

The Eastern Health Diversity Project: Examining Needs and Establishing Priorities

Report to Eastern Health and Community Stakeholders

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1 INTRODUCTION: BACKGROUND AND RATIONALE FOR THE STUDY

How well is Eastern Health doing with cultural diversity? What are the challenges, strategies, needs, and barriers related to providing effective and culturally competent health care?

This study examined patient and provider perspectives on the provision of effective and culturally competent care within the Eastern Health region of Newfoundland and Labrador (NL). We focused on two marginalized patient populations – the Indigenous and refugee communities of NL. Nationally, these two groups have experienced multiple barriers to accessing effective and culturally competent health care, including infrastructural, economic, socio-cultural, geographic, and linguistic barriers. There is a growing body of literature in Canada on the emerging challenges facing the health system by the influx of refugees; contributing to that literature is an important outcome of this study. The Truth and Reconciliation Commission has urged institutional leaders to move toward non-colonizing, culturally safe, and collaborative approaches to service provision for Indigenous communities in Canada, including in health care; this study also contributes to that agenda. The differences between the two groups – newly arrived refugees and Canada’s Indigenous communities – in terms of contextual features that pose barriers to effective care, are informative for understanding how and why barriers exist and how best to ensure care is provided effectively within our own health care system.

This research was driven by refugee and Indigenous patients and their health care advocates, along with service providers and Eastern Health decision makers.

2 STUDY OBJECTIVES

This study examined patient and provider perspectives on the provision of effective and culturally competent care within Eastern Health, focusing on two marginalized patient populations – the Indigenous and refugee communities of NL. The aim of this study was to produce recommendations for Eastern Health’s provision of care to refugees and Indigenous patient groups.

2.1 SPECIFIC OBJECTIVES

- (1) An in-depth account of needs related to culturally competent health care, from the perspectives of patients and providers
- (2) Recommendations for programming and staff diversity education, including
- (3) Evaluation of and recommendations for Eastern Health’s existing diversity programs, with generalizability to similar programs across the nation and elsewhere

2.2 SCOPE

This study does not focus on diversity in its broadest sense: it focuses only on refugees and visible minority immigrants and on Indigenous groups that use Eastern Health’s services. It does not specifically focus on the many other marginalized communities that comprise the diversity of the Eastern Health patient population.

Two important and interfacing concerns – diversity within the health care workforce of providers, other staff, and health decision makers; and diversity with respect to other marginalized patient populations –

were not within the scope of this project, though some of the findings may shed light on cultural safety within those larger communities.

2.3 RESEARCH SITE AND TEAM

This research is a collaboration between: (1) Eastern Health [EH]; (2) The Refugee Health Collaborative (formerly, Refugee Health Clinic) and MUN MED Gateway [Gateway]¹, which is a partnership between the Association for New Canadians [ANC] and the Faculty of Medicine; and (3) the Aboriginal Patient Navigator [APN] Program², which is a partnership between First Light (formerly the St. John's Native Friendship Centre, SJNFC) and Eastern Health.

This is patient-needs driven research. We used a community-based and patient-oriented research framework.

In this report, we refer to patients and their families and support people as “knowledge holders”. We refer to health care providers and community support workers as “knowledge users”. This research was based on a collaboration between knowledge holders, knowledge users, and health decision makers.

2.1.1 Research advisory committee.

A research advisory committee of knowledge holders, knowledge users, and health decision makers guided this research from inception to dissemination. The knowledge holders and knowledge users were actively engaged in a hands-on way. They assisted with recruiting participants, worked closely with the academics at each stage of the research – most importantly during the data analysis – and helped develop the recommendations that are found in this report.

2.1.2 Research assistants.

Data collection was facilitated by research assistants (RAs). The two community-embedded RAs were key to this project.

The *community embedded RA for the immigrant/refugee patient population* (Rouba Isshak) was responsible for support related to the immigrant/refugee component of the research. Rouba is a physician from Syria, who speaks Arabic. She arrived to St. John's as a government assisted refugee, and at the time of the research was a Diploma student in Community Health and Humanities. Rouba had experience as a professional interpreter on call to Eastern Health. She was responsible for assisting with recruitment. She accompanied Brunger to all interviews with immigrant or refugee patients, also providing interpretation for those who are Arabic speaking. She played a key role in data analysis.

The *community embedded RA for the Indigenous patient population* (Adriana Pack) was responsible for support related to the Indigenous component of the research. Adriana is a member of the Miawpukek First Nation, a youth representative for First Light (SJNFC), and the Atlantic Youth representative to the National Aboriginal Youth Council for the National Association of Friendship Centres. She was

¹Gateway provides health screening to all newly arrived government assisted refugee clients of the ANC and operates a refugee clinic out of the Family Practice Unit.

²The APN program offers support to NL First Nations (Innu and Mi'kmaq), Inuit, and Southern Inuit patients who are referred to St. John's for medical treatment. It also provides a valuable link between Indigenous communities and EH care providers.

completing her Bachelor of Nursing at the time of this research. Adriana liaised with the EH Aboriginal Patient Navigators, assisted with participant recruitment, and accompanied Brunger to all interviews with Indigenous patients.

An academic lead RA (Syaket Shakil) was responsible for management of the project during data collection. Two additional RAs (Rachel Hewitt and Valerie Webber) were hired following data analysis to assist with scholarly publications.

2.1.3 PI's motivation and experience.

The PI (Fern Brunger) has had active engagement with diversity programming at EH since the inception of the Diversity Steering Committee in 2003. She helped to conduct the original patient diversity survey that led to the establishment of the APN program, co-authored the first Diversity Report for Eastern Health (2005), was a member of the Steering Committee that initiated the APN program, and supervised the second set of diversity programming recommendations (2014). She was a faculty co-founder of Gateway, and has been a faculty adviser since its inception. She has had successful research relationships with Indigenous communities in the province. Her position as ethicist to Eastern Health has led her to have a knowledge of how the health system functions. This study builds on her previous research on cultural competency in health care and aimed to inform her scholarly work in general.

3 METHOD

How well is Eastern Health doing with providing effective and culturally competent health care? What are the needs and gaps? This study elicits the expert knowledges of refugee and Indigenous patients and their advocates, diversity and cultural liaison professionals, and health decision makers on the question: "What are the challenges, strategies, needs, and barriers related to the provision of effective and culturally competent health care?"

3.1 METHODOLOGY

Methodologically, our qualitative, ethnographic approach is both critical (influenced by theorists such as Foucault) and interpretive. That is, we take culture in its relation to power as our focus: our research is based on the understanding that culture permeates health and healing, including the ways that medicine constructs its objects of inquiry and ways of knowing, as well as the ways that disease is expressed and treatment is affected. In contrast to conventional ethnography which describes *what is*, critical ethnography also asks what *could be* in order to disrupt perceived social inequalities. Such an approach is appropriate for the study of diversity competence in health care. This approach means that we pay attention not only to explicit beliefs and practices about culture and health, but also to who creates and defines these meanings and who "resists" or transforms them in new ways.

Our research is also framed in terms of "two-eyed seeing", a methodological approach that recognizes the need for both Western and Indigenous ways of knowing in research, knowledge translation, and program development. Here, we extend the use of this concept to the ethnic minority refugee communities we are collaborating with. Therefore, central to our methodology is the juxtaposition of the knowledges of knowledge users (patients) and knowledge holders, in a way that assumes at the outset that both types of knowledge are expert knowledge.

Our method was interview-based, supplemented by an initial scoping survey and emphasising full team (knowledge holders/patients, knowledge users, and health decision makers) analysis utilizing a model that favours knowledge holders (patients) as knowledge producers.

The design was qualitative. In-depth, extensive interviews with patients and families, diversity service workers, health providers, and health decision makers were conducted to determine the gaps and strengths in health care delivery. As well, we did an initial survey with knowledge holders and knowledge users, asking about their views on how well Eastern Health is doing with cultural competency.

3.2 INTERVIEW METHOD: KNOWLEDGE HOLDERS (PATIENTS AND THEIR SUPPORTERS)

Our research framework assumed that knowledge holders (patients and their supporters) were experts on the subject matter.

We conducted 21 interviews with patients and patient supporters. An additional 6 knowledge holders were interviewed, but their role was also knowledge user (community support worker) and they are included in that count, below. Our interviews were designed to have these experts inform us (the academics) about the state of affairs within Eastern Health with respect to cultural competency. We were learners; our participant experts were our educators. We listened to the stories that people told us about diversity and cultural competency within Eastern Health.

Interviews were informal and conversational in style. We asked questions such as: How well is EH doing with providing care? What are some examples of barriers to access to care? What logistical, infrastructural, and cultural safety issues need to be addressed to improve clinical care? What is needed and why? In our interviews, we paid particular attention to whether and how perceptions of being marginalized affects care.

Interviews were conducted at a place most comfortable and convenient for the patient/family. About half of the interviews took place in a small conference room at the medical school, and half in participants' homes. For about 2/3 of the interviews, the participant had a support person with them, either a friend or a spouse. Interviews were informal in tone and conversational in style. The sharing circle-style interview technique is not only culturally familiar to many patients, it bears the strengths of focus group approaches to interviewing by serving to trigger other ideas during the interchange amongst participants. Interviews lasted 60-90 minutes. Questions focused on what knowledge holders identify as the challenges to accessing a culturally appropriate (competent; safe) health care system. Participants were instructed not to reveal personal health information (doing so was not important to the study objectives and would lessen patient confidentiality). Participants were instructed not to reveal names or other identifiers that may breach the confidentiality of staff or other patients (if they did so inadvertently, these details were struck from the transcript). Participants were directed away from details of types of traditional knowledge (e.g., what plant is used for a given health condition) as this was not in keeping with the study objectives and would represent inappropriate cultural appropriation of traditional knowledge.

3.1.1 Immigrant/refugee component

We interviewed 12 immigrant/refugee patients, many accompanied by support persons. (As well, four knowledge users who were interviewed were also knowledge holders with the lived experience of being newcomer or refugee patients). This group was comprised of individuals who self-identified as a visible minority and/or as non-mainstream in their cultural or religious health care practices, and who considered themselves to be newcomers to Canada. They spoke English, French, or Arabic (languages spoken by Brunger and Rouba). The group primarily included refugees (government assisted, privately sponsored, or blended visa office-referred refugees), but also included one economic immigrant who was a student.

Recruitment occurred in four ways: (1) Word of mouth through the community RA (Rouba Isshak); (2) Snowball sampling (participants referred us to other participants); (3) Self-referral via the survey (participants in the survey were informed that if they were interested in participating in an interview they could email the RA to indicate their interest); and (4) Via a recruitment poster circulated by: (i) the executive director of the Refugee and Immigrant Advisory Council [RIAC] on the RIAC website, Facebook page, and monthly email newsletter; (ii) the ANC, posted on their website and emailed to their listserv of newcomers; (iii) the Eastern Health Diversity Project Facebook page; and (iv) the personal Facebook pages of RA's Rouba and Shakil.

