in the summer. Inuit overheat easily and suffer from temperatures that are too warm.
- A significant number of Inuit smoke cigarettes and/or marijuana. A plan is needed for how these activities will be approached in future in an appropriate and respectful way.

4. Explain Their Illnesses and Treatment

Too many Inuit patients don't fully understand the nature of their illness and treatment or why they have been transferred to Ottawa. Language and culture are huge barriers. Some patients barely understand English; others can't or won't or ask the questions they need answered. Engaging patients in an ongoing conversation about their health and care should be a top priority for service providers at TOH.

- TOH staff should be trained to recognize and respond to the cultural needs of Inuit in their care. They should be encouraged to participate in cultural events and programs as part of this training.
- New methods of explaining illness, treatment, and travel should be explored. For example, we heard about a project to develop a "What to Expect" video that will inform patients about what to expect on the journey to Ottawa and how to prepare for it. Another project in Winnipeg is producing a video on colonoscopies and how to prepare for them. Videos on

other aspects of patient care could be helpful, including some on non-medical topics, such as activities in Ottawa's Inuit community.

- Our participants agreed that translation is a vital part of patient care. Some 80% of Inuit currently rely on it. While OHSNI was applauded for its translation services, most of our participants felt that overcoming the cultural barriers requires more of translators than proficiency in English and Inuktitut.

- **Technical skill:** Technical language should be broken down, and diagnosis and treatment should be explained to patients in ways they understand, which means the translators too must understand the technical points, which likely requires training and, possibly, specialization. (The Nunavut Tunngavik Inc. (NTI) Inuit employment plan considers keeping translators focused on one specialization or field to increase their skills and expertise.)

    - **Cultural competence:** Training for translators should include more than technical competence; it should include cultural competence. For example, they should be trained in how to deliver bad news in culturally sensitive ways. Currently, this is left to their discretion. We've also seen, for example, that how a question is asked matters, as does the way an answer is given – and that Inuit and medical professionals often see the world very differently. Translators need to be skilled intermediaries who can ensure the questions and the answers connect. This requires both a technical understanding of medical practices and a high level of cultural competence. The use of bicultural young people is a promising avenue here. They already have the cultural background and the technical skills can be acquired through training.

Working Together

Cultural competence starts by acquiring knowledge of the cultural differences that distinguish one community from another, then asking how to align medical practices and treatment with these differences. So far in this report, we've identified some important aspects of Inuit culture, then considered how different types of "navigators" can use this knowledge to improve patient care, especially for Inuit traveling to Ottawa. We've also provided four principles to guide these navigators.

In short, our discussion has focused mainly on improving the patient's experience as he or she moves through the medical system. But we can also ask how cultural competence might change the design and delivery of major programs in the system, such as Telehealth or palliative care. Our participants also had views on this. This final section presents some of their thoughts on how cultural competence might be applied at the program level.

Engaging the Stakeholders

While many of the proposals so far could be implemented by TOH administrators, say, through sensitivity training, hiring navigators, or providing better information and translation services for patients, others will require a more formal dialogue on patient care, involving the Champlain Local

Health Integration Network (LHIN), the Government of Canada, and the communities and Government of Nunavut.

When we asked some of our participants for ideas on how to establish this kind of dialogue, perhaps their most promising suggestion was to create a **Nunavut patient engagement council** to discuss some of the bigger challenges around better patient care, like making Telehealth work or designing a training strategy for system navigators.

Although this council would hold quasi-formal discussions with health-care stakeholders, the participants we talked to thought it shouldn't be a decision-making body. It should be an advisory body that exists to create a safe space where government officials, stakeholders, and community voices can come together for an informed conversation about meeting such challenges.

Having the right representation would be very important, especially at the community level. Community representatives would have to speak authoritatively for their communities, and get the support from them to move ideas ahead. Finding such people, we heard, shouldn't be too difficult. Every community already has a health committee. Perhaps the council membership could be drawn from these.

It was also noted that, at present, Nunavut doesn't have any health boards, which means there is no formal mechanism for local engagement on these issues. Participants thought that the council would help fill this gap by providing a forum for community leaders, TOH administrators, and officials from the Government of Nunavut and the Champlain LHIN to explore some important issues together.

The idea of the council resonated with our participants. They saw it as a natural way to move the dialogue on patient care to a new level. The remaining sections provide some examples of where they thought such a discussion is needed and could be fruitful.

Telehealth

We had some lively discussions about Telehealth Ontario. Participants agreed that many consultations that now involve a trip to Ottawa could be done this way, saving money and time, and making life easier for patients. Last year alone, the Government of Nunavut spent almost $60 million on medical travel. So why isn't the tool used more?

Effective use of this technology, said one, simply hasn't been a priority across much of the Champlain LHIN. The community has been slow to adopt it, especially if people don't see others using the tools or have had a bad experience with them. According to this person, getting Telehealth to work will require strong leadership.

A health-care professional from Nunavut told us that he has tried for years to raise interest in Telehealth, but with little success. The system, he said, is badly designed and almost impossible to use. Until it is fixed, there will be no real progress. In his view, a functional system requires new technology and more bandwidth.