Potential participants were told verbally about the project, following a recruitment script. If the potential participant expressed explicitly to the recruiter that they would like to be interviewed, then the RA arranged for the interview to be scheduled. In most cases, the RA was present for the interview; for Arabic speakers, she was interpreter for the interview. One interview was conducted by Skype, with the RA physically with the participants and the interviewer using Skype; the remainder were conducted in person.

3.1.2 Indigenous component.

For First Nations Innu and Mi'kmaq, Inuit, and Southern Inuit patients, we recruited and interviewed 9 patients and patient supporters, most accompanied by a family member or other support person. (As well, two of the knowledge users interviewed had the lived experience of being Indigenous patients). One of the interviews was conducted in Inuktitut via an interpreter (a family member).

Recruitment occurred in four ways: 1) Word of mouth through Aboriginal Patient Navigators and the community RA (Adriana Pack); (2) Snowball sampling (participants referred us to other participants); (3) Self-referral via the survey (participants in the survey were informed that if they were interested in participating in an interview they could email the RA to indicate their interest); and (4) Via a recruitment poster circulated on: (i) the Eastern Health Diversity Project Facebook page; (ii) posted in the APN office; (iii) posted on the First Light (SJNFC) Facebook page; (iv) posted at First Light (SJNFC) centre; (v) posted on the RA's personal Facebook page; and (vi) posted at the Aboriginal Resources Office at Memorial University. We recruited only those who spoke either English or Inuktitut (languages represented on the research team). The majority of participants were recruited through the APNs.

The RA arranged the time and location or type of interview (Skype, phone call, in person) with potential participants. For participants located in St. John's (for example, during their own or a family member's time receiving health care) interviews were in person. For those who were located in the rural and remote areas of the province, phone was used. No participants used Skype.

3.3 INTERVIEW METHOD: KNOWLEDGE USERS AND DECISION MAKERS

We conducted 25 interviews with knowledge users (health care providers and community support workers), including:

- (1) Community support workers, both formal (government programs, health care employees, and non-profit organizations) and informal (individuals who on their own initiative have been involved in refugee or Indigenous patient assistance with accessing health care) (14)
- (2) Health care providers (physicians, nurses, social workers) (6)
- (3) Health decision makers (managers, directors, VPs) (5)

Recruitment was done using three methods: (1) Convenience sampling by word of mouth from contacts previously known to the PI and research assistants; (2) Snowball sampling (participants referred us to other participants); and (3) Self-referral via the survey (participants in the survey were informed that if they were interested in participating in an interview they could email the RA to indicate their interest).

Some of the community support workers were already part of the wider research team (in the spirit of the collaborative approach to this research). For those individuals, participation in the project included early agreement to be interviewed; nonetheless, a formal consenting process took place and these individuals were informed that a decision to not be interviewed would not affect their ability to continue to be involved with driving and disseminating the research, nor would it affect collegial working relationships with any member of the team in or outside of the context of the research project. All collaborators agreed to be interviewed. Of the 14 community support workers, 6 were also knowledge holders (i.e., those with lived experience), but are not counted among the 21 knowledge holders listed above. *In this report, they are identified as both knowledge user and knowledge holder.* Four interviews were conducted by Skype, one by phone, and the remainder in person.

Health care providers and health decision makers were invited via email by Brunger. Interviews took place either in Brunger's office or in the professional space of the knowledge user. Interviews lasted about 45 minutes. They were open-ended and semi-structured, using a conversational style of interviewing. Questions focused not only on needs and gaps in diversity services, but also on systemic, economic, and health-cultural barriers to and enablers of diversity services. This included questions about the needs, resources, functioning, challenges and strategies of existing supports, including Gateway and the APN program. All were done in person.

3.4 INITIAL SCOPING SURVEY METHOD

Separate surveys were done for (1) Immigrant/refugee patients; (2) Indigenous patients; and (3) Health care workers. The immigrant/refugee survey and the health care staff survey were rolled out in Fall 2017; the Indigenous survey was rolled out in Winter 2018, following review and approval by the research advisory committees of Nunatsiavut and NunatuKavut.

The surveys were created using Survey Monkey and subcontracted to the Health Research Unit of the Division of Community Health and Humanities, Memorial University, for design, dissemination, and initial analysis.

Surveys for immigrant/refugee and Indigenous patients included: (1) Demographic information; (2) Information on use of the health care system; and (3) Challenges with respect to: (i) language

differences; (ii) respect/discrimination; and (iii) wanting to use traditional cultural/religious knowledges and practices. Information about and links to the surveys were disseminated through relevant community organization list serves and Facebook pages, and through the community-embedded RAs' Facebook pages. At the end of the survey, participants were invited to participate in an interview about their experiences of health care, by contacting the community RAs to arrange an interview.

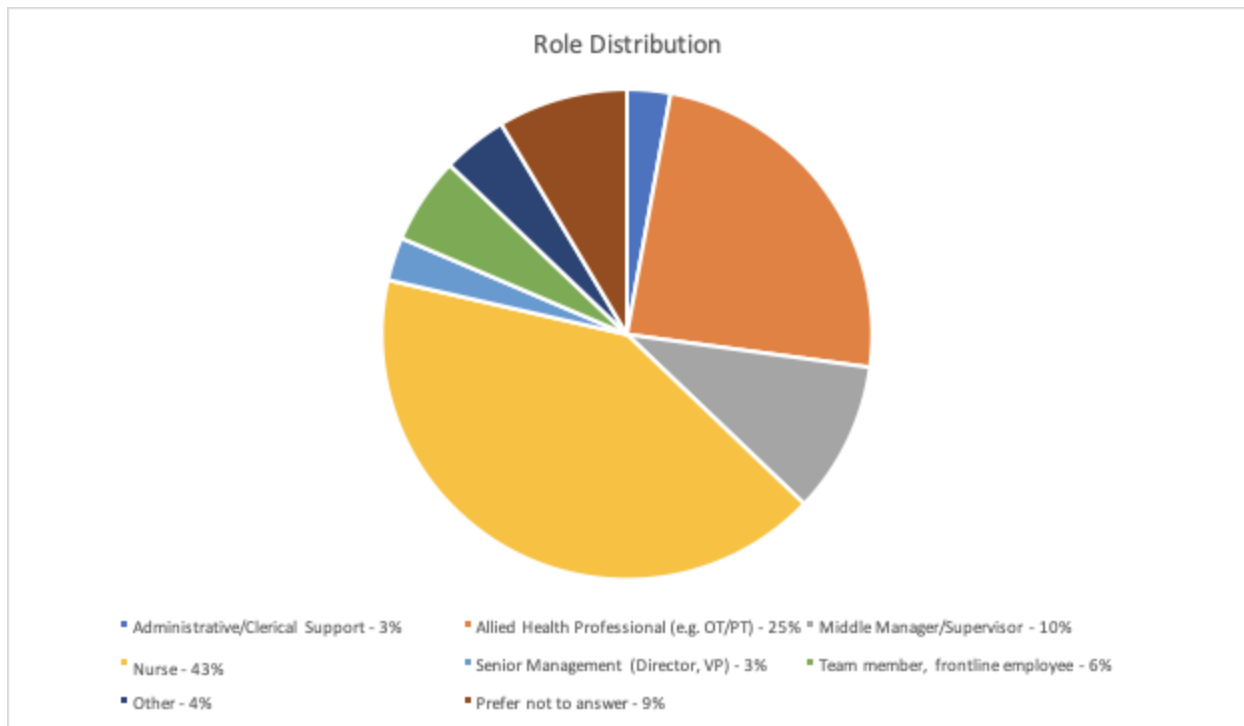
The health care worker survey included demographic information on roles, which were suggested by the EH Human Resources diversity lead on the project. The role categories were: Administrative/Clerical Support; Middle Management; Professional/Specialist/Technician (not a manager, supervisor or team leader); Senior Management (Director, Vice President); Supervisor/Team leader; and Team member/Frontline employee. The survey asked questions about health care providers' perspectives on how well EH is doing with diversity, providers' own experiences of discrimination, and their needs with respect to competency training. One of the EH health decision maker collaborators on the project circulated the survey link to all nursing and allied health professional staff, including managers and directors.

The *Réseau immigration francophone de Terre-Neuve-et-Labrador* heard about the survey through ANC and requested to have a French language version of the refugee patient survey available, and this was done.

The surveys had a total of 193 respondents: 115 responded to the health care worker survey, 45 to the immigrant/refugee survey (two to the French language version), and 33 to the Indigenous survey.

The immigrant/refugee and Indigenous survey components suffered from a low response rate and an even lower completion rate. The answers given often lack the context that would make them properly interpretable. While response rate was too low to draw statistical significance/power, open-ended responses offered additional data, and some quotes from survey participants have been included alongside the interview quotes.

The health care worker component enjoyed a greater response and completion rate. Of the 115 respondents, seven self-identified as a visible minority, three identified as Indigenous, and one identified as a member of a minority religion or spiritual community. The remainder did not select any non-dominant ethnic/racial/religious group identity. Nearly half of the staff survey respondents were nurses (43%); a quarter were allied health professionals (25%); about 10% were Middle Manager/Supervisor (10.45%); and a small number identified as Senior Management (3%) and Administrative/Clerical support (3%).



Results from the 115 staff respondents generally support what staff said in interviews. In this report – primarily in the recommendations section – we have included some of the qualitative survey responses to help explain staff perspectives.

3.5 METHOD OF ANALYSIS

Interviews were transcribed in full. After collecting the stories of knowledge users and knowledge holders, we organized our learning into themes. We discussed those themes in kitchen-table style meetings with our advisory committee – referred to as “research team meetings” throughout this report – and came up with recommendations for Eastern Health.

Unlike hypothesis-driven research, our goal was to describe in detail the key themes that emerged out of the interviews, in order to generate understandings and convey meanings about the way things are, and suggest things to change. These themes were identified on the basis of their salience for understanding barriers and strategies to effective and culturally safe health care from the perspectives of patients, supporters, providers, and decision makers.

Analysis of interviews attended to health care experiences and needs but also involved scrutinizing the normative assumptions and practices surrounding ethnicity and indigeneity in relation to clinical care from multiple stakeholder perspectives, in order to produce “thick description”. We considered points of divergence (and convergence) between patient, provider, and decision maker accounts, as well as within and between the three key communities of interest. Analysis occurred through kitchen table-style meetings of the research advisory committee. In the partnership model that we employ, researchers, knowledge holders (patients), and knowledge users are understood to have equal authority and

legitimacy as the producers of knowledge. The data is not so much contained in the words of the transcripts, as in the *discussion* about the words in the transcripts by insider knowledge holder/user experts. Research team analysis meetings were recorded with permission, and transcribed in full.

3.6 ETHICS

This research proposal was reviewed by the NL Health Research Ethics Board (HREB) and the EH Research Proposal Advisory Committee (RPAC) and was conducted in accordance with the HREA Act and the Tri Council Policy Statement (2014). While this research was conducted only within Eastern Health and in collaboration with First Light (SJNFC) and thus technically did not require Indigenous community consent beyond First Light (SJNFC), the survey and interviews could produce information about Indigenous identity. Therefore, we also consulted with Nunatsiavut and NunatuKavut (the two communities that have formal approval requirements for research) and received approval from those research advisory committees before initiating the survey and interviews with the Indigenous communities.

For research advisors who are not employees of Memorial University or Eastern Health, honoraria were provided for attending research team analysis meetings at the rate of \$150.00 per meeting for each advisor. This is in keeping with a methodology that privileges the expertise of patients and other community-based knowledge holders. Patient/family participants were provided a \$25.00 cash honorarium for their participation, as well as a snack and beverage during in-person interviews.

3.7 SHORTCOMINGS OF METHOD

The study was limited to participants who spoke English, French, Arabic, and Inuktitut, the languages of the study team (Bengali was also a language of the study team, but no participants required this interpretation). We note that expanding this component of the study to include large numbers of immigrants and refugees and to include other language groups would have provided a greater depth and breadth of information, but we did not have the budget or personnel for this.

Having the initial survey only available in English limited the range of responses from the most marginalized community members. While we offered free interpretation for those languages spoken by team members, this logistical/resource shortcoming remains a flaw.

4 GENERAL OVERVIEW OF DIVERSITY PROGRAMMING AT EH

There are four specific sites within Eastern Health where a cultural diversity plan has been envisioned and implemented, and several other “tentacles” of diversity programming scattered throughout the health authority:

- (1) **The Diversity and Inclusion Committee**, housed with Human Resources. The Diversity and Inclusion Committee attends to diversity amongst and diversity training for EH employees. It has hosted initiatives such as staff diversity awareness and education and support for international staff recruitment (most notably, with respect to recruited Jamaican nurses).³
- (2) **The Aboriginal Patient Navigator Program**, which is described at length in this report.
- (3) **Cancer Care**, which implemented the Big Land Project which, among other things, provides awareness and education about Indigenous cancer patient care needs.
- (4) **Pastoral Care and Ethics**, whose work in the early 2000s led to the implementation of the EH Diversity Steering Committee and the Aboriginal Patient Navigator Program.

Other diversity initiatives within Eastern Health include:

- A **nurse practitioner** at the Refugee Health Clinic (which is housed within Memorial’s Family Practice Unit), a position that has been funded by EH since 2016⁴.
- **Client and family centred care, housed under Quality and Safety**, attends to appropriate access to services (such as how to obtain a kosher meal).
- **Diversity “champions” scattered throughout** Eastern Health. These are individuals with a passion for advocacy for refugee patients. These individuals are creatively finding solutions to challenges to health care and are self-educating themselves and their teams, in the absence of infrastructural or other supports from Eastern Health, and implementing changes to care in areas such as **Mental Health and Addictions, Pediatrics, and Obstetrics**.

As well, Eastern Health works closely with other organizations committed to the health of Indigenous patients and newcomers to the province:

- (1) **Memorial University** hosts a cluster of services that include: (i) the **Family Practice Unit’s Refugee Health Clinic**; and (ii) the **MUN Med Gateway Project**, both working in collaboration with the Association for New Canadians and Eastern Health’s Public Health Nurse.
- (2) **The Association for New Canadians** and other community-based formal and informal organizations providing health care, settlement support, and advocacy to refugee newcomers.
- (3) **First Light (SJNFC)**, which co-hosts the Aboriginal Patient Navigator Program.

Attempts to have a unified approach to diversity within Eastern Health have not manifested, something that is explained below and will be returned to in the Recommendations section of this report.

Here, we review each of these initiatives in turn.

³<https://www.assembly.nl.ca/business/electronicdocuments/EasternHealthAnnualReport2016-17.pdf>

⁴ In 2020, the Refugee Health Collaborative was established within Eastern Health, a significant change to the landscape of how Eastern Health engages with refugee health care. This will be addressed later in this report.

4.1 EASTERN HEALTH'S DIVERSITY PROGRAMMING

Eastern Health's attention to diversity began formally in 2003 and by 2020 had two main emphases: Indigenous patient care, and human resources (HR) employee diversity programming.

4.1.1 Early years

The Health Care Corporation of St. John's (HCCSJ) Cultural Diversity Working Group was initiated in 2003, under then Director of Pastoral Care and Ethics, Rick Singleton with Fern Brunger and with representation from First Light (SJNFC), the ANC, and Eastern Health's French Interpretation Service, along with three community members who were advocates for support for immigrant newcomers to the community. A cultural diversity survey was conducted of patients and providers and 188 completed questionnaires were returned. As well, community groups were invited to present briefs to the Working Group; members of the Mi'kmaq, Innu, and Inuit communities did so. In 2005, a Report on Cultural Diversity was produced for the (then) HCCSJ.⁵ Challenges with access to care were categorized into themes of: verbal and written communication challenges between patients and EH; EH insensitivity to distance and time with respect to patients travelling from Labrador; access difficulties relating to disabilities and special needs; discrimination related to sexual orientation; and ageism.

The report recommended that the HCCSJ be responsive to its culturally diverse community by:

- (1) Adopting and promoting Principles of Diversity. Principles of Diversity would assist with integration of cultural sensitivity through proactive initiatives rather than reacting to issues, problems, or complaints.
 - This was completed while the Standing Committee on Diversity was still led by Pastoral Care and Ethics, in 2008.
- (2) Creating a Standing Committee on Diversity.
 - This was completed, in the form of a Steering Committee within HR.
- (3) Building structural accountability for cultural diversity within the HCCSJ.
- (4) Ensuring that Human Resources consider cultural diversity in recruitment, training, and policies.
 - HR has since adopted some policies for staff diversity. For example, as part of the HR emphasis on diversity within its employee population, a study was conducted on the experiences of Jamaican nurses recruited to work in the province⁶.
- (5) Integrating cultural awareness into core educational programs
 - Most professional education on cultural awareness has focused on Indigenous patients and has been conducted by First Light (SJNFC) through the APN program and as part of Cancer Care's Big Land Project. In terms of ethnic cultural awareness training, there was some broad training conducted in 2009. Since then some individual programs have provided training, on a somewhat ad hoc basis, relying primarily on the ANC and RIAC as educators.
- (6) Targeting the needs of Aboriginal [*sic*] people in the province (which was deemed to be the highest and most immediate priority).
 - The APN program and Cancer Care's Big Land Project were responses to this recommendation.
- (7) Providing a mechanism to identify and support competent translators.

⁵Report on cultural sensitivity. The Cultural Diversity Working Group, the Health Care Corporation of St. John's, December 19, 2005.

⁶Heidi Ball, Evaluating the orientation of internationally educated licensed practical nurses from Jamaica working in a long term care program in St. John's, Newfoundland. Master of Nursing Practicum Report, Memorial University of Newfoundland, October 2016).

- A telephone interpretation service was initiated, but has proved to be drastically under-utilized, a matter that will be addressed later in this report.
- (8) Collaborating for research on diversity with other community stakeholders.

In 2006, a Diversity Steering Committee was formalized within Eastern Health and was mandated to continue implementing the recommendations of the Report on Cultural Sensitivity with a broader view to include a full continuum of care.

4.1.2 The Diversity Steering Committee: 2008-2016

In 2008, the Department of Citizenship and Immigration Canada provided funding for a two-year Enhancement of Diversity Project within Eastern Health. The main goals of the project were to broaden employee awareness and understanding of diversity through education. In January 2009, a Diversity Project Coordinator was hired to lead this project to completion. The Project Coordinator developed a training session which she gave to about 300 people, with the aim of creating awareness of diversity. The Steering Committee also organized a two-day conference at that time.

By the end of the two-year term, a Diversity Framework had been developed and was presented to and accepted by the Executive⁷. The framework was based on a set of guiding “principles of diversity” as had been recommended in the 2005 report:

- (1) Respect for Diversity is a Fundamental Human Right
Values and policies which ensure the dignity, worth, and respect of all members of the community must be founded on fundamental human rights.
- (2) Diversity is Enriching
Individuals maintain a unique and valuable perspective that is influenced by cultural patterns and history within their communities. Diversity can be found within any given group. It is enriching and should be respected.
- (3) Collaboration is Enabling
Collaboration, including consultation and cooperation, is manifested through respectfully supporting each other, sharing resources, and initiating and maintaining appropriate programs and services to ensure the integration of diversity throughout EH.
- (4) Health Care Services Should be Accessible, Equitable, and Inclusive
We support the wider goal of providing sustainable and just health care services to the diverse communities of Newfoundland and Labrador.
- (5) Oppression is a Determinant of Health
We recognize that neglect and discrimination directly affect health and well being. We actively encourage initiatives and research that supports this principle and seeks to eliminate the health risks associated with oppression.

The Framework focused on three key stakeholder groups: (1) Employees & Agents of EH (physicians and volunteers); (2) Clients (patients, residents, clients); and (3) Partnerships (education institutions, community groups, government departments, etc). Recommendations for employees and agents focused on creating a respectful and inclusive work environment, including diversity education and training for employees. Today, that initiative rests within HR. The second focus –patients, residents, and clients – had four target areas for improvement in its recommendations: (1) Culturally sensitive and

⁷A Place for All: Creating a Culture of Inclusion. Eastern Health Diversity Framework, December 11, 2011.

appropriate care for Indigenous persons; (2) Interpretation services; (3) Service delivery environment; and (4) Education and training. The third focus – partnerships – emphasized the need for EH to collaborate with Memorial University, government, and community organizations.

Most importantly for our purposes today, the Framework outlined recommendations for where, in the leadership structure of EH, diversity should be housed, emphasizing an integrated model of “diversity champions” working in clinical, community, and administrative settings throughout the health care system. We return to this recommendation of the 2009 report in the Recommendations section of this report.

A second proposal for funding was submitted to the Federal department of Citizenship and Immigration but was not successful. “We were deflated by the whole thing” said one EH staff, “We wanted to try to have funding for three years and that didn’t work” [EH decision maker 5].

4.1.3 The Aboriginal Patient Navigator Program

In 2008, one of the first tasks of the newly formed Diversity Steering Committee was to make an application for funding to the Aboriginal Health Transition Fund “Adaptation Envelope.” This led to the appointment of two patient navigators as a pilot project in collaboration with First Light (SJNFC). The program became operational in Winter 2009.

The Aboriginal Patient Navigator Program is based at the Health Sciences Centre and is administered by First Light (SJNFC) under a signed contract with Eastern Health. The Aboriginal Patient Navigators support the provision of health care services (acute care, residential care, mental health, community services, etc.) to Indigenous patients/clients, caregivers, and their families. Their work includes ensuring that care is available in the patient’s own language at times of diagnosis and treatment; navigation from the time of the patient’s arrival in St. John’s to the point of return to their home community; effective follow-up care. The APNs act as a resource for health care providers and Indigenous patients to ensure care is culturally safe. They provide a link between Indigenous communities and EH care providers. Specific goals at the time of initiation of the program were to: select and train staff on Aboriginal issues and barriers, Eastern Health systems, and medical terminology; promote the program to Aboriginal organizations and governments; establish an advisory committee to support the project; translate available educational materials; establish referral and file transfer protocols; provide information on available services dealing with logistical issues, i.e. transit, child care, accommodation etc.; monitor patient/provider communication; engage patient escorts in follow up care and discharge planning; and conduct routine follow up monitors after three months.