Others were more positive, and there are lots of positive stories about telehealth. Many hundreds of clinical hours are already being provided to patients and their families via telehealth and there is a

desire and willingness to further expand programming. There is also encouraging news about improvements in the technology and the bandwidth. In September 2017, for example, the federal government committed $50 million to increase bandwidth in Nunavut. Telesat, the company that provides the service, is launching a new satellite that will increase internet speed by three to five times by 2019.

A second issue around Telehealth involves patient participation, especially around scheduling. We were told that scheduling patient meetings has proven difficult. Patients are often unavailable when practitioners are, especially during the summer months when many Inuit are on the land.

However, we also heard stories that show that Telehealth can work. At Akausivik in Ottawa, doctors regularly consult by phone, thereby reducing in-person visits. Notably, these appointments are directly with a doctor, not administrators, which, apparently, does happen elsewhere. Making patients more receptive to Telehealth poses challenges, but there is no reason to think it can't be done. One suggestion was that patients should be introduced to Telehealth in follow-up appointments, rather than initial consultations, where more hands-on interaction may be needed.

As for our participants, the general view was that Telehealth offers a huge opportunity to improve services and save money. However, to succeed, two conditions must be met: (1) the technical challenges must be overcome; and (2) TOH and the Nunavut government must join forces to provide strong and committed leadership to change the culture around doctor-patient consultations. Such an effort must be well-resourced and target both practitioners and patients.

Palliative Care

Our participants were strongly in favour of bringing patients back to Nunavut for palliative care. Not because the services in the South are poor, but because Inuit feel very strongly about being with their families when they die. Given the distance to Ottawa and the size of many Inuit families in Nunavut, most relatives are unlikely to make the trip south to be with a loved one who is passing. If the patient remains in Ottawa, he or she is therefore likely to die alone or have only a few family members around them. For people with such deep ties to family, this is as much a tragedy for the families as for the patient.

The lack of doctors in Nunavut did raise questions about providing palliative care in Nunavut, such as who will be responsible for pain management. But participants felt issues like these could be managed by qualified nurses. There was also a question of institutional capacity. With just 20 beds, QGH is not equipped to handle many palliative care patients. In the end, however, most Inuit prefer to die in their homes with their families around them. Our participants felt this was often the right option.

Enhancing Communications and Information Sharing

TOH is exploring ways to provide Indigenous communities of all sorts with health-related information, so we asked participants how communities in Nunavut receive information on subjects of public concern and how they use it within their communities. We were told that:

- Everyone has smartphones and most now use them for transactions as well as messaging, including operations involving private or sensitive personal information.

- Inuit culture isn't as verbal as some. It is more visual, which makes certain social media tools attractive and user-friendly, especially Facebook.

- Community health researchers already use social media to schedule meetings, collect medical information, and manage relationships with patients.

- Although local radio remains very popular in Nunavut, social media are now at least as promising a tool to reach people, including many in the 60+ age-range.

- Some of our participants thought TOH should hold monthly or quarterly education sessions, such as webinars or other open forums, to engage the communities. TOH could work with local health centres (and the nurses in them), who, in turn, could engage patients.

- Health centres could also help identify which groups of people in the community might be most interested and what kinds of information they need.

- Health centres in Nunavut already have some chat groups set up. This kind of initiative would build on existing programming.

- Despite its popularity – or perhaps because of it – social media can have very negative impacts on communities. The small populations in Nunavut mean that all the details of an important story will be quickly disseminated, such as who was in charge when something went wrong on a medical file. This can lead to nasty social media "gang ups" on health professionals and/or others when something goes wrong.

In summary, social media constitute a new and highly promising suite of engagement tools for Nunavut, whose surface has barely been scratched. While the points raised by our participants merit closer consideration, some of them were quick to add that more outreach is needed. They thought TOH should join forces with other key stakeholders, such as the Nunavut and Canadian governments, to engage Inuit organizations and communities in a deeper and more systematic way, and to canvass their views on how to disseminate health information and/or engage them in a dialogue on health issues. They may have some surprising answers.

Conclusion

Stronger Voices, Better Care was launched to gather informed views on how dialogue and engagement can improve care for Inuit patients from Nunavut. The answers fall into two broad categories. Some focus on how better communication at the doctor-patient level can enhance diagnosis and treatment, which, in turn, will build knowledge and trust. We can call this the "bottom-up" approach to patient-centred care because it engages patients directly in the work of diagnosis and treatment.

But patient-centred care can also be approached more from the top down by bringing key stakeholders and community spokespersons together to discuss how well services are meeting patients' needs and what can be done to improve them.

This report looks at the opportunities and challenges on both sides. It is meant as a first step in what we hope will be an ongoing dialogue between TOH and Inuit patients and communities during the coming engagement process to support the vision of the new campus.

Finally, let us note that TOH also serves other Indigenous communities, including Mohawk and Algonquin First Nations and Métis. The hospital plans to reach out to them in a similar way. *Stronger Voices, Better Care* is thus the first of three dialogues to be carried out with Indigenous Peoples in the Champlain region.