The APNs role with respect to training staff at EH includes: identifying information gaps and misunderstandings; providing information on barriers; liaising with staff development regarding training; developing a training model to address gaps; and scheduling and conducting staff training.

Responsibilities toward patients and clients include: arranging transportation from airport to accommodation; orienting patients to city and the institution; responding to concerns over accommodation, care, transportation, childcare, transit, commercial, and recreational facilities; accompanying patients to appointments, support, and/or translation; and maintaining contact with patients following discharge.

Beyond these specific roles and tasks, the APNs were expected to raise awareness within the health care system regarding cultural differences, practices, and traditions; to ensure enhanced coordination of

after-care for patients returning to their communities; and to develop policies and procedures in all of the above areas.

An evaluation of the project at the end of the pilot project recommended that the APN program be “embedded as a continuing visible and key component of Eastern Health services”.⁸

In the 2010 report, key challenges for the APNs to effectively carry out this tremendous workload were identified: (1) The Aboriginal Patient Navigator Program needs more space and visibility within Eastern Health to effectively meet the needs of the patients; (2) Staff were not being sufficiently oriented to the program; and (3) There were problems with availability of interpreters. These issues will be returned to in the Recommendations section of this report.

4.1.4 Ongoing work of the Diversity Steering Committee: 2010-2016

The Diversity Steering Committee continued to be active, alongside but independent from the APN program. The Steering Committee was housed within HR, and a major component of its work was diversity awareness by and for employees. By the early 2010s, despite clear visions of what was needed, there was a feeling that the work had stagnated. As one Eastern Health staff described it, “diversity was always at the corner of the desk of one person or two people ... but diversity was never really a priority” [EH decision maker 5].

The department of Pastoral Care and Ethics continued to play a role with advancing cultural diversity awareness and action. Under their leadership, the 2011 Statement of Rights and Responsibilities for Clients, Patients, and Residents of Eastern Health (February 28, 2011) contained a clause about diversity. It states that clients, patients and residents have a right to

receive sensitive care that respects diversity including age, gender identity, race, sexual orientation, physical and mental ability, health status, life style, faith group affiliation, education, income and housing status, immigration or refugee status, marital and parental status, and degree of geographic isolation, as well as ethnicity, language and culture.

As well, Pastoral Care and Ethics produced a guidance document on Cross Cultural Accommodation for Health Services in 2012, stating that

Our Statement of Rights and Responsibilities highlights our regard for every person’s right to receive care and services that are respectful and culturally sensitive. It also highlights our expectation that people identify their needs and concerns to staff.

The programs and services at sites of Eastern Health are accommodating to most needs of most of our clients, patients and residents. Some things cannot be accommodated due to reasons of safety or lack of resources. We make special efforts to adjust programs and services, to the extent possible, while maintaining safety and professional standards, and within available resources.

The guidance document includes a statement of what EH can and does accommodate for:

- (1) **Communications:** interpreters, and telephone interpreting service.

⁸Final Report: Aboriginal Patient Navigator Program. Prepared by Axis Consulting for Eastern Health, September 30, 2010.

- (2) **Religious observances:** ablution and bathing, prayer and meditation in the bedroom or interfaith chapel.
- (3) **Dietary needs:** menu or special order.
- (4) **Pastoral Care:** Pastoral Care Contact Person identified by respective faith groups are available through the Pastoral Care and Ethics Department.
- (5) **Informed Consent and Information Exchange:** Particular issues and concerns regarding procedures, medications, or care can be discussed with the physician or other members of the care team to ensure special needs are identified and that accommodations are arranged to the extent possible.
- (6) **Visitation:** Times are scheduled for general visitation. Special needs and circumstances can be accommodated.
- (7) **Gender Specific Needs:** Scheduled and elective procedures can be adjusted through referral and consultation processes to accommodate the request of the individual.

In 2013 there was an upsurge of activity around cultural diversity. A Master of Health Ethics student took on diversity as the capstone project for her degree. “She took what we had done ... and kind of made the strategy stronger and added to it; but again, that sat, because nobody was really – I think there was too much going on around for diversity to become a priority. That’s what I would say” [EH decision maker 5]. Under the direction of the Steering Committee, a qualitative survey was sent out to program managers and leaders, including the following question: *How do you and your program respond to the needs of our diverse patient and client population? Please describe specific programs, policies, initiatives, or approaches.* Responses from Home and Community Care, Public Health and Primary Care, Long Term Care, Cancer Care, Rehab and Continuing Care, and Mental Health and Addictions perspectives indicated that there was a patchwork of activity related to diversity, with the most attention paid to LGBTQ, Indigenous, and bariatric patients and virtually no programming of relevance to cultural diversity in terms of ethnic diversity.

4.1.5 Diversity Inclusion Committee: 2016-2017

In 2016-2017, one of Eastern Health’s VPs (Debbie Malloy) was approached by members of the Diversity Steering Committee with the suggestion of making diversity more of a priority⁹. Malloy joined the committee, which was recast as the Diversity Inclusion Committee, and her enthusiasm ignited the committee once more.

In Summer 2017, an Eastern Health diversity educational event was held with about 200 people in attendance. Around the same time, a staff survey was conducted through HR, with about 70 staff providing feedback on their needs with respect to diversity training. Respondents identified areas for improvement, including: more education on respectful and inclusive workplace practices for both frontline staff and managers, including increased education on diversity for medical students; the need to address unrecognized prejudices towards minorities; and the need for diversity amongst leaders in management positions. Throughout 2016-2017, Eastern Health developed action plans in the form of a “road map” to address areas of concern identified through the survey¹⁰. The survey also asked employees who wished to become involved in diversity programming to come forward, and 18

⁹At this same time, the 2017 Accreditation Report for Eastern Health reported that the Ethics service had identified that “diversity in culture and recognizing the several cultures present in Newfoundland and Labrador” is a gap in current operations (pg. 36).

¹⁰<https://www.assembly.nl.ca/business/electronicdocuments/EasternHealthAnnualReport2016-17.pdf>

individuals identified themselves as wanting to be involved with the Diversity Inclusion Committee, which was taken as a sign that the time was right for creating energy around diversity [EH decision maker 5].

4.1.6 The Big Land Project – Cancer Care: 2013-2017

One of the most significant achievements with respect to providing access to culturally competent care to Indigenous patients was Cancer Care’s “Big Land Project”. *A Journey in the Big Land: Enhancing Cancer Care Services for First Nations, Inuit and Métis*¹¹ in Labrador was an initiative aimed at enhancing the cancer care journey for First Nations, Inuit, and Southern Inuit patients in Labrador.

Work on the cancer care project first started when a group of cancer survivors, caregivers, support workers, and health-care providers in Labrador, along with cancer specialists and administrators from Eastern Health and Labrador-Grenfell Health met at a forum in Labrador in the Fall of 2013. This forum provided an opportunity to reflect on areas of action for improving cancer care for Indigenous peoples. With the stakeholder’s concerns identified, the Big Land Project was formalized in March of 2014, and ran until 2017. The initiative was a partnership between Eastern Health’s Cancer Care program with funding assistance from the Canadian Partnership Against Cancer. The main goals of the project were to make improvements to transitions in care, enhance tele-oncology services, and enhance cultural safety. To that end, the initiative generated a number of novel and important outcomes and resources. These included community and clinic profiles, an orientation video tour of the Cancer Centre in St. John’s and the hospital in Happy Valley-Goose Bay, and the development and implementation of a cultural safety training program for health care professionals.¹²

Prior to the Big Land Project, there was a dearth of awareness about the context of health care in Labrador, and advice for follow-up home care was often inappropriate. One decision maker tells the story of the lead-up to the Big Land Project.

We had sent a man home on a Friday, a long weekend, who had major cancer surgery ... He couldn’t eat, he had a feeding tube in so he spent a long time here [in St. John’s] recuperating. He didn’t want to go to Goose Bay hospital. When people are ready to go home they want to go right back to their community so we sent him back to his community. Nobody knew there was no pharmacy, nobody knew there was no road, nobody knew that landing this man back in [small town in Labrador] meant he had no feeds, he had no food until someone flew something in for him four days later. Just an event like that to realize our discharge planners really had no idea – they made assumptions that there would be a pharmacy, that there would be something or access to some of this before ... [We] went to Labrador and met with all the elders and Indigenous groups. We spent a lot of time, and said “*What are your issues?*” [EH decision maker 3]

Community and Clinic Profiles were created and made available on each of the units. The working group developed glossaries (“body charts”) to help patients and informal interpreters better communicate between patient and provider. The community and clinic profiles are very in depth, describing

¹¹At the time of the project, the Southern Inuit represented by NunatuKavut were still being referred to as the “Labrador Métis”.

¹²Shea, J. (2016). Navigating the Journey: Aboriginal Health Initiatives at Eastern Health. Eastern Health’s StoryLine. Retrieved from <https://storyline.easternhealth.ca/2016/06/22/navigating-the-journey-aboriginal-health-initiatives-at-eastern-health/>.

transportation, roads, resources including police, social work, and education, as well as health care resources locally and in the nearest larger centre. This innovation won a national leadership award. While that project focused on Labrador, it is being expanded to the island Indigenous communities. Alongside the creation of these educational resources for health care providers, a professional video was created for patients from Labrador, explaining the St. John's based cancer care system, including what patients might expect from the time they leave their home to the time they return.

As part of the roll out of the Big Land Project, formal training in cultural competency was offered to health care providers. The half day program was attended by 1110 staff and was well received, with leadership reporting that the evaluations were "the best evaluations I've ever, ever seen on any training program we provided" [Eastern Health decision maker 3]. A follow-up a few months later revealed that staff were using the tools learned. The training was provided by First Light (SJNFC) which was contracted to do the work. First Light (SJNFC) continues to provide the training when requested, for a modest fee per person attending. The training program was also developed into a 1.5- hour modular online e-learning program for the province, and all regional health authorities provide a link to the training on their websites.

Both the APN program and the Cancer Care initiative are success stories for Eastern Health. The patients and providers we spoke with agree that these structured initiatives go a long way to promoting a context of cultural competency and cultural safety for Indigenous patients. However, as stories told by patients and their supporters revealed, systemic racism and marginalization is still very much a part of the patient experience, and a lot of work is needed to promote cultural safety for Indigenous patients. Similarly, the Diversity Steering Committee is an important part of ensuring diversity is attended to within the population of employees at Eastern Health, and should be lauded for its efforts. However, there are massive strides still to be taken toward a context of cultural safety. This will be returned to in the Recommendations section of this report.

The story of providing health support to refugee newcomers is in large part situated outside of Eastern Health and its diversity initiatives. For that recent history, we need to turn our gaze to Memorial University's Family Practice Unit and its intersection with the Association of New Canadians, the MUN MED Gateway Project, and the (eventual) creation of the Refugee Health Clinic. That story is embedded in the Refugee Component section of this report.

5 INDIGENOUS COMPONENT

In this section, we report on our findings related to access to care for Indigenous patients. We are very grateful to the Indigenous patients and patient supporters who took the time to discuss their concerns so frankly with us. They were quite clear that the path for Indigenous patients receiving care at Eastern Health is one that is defined by the broader experience of systemic racism in the province in general. Moreover, they conveyed a strong perception that there is an ongoing and troubling lack of awareness by staff of the experience of being an Indigenous patient at Eastern Health. Here, we review the main challenges raised by patients, patient supporters, and staff, focusing on: the logistics of travel from Labrador posing undue hardship on patients and their travel escorts; communication barriers posing risks to patients in terms of care as well as informed consent; cultural differences exacerbating the lack of trust by patients in the health care system; racism and marginalization shaping the experience of care; and settler-Indigenous power relations more generally shaping mistrust in the system.

An important positive finding was that the APN program effectively responds to the needs of patients at Eastern Health. The program was described by patients, patient supporters, and health care providers in an overwhelmingly positive light.

5.1 LOGISTICS OF ACCESSING CARE

Patients travelling from Labrador to St. John's have their travel arrangements made on the Labrador side of things¹³. That includes arrangements for air travel, accommodation, food vouchers, and transportation within St. John's for the patient and one escort (when required for patient care, such as following surgery) and, when required, an interpreter. Costs are borne by Indigenous governments, either directly (in the case of Nunatsiavut) or through Health Canada (in the case of the Innu First Nation). Southern Inuit members of NunatuKavut did not have a formal land agreement at the time of these interviews. Medical transportation costs for this group involved applying for MTAP (Medical Transportation Assistance Program), whereby patients could receive a reimbursement of up to \$1000.00 with receipts¹⁴.

Here, we describe some of the logistical challenges of accessing care for those travelling from Labrador to St. John's. Key challenges are: lack of awareness by staff about the APN program; geography and the challenge of scheduling appointments; poor communication to patients prior to travel about supports available once in St. John's; perceptions of unequal access to transportation within St. John's; inadequacy of food vouchers; and general financial burden¹⁵.

¹³As this report focuses on Eastern Health, it was not our intention to examine or discuss the responsibilities of Labrador-Grenfell Health region or the Indigenous governments. In this report, when we discuss patient concerns about events that happen prior to arrival at Eastern Health, we intentionally gloss this as "the Labrador side of things".

¹⁴A pilot project has since been initiated, whereby NunatuKavut does cover costs, similar to Nunatsiavut Government and Health Canada.

¹⁵We do not include experiences with accommodation. Concerns were few, and we deemed this to be sufficiently outside of the scope of Eastern Health that we excluded this information.

5.1.1 Staff awareness of APN program

For the most part, EH staff are aware of the APN program. However, at the time of the interviews, the APNs were still facing challenges with some staff who do not understand or appreciate the APNs' roles and responsibilities within the circle of care. For example,

[There is an expectation that] the APN calls the community health contact to arrange follow up care, but it's the discharge planning nurse who should be doing this; or to arrange the prescriptions in Labrador. [APN]

Some Eastern Health staff still fail to appreciate that the APNs are within the circle of care and need to be able to access patient information to fulfill their duties.

We will request appointment confirmations for patients – because they need that to book travel – to send that into their insurance. So we have a lot of issues getting that information. Like just a month ago I was contacted by a patient – they wanted me to get an appointment confirmation because they had misplaced their appointment. Their appointment was in two days. They had to come from Goose Bay. I called the doctor's office and it turned out that he was on holidays and this receptionist was not going to be checking messages until the day. Of course, the patient had the appointment, so that wasn't going to work, because if it was like 9:00 in the morning it's going to be impossible. So I called the admitting department to see if I could get a copy of the appointment. I said who I was and they said *"No, sorry we can't give that information to you"*. So I said *"What am I going to do, who am I going to call, how am I going to get this information?"* I'm limited to what we can see on Meditech. So I called one of the social workers for the urology patient. I called the urology social worker and I said *"Okay, this is the situation; is there anything you can do?"* She, the social worker, knew one of the clerks down in the outpatient department very well, so she called and asked for this favour and she got it from them. [APN]

A misunderstanding of the role APNs play in the circle of care complicates their ability to make appropriate health care arrangements. As the next section discusses, even when EH staff understand the role of APNs, there are additional travel and scheduling difficulties.

5.1.2 Scheduling appointments

Scheduling appointments in Eastern Health for patients based in Labrador has posed challenges. The Cancer Care Program's Big Land Project was designed to help health care providers understand the geographical and social context of Labrador, to avoid making mistakes. Yet, at the time of these interviews, patients and supporters continued to lament the lack of knowledge by St. John's based staff about the geography of Labrador and the realities of air travel. One of the APNs explained this:

[The hospital] called him one day on a Friday morning, 11:00 in the morning, and said *"Okay your bed is available, can you be here this afternoon?"* – I don't think so! He has to come from Nain, right. So, there's only flights on Monday, Wednesday, Friday in Nain so it's usually 9:00 in the morning the mission plane is gone, so he had to wait until Monday ... What should have happened there they [St. John's booking] should have called the clinic [in Labrador] and said *"Okay, can you get a hold of this patient and let them know?"*; [Labrador-based clinic] should be able to say *"No, our Mission plane is gone for today, we'll have to reschedule"* ... Some of that is common sense too, right. If someone is booking an appointment, they see that the

person is in Labrador, you should hopefully take a second to think about how long it takes to get down from Labrador too. [APN]

Many patients raised this issue, captured in this Inuit patient's words:

I come in [from Labrador to St. John's] for my appointment. Got to the appointment desk and they were like, *"Yeah, we tried to call you and let you know that it's changed to next month."*

[Indigenous patient 3: Inuit woman – patient and patient supporter]

When patients from Labrador having non-emergency surgery leave home for St. John's, only to find that the procedure has been postponed and they need to wait in St. John's for an unknown period of time, the geographic barriers create additional social and economic burdens.

We're just waiting for the surgery, whatever timeline that is ... We don't know – today or tomorrow; I don't know. It's still up in the air ... We don't know what's going on today, maybe it's too many patients here who are having [names type of surgery], that kind of thing.

[Indigenous patient 1: Innu man – patient, patient supporter and interpreter]

Patients and supporters expressed frustration that nurses sometimes do not appreciate the long distance that has been travelled to attend an appointment and do not understand the need for food or rest. With the schedules of flights within Labrador, and then from Labrador to St. John's, there may not have been an opportunity to eat for hours before appearing for an appointment. This Innu patient/supporter explains:

There's this patient, she was really hungry and she wanted to eat because where she was emerged [i.e., in emergency] in St. John's and she hadn't eaten for over eight hours and she has to eat something; she said *"I'm starving can I have something?"* She kept buzzing her thing until the nurse or someone came into the room and she said again, *"I want something to eat, I'm starving ... I never ate nothing since I came from Goose Bay"*, and so all they gave her was a glass of water and one slice of bread. [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

Scheduling air travel – both by air ambulance and on commercial carriers – can compound the complexities of booking appointments for patients coming from Labrador. We heard the story of an Innu patient who could not travel to St. John's for a scheduled specialist appointment because a series of emergencies meant that he kept getting bumped off the list for travel by the air ambulance. Meanwhile, the (adult) patient's parents had already successfully travelled to St. John's to be with him (having taken a commercial airline), and were waiting there for him to arrive.¹⁶

We're going home tomorrow because my son never showed up ... That's the ambulance's fault, it's not our fault at all ... So we had to reschedule that for [2 months later] ... They kept pulling us back and they'd tell us it was sometime tomorrow morning or sometime this evening but it was never done. So I called my son this morning and told him that he can't come [to St. John's] now

¹⁶If the medivac is coming from the coast, then typically there is not just the patient but also the patient escort travelling with them (if there is a medical reason to support an escort). Between St. John's and Goose Bay, depending on if there is also another patient and the severity of that other patient, it is possible that there will be no room for a patient escort. In such cases, a seat will be booked on the next available commercial flight (still paid for by the funder).

so we're going to have to cancel it and get rescheduled ... The doctor never cancelled out until Monday [the day the patient was to have the appointment]. Tuesday, Wednesday, and now today is Thursday and the doctor was all open to see him but the air ambulance was full.
[Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

In that case, the lack of available space on the air ambulance over a series of days meant a considerable loss of finances and time for the family. The arrangement of travel for escorts can be last minute and can vary between air ambulance (“medivac”) and commercial airlines, posing additional difficulties. If the medivac is coming from the northeast coast, then it may be that there is not just the patient but also the patient escort travelling with them (if there is a medical reason to support an escort). Between St. John’s and Goose Bay, depending on if there is also another patient and the severity of that other patient, it is possible that there will be no room for a patient escort. In such cases, a seat will be booked on the next available commercial flight (still paid for by the funder). This variability of how escorts travel can lead to problems with reimbursements for travel, and problems for the APNs at the St. John’s end of things. A funder sometimes does not know that an escort is on the medivac plane – for example if the travel was arranged at the last minute because there was space on the plane, and the travel happened after hours or on the weekend. The APNs, meanwhile, will receive notice that the patient and escort are there, but the funder may not know, making administrative processes very difficult at both ends.

Scheduling of patients on commercial airlines, for those who do not require air ambulance, also has its challenges. This Inuit patient/supporter explained the experience of travelling to a St. John’s medical appointment, using the example of a particular woman who had travelled with her two young children from Nain to Goose Bay and then from Goose Bay to St. John’s for a specialist appointment.

She never arrived to St. John’s until around 12:00 midnight from Goose Bay, because they put her on a nighttime flight, like 9:30 [pm] or something ... travelling with two children Sometimes it happens that way, like they’re making you travel all the way to St. John’s and then you get to St. John’s 12:00 midnight and then you have to wait for somebody to pick you up. Then the driver got to take you down to the Governor Inn, then you got to check into the Governor Inn and by that time it must be like 1:00 in the morning. Then you like you go to bed or whatever, and you have to get up again say 6:00 or 7:00 in the morning for your appointment that is at 8:00 in the morning, you know sometimes that does happen. [Indigenous patient 6: Inuit woman – patient, patient supporter, and interpreter]

The long distances Labradorian patients and their families/supporters must travel, combined with a lack of acknowledgment or appreciation of those distances by EH staff, can create delays and disruptions of care that are costly, confusing, and uncomfortable. A clear understanding of what supports are available upon arrival to St. John’s can ease the burden of this travel, but as the next section explores, these supports are not always made obvious to travelling patients.

5.1.3 Communication about supports available in St. John’s

Typically, patients and their escorts and interpreters travelling from Labrador to receive care in Eastern Health are pre-approved (either by Health Canada and/or the Band council or by Nunatsiavut Government) and have arrangements made for housing, transportation, and food vouchers. Housing is

typically at one of a handful of designated hotels, or at the First Light (SJNFC) hostel¹⁷. Transportation can be in the form of reimbursement for taxis or bus, but typically is by pre-arrangement with the First Light (SJNFC) van. Food vouchers are provided for use in the hospital cafeterias. At the Labrador side of things, they are also informed that the APN program is there to assist them in St. John's.

Across the board, for all patients coming from Labrador, there were challenges related to not having received sufficient information at the Labrador side of things prior to arriving in St. John's.

I didn't know that [the APN program] existed – the only reason I knew was because I had Facebook and a few people, a few friends of mine, had told me to get a hold of Katie, to go see her and she would be able to help me. So I ended up finding her and looking her up and she did everything for me and it worked out really good. [Indigenous patient 5: Qalipu man – patient and patient supporter]

Say when I fly from Nain to Goose Bay, we're picked up in Goose Bay and then we're brought down to the hospital [in Happy-Valley Goose Bay] to check in ... there's somebody there in a little office [in the hospital in Happy-Valley Goose Bay] that checks you in ... *"This is your appointment time and here's your blue slip"* and they ask you where you're staying and stuff like that, or like, *"You can get a ride here and there"* or whenever. Then they give you your information that you need to take to go to St. John's. But one of the things they don't tell you about is the food vouchers that you could get at the hospital if you're there. [Indigenous patient 6: Inuit woman – patient, patient supporter, and interpreter]

According to the APNs, the problem with lack of information was particularly the case for Health Canada clients.

Some of them [patients] come with nothing, like no papers, no nothing. They're just like *"I don't know who my appointment is with, or, I don't know why I'm here."* ... They don't know who they have to see or which doctor and where to go ... [Health Canada is] based in Halifax, so it's like there is no accountability – they're not working directly for the bands ... [It's mainly the] Health Canada clients – that's where I think a lot of the problems are; there's no communication. They don't hand them any information at all about their doctor's appointments ... A lot of the times a lot of the Innu patients will come to our office, *"Okay can I get a meal voucher?"*, and they'll think we already have the paperwork but, no. We just had a situation earlier where a man asked *"Can I get a meal voucher? Do you have my paperwork?"* and I said no. I said *"The way things work ... when you're coming, you have to tell [Happy-Valley Goose Bay liaison workers] what you want"*. I said *"If you want to have your lunch here at the cafeteria, you have to tell them, and then they will send that information to Health Canada, and we'll get the paperwork and say yes we'll be glad to give you a meal voucher you can go through the cafeteria"* – that's the way things work. [APN]

One particularly vocal Innu patient/supporter, in the context of describing the inadequacy of food vouchers allotted to patients, described his ongoing efforts to lobby Health Canada to be more aware of and responsive to the concerns of patients:

¹⁷The First Light (SJNFC) hostel has been closed since December 2020. The under-volume of use in the context of the pandemic made costs proportionately too high for the hostel to be sustainable.

Because if you're not going to complain about it, you're not going to get anywhere. I told Health Canada many times even — I want Health Canada stationed in Goose Bay, rather than out in Halifax so I can go in there and bang on their door when I need to. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

He contrasted what he sees as the shortcoming of Health Canada officials with the success of the St. John's-based APNs.

I'm happy that Katie and Sol are doing a good job on it because, me, when I call [Health Canada] – I don't even want to speak with Health Canada by myself, because I don't like those people. I've had a hard time with Health Canada figuring out meal arrangements, accommodations, all kinds of things. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

He summarized his perspective on the shortcomings of Health Canada by stating that instead of the Health Canada officials being in charge of information and logistics, *"It would be better if we had people in Goose Bay like Katie and Sol"* [Indigenous patient 7: Innu man – patient, patient supporter and interpreter].

Patients travelling from Labrador would be well-served by a clearer understanding of what is available to them in St. John's and what they need to prepare. Transportation within St. John's was an area of particular concern, as the next section describes.

5.1.4 Transportation within St. John's

In 2018 a change to the First Light (SJNFC) van transportation process was implemented. A phone line became dedicated to van transportation, as opposed to the previous system where the general First Light (SJNFC) phone line was used and then the call transferred. The system was seen to be significantly less convenient for patients, as there was not always someone available to answer the designated line¹⁸. The APNs explain:

It's hard to get through down there. I can see why some people are getting frustrated ... Like, you know they have different departments – like there's a line for the APN's, there's a line for education, there's a line for training, there's a line for like all different departments. They had one there for transportation, but they took it out. It doesn't make any sense so now – all the phones are redirected to us after hours. We're getting all these calls like *"Okay, I'm here at the airport can you come pick me up?"* ... There's an 8:00 to 4:00 [pm] number that you have to call Monday to Friday. After hours, on holidays, or on weekends, there's a different number that you have to call. Once [First Light (SJNFC) staff member] is gone for the day, she forwards the phone calls to the cell phone number that the drivers take because they're working until 11:00 at night. After 11:00, that phone is dropped off to the shelter, because there's somebody there 24/7 ... and there's a lot of missed calls and there's lots of problems with that phone system. [APN]

Patients were calling the APN day line, and getting no one, and getting stuck at the airport late in the evening with no ride to their accommodation. We heard many stories of patients whose flight had arrived later than scheduled and therefore had no First Light (SJNFC) van to meet it. In those cases,

¹⁸The APNs report that since December 2020, in the context of the pandemic and the closing of the First Light (SJNFC) hostel, now only one telephone number is in use, directed to a call centre for patients calling after hours. That new system is working effectively.

patients would have to take a taxi. While they would be eventually reimbursed for that taxi fare, provided they had the receipt, this arrangement was very problematic for those on low income. This Inuit patient/supporter explains:

You walk out to the terminal and you expect the van to be there but it's not ... If I didn't have a cell phone, how would I get a hold of them [First Light (SJNFC) van driver]? And I've heard of a few people now that that's happened to, you know, and they're just waiting there not knowing what to do ... And there's times when it's after hours, you know what I mean, like you could get there in the night time and lately there's been patients being flown from Goose Bay to St. John's and they're putting them on the late flights and they're getting there like 12:00 midnight in St. John's. [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

Many were confused about whether patient supporters had access to the First Light (SJNFC) van, with some feeling that access to the van was not allocated fairly. However, unless such an arrangement was made in advance, additional supporters beyond the approved patient escort would not automatically receive services such as transportation via the First Light (SJNFC) van. Lack of communication, in advance, to patients and supporters about the way that standard payments work, and how to manage a request for an exception to the standard policy, led to frustration and a feeling of unfairness for some patients. The words of this Innu patient/supporter capture this frustration:

Transportation-wise they [the First Light (SJNFC) van] won't take us because you know ... I have to pay for my own taxi here, and from here to the motel ... Because you've got to be a patient or an escort ... For example, my brother-in-law got an escort, but he's using taxis paid by Health Canada; and we came out on our own, we haven't been recognized as a support worker, you know what I mean? [that is, because there is already an official escort, and this individual's role of interpreter and cultural broker is apart from that] ... Yes because they don't look at it that way [that interpretation is a necessary service] ... They won't – they consider me nothing, you know what I mean. So that needs to be corrected as well. [Indigenous patient 2: Innu woman – patient]

This lack of effective communication at the Labrador side of things was a source of frustration for the APNs as well. They reported that at times, travel arrangements are made for a patient to be accompanied by more than one supporter, but without the accompanying arrangements being made for transportation within St. John's.

"Okay, you're going to St. John's, you're going to the Holiday Inn". They don't ask them if they need transportation. So, when this person gets picked up at the Holiday Inn the rest of the family tries to get aboard, but they're not on that authorization. [APN]

An additional change to the van transportation process was that patients or family members could no longer request the van for visits to their accommodation or elsewhere during the day. In the spirit of ethical resource management and stewardship of scarce resources, the revised policy is that individuals are only transported to and from accommodations and the airport or the hospital site; patient escorts can only have one return trip from their accommodation to the hospital each day. The APNs pointed out that such a "one size fits all" policy needs to have exceptions made and be occasionally adjusted for compassionate reasons. They told the story of an elderly husband of a patient at St. Clare's who typically would arrive at the hospital early in the morning and spend the full day with his wife. However, during

one particular week of this hospital stay, the hospital cafeteria had extremely limited hours and was in fact closed most of the time (presumably for renovations):

So anyway here he was, being there from 8:00 in the morning until like 10:00 at night, and he was spending his own money going to different places around St. Clare's that were close by for something to eat. So then I argued with Nunatsiavut that this is not right, I said "*St. Clare's cafeteria is not open, it's closed now for this week ... He needs to go back. You need to approve an extra ride for him*". And so they got it approved and said "*Okay, you can have two rides now until the cafeteria is open again*" ... We had that situation before too, a similar thing at St. Clare's, and [the husband] was like 75 years old and he was beat out. He was there for probably a month with his wife, and so anyway I said "*No he's exhausted, he cannot be there all day. He wants to be but he needs to go back and rest.*" So they approved an extra ride for him. [APN]

The APNs feel that the revised system of restricting the numbers of van rides is fair, provided that those who require additional rides for specific (rare) reasons are accommodated.

Right now we have a mom, her baby is in an ICU at the Janeway ... She's doing her feedings, and they want her to move over to Ronald McDonald House but we couldn't get her in there, so Health Canada had to approve her three rides per day because she's got to come back for feedings. [APN]

Some patients/supporters expressed a concern that the new policy of restricted transportation could result in patient supporters putting their own health put at risk because they have no means of going back to the hotel to rest.

[It used to be that] I'd call the van, they would drop me off at the hospital and then I can call them again "*Okay, you can pick me up now, I want to go back to the hotel*", and maybe like get some rest or whatever and then I call them again later on and they'll pick me back up again and bring me back to the hospital again ... But now they can't do that, so that means you got to stay at the hospital. Like if you want to stay with your husband or whatever you got to stay there all day unless you get your ride by taxi or whatever. [Indigenous patient 6: Inuit woman – patient, patient supporter, and interpreter]

Lack of transportation access also means patient supporters are unable to easily go off site in search of lower-cost food. The option of taking the bus is not an easy one for people from rural and remote areas who are not used to it.

People are afraid, like where they're so used to living in isolation, and then coming into St. John's it's such a big city for them. Sometimes they're afraid to take the bus, which is convenient and cheap because it's only \$2.50, but still some people are scared because they're not used to so many strangers [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

Transportation needs once in St. John's are an important aspect of safe and supportive care. Similarly, accommodations for sufficient, low-cost, and nutritional food are essential, as the next section discusses.

5.1.5 Inadequacy of food vouchers

There was widespread concern that the food vouchers allocated are insufficient to meet basic needs. The food vouchers do not stretch very far in the relatively expensive hospital cafeterias, and patients and their escorts very often have to contribute extra toward food costs, either on their own or by looking for additional resources.

[Government will] pay for \$12.00 worth of your breakfast and ... even if you just order like a cup of tea and toast and maybe one little other thing, usually that goes over \$12.00 ... You can't have a good breakfast Then lunch time you might want to get a clubhouse sandwich and fries and soup or something but then that's going to be like twenty something dollars, so that breakfast and lunch money don't really cover what you want to have. [Indigenous patient 6: Inuit woman – patient, patient supporter, and interpreter]

The food is very expensive in the canteen [hospital cafeteria] down there and then when it comes to the weekend the canteen is not open so, our vouchers, you can use them at the Tim Horton's ... and I mean nobody wants to be living on muffins or donuts or coffee, right? The food is very expensive in the restaurant in the hospital ... There's a healthy place there with healthy food over to the side but your voucher is no good over to that place. [Indigenous patient 5: Qalipu man – patient and patient supporter]

One patient supporter reported that patients and escorts are forced to take some of their daytime meal to save for an evening snack because they cannot afford both:

The hardest part I see is when I know that there's patients here and they have such a low limit on the amount of funding for food ... Like a sensible breakfast, a sensible meal, a decent meal without worrying Sometimes, like say, if they ordered a sandwich during meal time, [they'll] take half the sandwich and save it in the night time for a snack [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

It is important that this concern does not get glossed as a “Labrador side of things” issue to resolve. The reason why the food vouchers are insufficient is in large part related to the lack of low-cost nutritional food on Eastern Health premises. This relates to the next section, which discusses the financial burden of receiving care more generally.

5.1.6 General financial burden

In general, the costs of resettling in St. John's to receive care at Eastern Health, whether short-term or longer-term, were very draining. For some, we can imagine that the costs may be prohibitive and would lead someone who is non-urgent to delay or postpone receiving tertiary care.

We were struck by how often escorts and informal volunteers provide financial assistance to help offset the burden of the stay in St. John's.

Because I'm after going to a few places where people have stayed and I just go visit them and they'd be going to have their meals, and they'd be worried about eating, saying *"I can't have that because I don't have no money"*, and I said *"Just get it, I'll pay the difference ... Put your voucher towards that and I'll pay the difference."* [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

I'll do anything if I'm around. I try to help out as much as I can with people around here, like when we were staying down at the Holiday Inn, there were a lot of people out there with no money and no smokes and no nothing. I try to help them out a little bit. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

[Patient] wanted to get a few things before her operation today, and we had to pay money out of our own pocket because there's no [First Light (SJNFC)] van [because case workers in Labrador had failed to initiate the paperwork] I mean like I said, she's out on her own and welfare don't give a hell of a lot of money right you know. It's pretty – it's a sin right, I mean I forked out my own money to help with cabs since I come here, yeah. [Indigenous patient 3: Inuit woman – patient and patient supporter]

The Inuit patient/supporter quoted above explained in greater detail the challenges faced by the economically disadvantaged staying in St. John's as a patient or patient escort:

So I started looking for other resources [for a patient and escort] and I found out the bonus part, there's a Salvation Army here and they give \$6.00 extra for dinner, \$6.00 extra for supper and you know breakfast and so on right ... [Patient] case workers [in Labrador] are supposed to help them as best they can, right, and they're not doing nothing ... To me truthfully, do you want to know my opinion, it's elder abuse. It's elder abuse what they does to their people. It's cruel. I feel really, really, really, really bad for them ... You know it is degrading actually. It makes them feel degraded. Like I mean [woman's name] looked at me last night crying, she said [participant's name], she said, *"I would never have made it without you"*. I was like *"Don't be so foolish"*, I said, you know *"I'm here, we're going to get it done right"*. It's sad, really sad. [Indigenous patient 3: Inuit woman – patient and patient supporter]

Travelling long distances to receive care, especially for people already living on a low-income, incurs a great financial burden. Beyond the many economic and logistical barriers to arriving in St. John's, there are also many linguistic barriers that impede care upon arrival. The next section explores the various facets of accessing translation and interpretation services.

5.2 COMMUNICATION

Patients travelling down from Labrador for a scheduled appointment or procedure who require an interpreter will have an interpreter travel with them at no cost to the patient, paid by either Health Canada (for Innu Nation) or Nunatsiavut Government (for northern Inuit beneficiaries). According to an EH decision maker, for those who do not have an interpreter with them – such as patients in non-planned (emergency) situations – interpretation is provided: the APNs will arrange for an Innu interpreter through First Light (SJNFC), paid for by First Light (SJNFC). For Inuit patients, one of the APNs also acts as interpreter when required¹⁹.

5.2.1 Challenge with access to interpretation

However, we found a great deal of confusion amongst patients about whether interpretation is available to them. This was particularly true for Innu patients. At the time of the interviews, the APNs themselves

¹⁹At the time of the interviews there were two APNs, with one available to interpret in Inuktitut. An Innu APN was later added to the team for a period of several months until their resignation for personal reasons. The Innu staff position is in the process of being restructured.

were able to fill a gap in interpretation for Inuit patients by providing the interpretation themselves; but this was not so for the Innu patients. The APNs have an Innu interpreter affiliated with First Light (SJNFC) that they call on in emergencies, with the costs borne by First Light (SJNFC). First Light's (SJNFC) Innu interpreter is not always available. On those occasions, when the Innu interpreter affiliated with First Light (SJNFC) is not available and is required because of an issue that has arisen outside of the normal context of the planned procedure, the APNs sometimes need to be creative about where to turn for assistance. Here, they relay the story of turning to the Innu liaison workers in Goose Bay for assistance.

We had a patient probably two months ago up in the special care unit. She was up there for probably two months. I had just come in the doors at 7:00 and got the call ten after seven saying they needed me upstairs ASAP. By the time I got upstairs, four family members from Sheshatshiu were there. She had just passed. The patient had just passed. She was sitting up in bed ... They were shocked that she passed away, and so we needed to get an interpreter. At that time [Innu interpreter with First Light (SJNFC)] was not here, she was away, so I called the liaison worker in Goose Bay to get an interpreter to ask if she could speak to the family. They were all in tears and shocked. I called her [the interpreter] and thankfully she answered, and said she could interpret for them so they did it by phone and explained to them, well she died, like you know, and what happened and whatever. [APN]

Innu patient/supporter experiences were also that there is insufficient access to interpretation. This patient supporter, who had often accompanied patients as a paid interpreter, was concerned that the current policy of having interpreters arranged only for specific procedures is insufficient, expressing his concern that there should be someone embedded in the system more readily available to assist when needed:

We don't have somebody [to provide interpretation for the Innu communities]. Sometimes there's a language barrier. People don't speak English at all, so there's a problem that exists when nobody understands English ... You need to have a translator as well in this system, because without that people are lost, or they don't understand the technical stuff like the words coming from the doctors, so we need translators – that's what I'm saying. [Indigenous patient 1: Innu man – patient, patient supporter and interpreter]

A second Innu patient/supporter expressed similar concerns. He is often called on to do interpretation in hospitals, and emphasized that there is a need for Innu interpreters in St. John's.

Participant: There is a problem with Innu people from Natuashish and Sheshatshiu I think, most people, like elderly people who are my age, 60 years, they're not going to speak English ... They need an Innu interpreter in St. John's ... When a person is sick down here, he can manage to tell the doctor what kind of pain he's having [but] he's not going to understand the doctor [about] the medication he needs. Some people don't understand; they don't take their medication properly.

Fern: When you do interpretation for people for the hospital system, do you ever get paid for that?

Participant: No, I just do it out of my time if I'm around. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

While Inuit patients appear to be better situated with interpretation they, too, occasionally rely on volunteer interpreters outside of the EH and APN system.

Participant: Where I speak fluently in Inuktitut, people get my [phone] number ... I'm well-known by people for interpreting; like sometimes people come to me in advance [of a medical appointment] ... Say an elderly patient is coming up [i.e., has a medical appointment planned], so they'll say call me. [People say] "*She'll help you out if you need help*", because I'm so used to helping and I don't mind doing that.

Fern: Okay and do you get paid for that?

Participant: No, no I just volunteer ... I don't work with [Eastern Health], I'm just a person on the street ... someone well-known for speaking the language.

Fern: So who is it – is it Katie and Sol that call you up, or does the health care system – like do the nurses and so on also have your number?

Participant: No, no. No one has my number, it's just outside the clinic – people who know me just call me, it's nothing to do with the health care system, or Katie and Sol. [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

There is a need for translation services between languages; in addition, more general communication challenges and breakdowns were also a frequent concern, as the next section describes.

5.2.2 Communication challenges more generally

APN is a blessing. Doctors and nurses in emerg are degrading to indigenous let alone average people. All health staff that aren't indigenous just don't understand how to care for our population. I.e. our preferred care and our way of communication and community organization. I.e. many people are intimidated by professionals and will not speak up or question anything.
[Anonymous response, Indigenous patient survey]

The APNs stress the importance of having not just an interpreter, but an advocate who can act as a cultural broker between patient and clinicians. They clarified that it is often not just language differences, but the culturally-shaped way of communicating that causes communication barriers. They shared the story of an Inuit patient whose first language was Inuktitut and was able to speak English quite well. The APNs had asked him if he wanted them to accompany him to the clinic and he declined, stating that he would be fine on his own.

APN: And [patient] came back and Sol said "*How did it go?*" and [patient] said "*I never understood a thing he said*". So it's common for Aboriginal people to just say yes but the doctor is talking to you and asking you questions and you're just agreeing to agree, just saying yes. They're not getting the information, they just say yes.

Fern: And so the solution for that is, if you could, to provide training to physicians?

APN: [nodding] "*Tell me what I just said to you.*" Ask them to relay back what we just shared. Like when we're there, we help them to better understand because we're saying "*Okay do you understand what's being said, do you have any questions?*". So they feel a lot more comfortable because we're there to ease them I guess, to make them feel supported and be their voice.

This physician, discussing challenges with providing care to children whose parents do not speak English, had a similar observation:

I do find, culturally, that group of patients [Indigenous patients], it's often very difficult to engage them. They're often not as verbal or forthcoming as we're used to seeing in our culture, so it's a little bit more challenging. So I always worry that they're unhappy with the care, or that ... there's something else wrong, that I'm not explaining right ... Sometimes I find one parent will speak English and the other will speak Inuktitut, and they'll be talking to each other and I won't know what they're saying, whereas if I'm seeing [refugee patients], the interpreter can say "*Oh, yeah mom and dad are confused about this, confused about that.*" [Physician 3]

A related challenge with communication is low literacy in general and the barrier this poses, even for fluent English speakers, to fully communicate with clinicians. This Innu patient/supporter explains:

Some of those young people drop out of school when they're like, four and five years old, I guess, so it's enough [education] to understand I guess, and that's about it [i.e., that's the limit of their ability]. And the complicated words – like myself, I can't name those pills [when asked by a doctor to describe what medications are being taken] because they're so hard to explain. "*I can't have my pills on me all the time,*" I told the doctor. I told them: if they're not too lazy, look in their files – just look. Many times I get frustrated at them too, because I just told them, "*I can't bring my medication out, I can't name you my medication, because I don't know what they're called*". All I know is there's medications, that's all, but I can't name them. Lots of people are like that I guess. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

This same patient/supporter noted the compounded challenges of language ability and low literacy in the remote regions of Labrador, given that the St. John's based physicians are failing to ensure that patients adequately understand instructions for medications.

They [patients] got to find somebody to read the label on [medication] to take what they want. An elderly person probably would take the whole bottle of pills if it wasn't for them [people who interpret for patients in the community]. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

My dad is a very low speaker [i.e., not well educated, not very good with communication in English] and when the doctors talk to him, he doesn't understand, so I have to put it in what you call laymen terms for him. He wouldn't know what was going on unless I was there, they [doctors] don't explain themselves. They're just in a rush: get you in, get you out, like "*Here you go, deal with it.*" You know what I mean? It's sad, yeah, they don't – the quicker they get you in, the quicker they get you out. They're happy, but like my father looks at me going "*What just happened?*" ... The biggest misunderstanding is the patients don't understand their doctors, because they're talking to them in their [medical] terms. When the person doesn't understand, and then you have to take five minutes after we're out of the room, and I've got to take at least five or ten minutes to explain to my father, "*Well yeah your heart is starting to fail and they need to put this inside of you to make it work*", and he's looking at me going "*He [the doctor] didn't say that.*" I said "*Yeah, he did Dad*", like you know. And it's complicated, it's really complicated because I mean elders in this day and age, they might have gotten Grade 3 [education]. Some of them didn't even have that. My father got as far as Grade 3, so I mean, yeah, it's pretty complicated for them. [Indigenous patient 3: Inuit woman – patient and patient supporter]

It is important for EH staff and healthcare workers to appreciate that communication styles are culturally shaped, so that even if a patient speaks English, communication can break down in other ways. In addition, patients may have different reading and comprehension levels than is apparent. As the next section explains, some staff and clinicians do understand these facts, but then falsely assume who is capable of and responsible for such linguistic interpretation and cultural brokering.

5.2.3 Role confusion of interpreter and escort

Typically, a patient will arrive with one escort, if required for medical care. That person typically is also the interpreter, but not necessarily. Patients and the APNs reported that occasionally clinicians will assume escorts/supporters are interpreters, or that interpreters are escorts/supporters.

For the APNs, one of the major concerns with roles being confused or inappropriately conflated is the potential for misidentification of the legal substitute decision maker. They recounted, by way of an example, one story told to them by an interpreter who had recognized the inappropriateness of being asked to act as substitute decision maker and had refused, explaining to the doctor that she was just an interpreter, not a decision maker, and pointing to a second individual (the escort) whose role was to be the substitute decision maker. It is likely that there are cases where neither the interpreter nor the escort are the legal substitute decision maker, exacerbating the potential for having decision making done by someone who is not authorized to do so.

A second challenge related to role confusion had to do with appropriate compensation, whether reimbursement for expenses or pay for interpretation services. The APNs told the story of an individual who assumed she was accompanying a patient to St. John's as an interpreter. However, the patient was having surgery and required an escort to accompany her back to Nain once discharged; so the interpreter was approved as the escort, rather than as an interpreter. The documentation attesting that she was an interpreter was never completed, without the woman's knowledge. She accompanied the patient to St. John's and interpreted for her.

So this person assumed that she would be getting paid as an interpreter; but she was not approved as an interpreter. She was approved as an escort ... I called and I said *"Okay this person is here,"* I said, *"She's wondering now where her pay is."* [The administrator in charge at the Labrador side said] *"What are you talking about? She's not an interpreter, she's there as an escort because the person is having surgery."* [APN]

An escort is only required if the patient's medical condition requires it. As noted above, when an interpreter is also needed, very often the escort will be the interpreter. However, that individual will only be paid as an interpreter if this has been arranged and authorized in advance – otherwise, the assumption is that the family member or friend who is the escort is doing the interpretation out of the goodness of their heart, as part of their support for the patient. These leads to two types of confusion. First, escorts who also happen to be interpreting (but without advance authorization as an official interpreter) sometimes expect to be paid as an interpreter and are surprised when this does not occur. Second, interpreters who also happen to be known to the patient and can double as escort are not appropriately authorized as an official interpreter at the Labrador side of things. As a result, some individuals are unfairly not paid as an interpreter even if their primary role for accompanying the patient was to interpret. To compound the confusion, according to the APNs, sometimes Health Canada clients

are authorized as official interpreters, but are primarily escorts and are in fact not able to effectively interpret, and the APNs then need to scramble to find an interpreter at the last minute.

5.2.4 Role confusion of informal vs approved escorts and interpreters

For health care providers, the confusion over who is meant to be on-site as a patient supporter and/or interpreter can be compounded by the use of informal volunteers. These informal volunteers either live in the St. John's area or are in St. John's as escorts, interpreters or family members of other patients. They are individuals who are known and respected within the particular Indigenous community and are called on by the patient (or family, or escort) to provide additional support. This includes providing interpretation, patient advocacy, cultural brokering (explaining how the medical system functions and how the city functions to patients; interpreting the cultural and social context of a patient's needs to health care providers), and running errands, as well as visiting and providing emotional support. Informal community support workers often work long hours. They provide the support out of compassion for their community members:

It's a privilege. It makes me feel good, and it makes the patient feel good too, they just keep saying "Thank you, thank you" and I'm like "No you don't need to thank me." I just want to say "Okay, you're here to get better and that's all that matters." [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

These informal volunteers are well known to the APNs (and vice versa). They are an integral part of the care system for patients travelling from other parts of the province to St. John's. The important role of these volunteers, and the potential role they could play as knowledge holders advocating on behalf of patients, will be returned to in the Recommendations section. The importance of cultural brokering is expanded upon in the next section on some key cultural differences faced by Indigenous patients.

5.3 CULTURAL DIFFERENCES

When we raised the question about challenges or concerns related to cultural differences, two topics emerged in multiple patient/supporter and staff interviews: visitor restriction policies, and the use of traditional Indigenous healing practices.

5.3.1 Visitor restriction policies

Visitor restriction policies were raised by staff as a challenge for some families to adhere to, and by patients as a barrier to traditional family healing practices. From the perspective of health care providers, including the APNs, the policies are sometimes breached by Indigenous families and this causes disruption to the functioning of in-patient units.

[Having too many family members accompany the patient to Eastern Health] has actually become an issue on several different occasions where we were contacted [and told] that too many of the family members were in the room. Obviously, you know, some rooms have three other people in them, and then here you have a family of ten people here around this one bed. I mean the others are feeling overwhelmed, saying "Okay you're being too loud" and kids are running around and you know, we've been contacted numerous times [being asked] "Can you come and fix this situation, make them understand that there are only two people allowed per visit at a time?" [APN]

For some patients, having the family gather round the bed of a sick loved one is an important part of healing.

Sometimes we have those [rules] here in the hospital ... so many patients in one room. It's only two people that can visit ... but when someone is really sick, then we need the whole family because we come from Labrador, way far, but we need to stick together and support our patient because that's how we support each other, right. [Indigenous patient 1: Innu man – patient, patient supporter, and interpreter]

[Southern Inuit patient supporter describing Innu practice of family coming together to deal with sickness] The Innu are really into that. I know the hospitals frown on it, absolutely frown on it. They you know – actually there's an elder ... she's a friend of my family, and the whole family comes out [to support her] and before she went into surgery they wanted to go in and do their traditional prayer with her and the [hospital] wouldn't allow it. I mean, it's their culture. It's how they deal with things. They deal with it as a family, not as, you know, three people in a room, or one person in a room. [Indigenous patient 3: Inuit woman – patient and patient supporter]

An easy solution to the dilemma of how to accommodate large families who have come from far away to be with a sick or dying loved one is to create a family space. The APNs explain:

What we wanted was to have family space, an Aboriginal family space, where they could come in and sit down, have a cup of tea, just to relax and wait ... an Aboriginal space where they could just do smudging, have maybe a bed or two there for them to rest, if they'd been up all night, and go in and just have a rest and stuff like that. [APN]

A proposal for such a space had been put forward when the APN first started, but was never revisited. Thoughts on and requests for additional traditional healing practice accommodations are discussed in the next section.

5.3.2 The incorporation of traditional healing practices into health care

There is an interesting dichotomy in terms of how traditional Indigenous healing modalities are described and discussed by health care providers and decision makers. On one hand, complementary and alternative medicines (CAM) are treated very seriously, as well as framed as being culturally interesting and somewhat exotic (e.g., attention to the land or other aspects of the external natural environment). The Cancer Care Program's Big Land Project led to greater awareness about the needs of Indigenous patients with respect to staff levels of cultural competency.

We knew a fair bit about holistic medicine, but we need to understand how important the earth and the land and the culture, and even you know, working – trying to provide health care services to those who leave their communities and they go into the woods or they go wherever they go for three months and don't understand why they're not coming back for their chemo. So it helped us develop strategies so that we could even target people's treatments in a more appropriate way. [EH decision maker 3]

You know the cancer program, in terms of Journey in the Big Land, has also been really helpful [in framing our] approach and [nuancing how we understand] culture, and understanding you know people's world, and their environment, really, and how we provide services in our environment

and how our approach and the assumptions we make are completely different sometimes. [EH decision maker 4]

On the other hand, there is a suspicion of and concern with CAM as representing unscientific practices that are harmful. Providers are concerned that patients are not volunteering information about their use of CAM out of fear of criticism or lack of respect. In areas like oncology where “people are desperate to try anything” [EH decision maker 3], an explicit attempt is made to inquire about it and attention is paid to respectfully accommodating individual wishes for complementary care.

Yes, it has to be incorporated into your treatment plan because people will not voluntarily tell you about it unless you ask ... Of all of the work we’ve done on pharmacy networks and this kind of thing, in my mind that’s one of the gaps ... There’s a lot of misinformation, and there’s a lot of valid information out there so we have a philosophy that we try to incorporate patient’s wishes into their care alternate therapy, and holistic medications are something everybody’s asked about ... We got a really good strong team in oncology, so you know lots of times physicians will defer to the pharmacist to have the discussions about [drug] interactions and that type of thing ... There’s a couple of physicians over there who are really supportive they incorporate holistic [approaches too] because they do they attempt to try and meet patient’s wishes where they are. [EH decision maker 3]

Patients report not telling their physicians about their use of complementary and alternative medicines.

Some people are relying on remedies ... like myself, I know from those remedies from my mom when I grew up ... No I wouldn’t tell the doctor my remedies no, no. If they’re doctors I don’t have to tell them anything. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

Comments submitted through the Indigenous patient survey indicated that health care providers are not always receptive to the idea of patients using alternative healing modalities:

When I asked to have an elder conduct a ceremony I was told no because there was no smoking. I tried to tell them it was not smoking but they still said no. [Anonymous respondent to Indigenous patient survey]

A patient should be able to smudge if needed, or light the Kullik, or have traditional medicines brought in by a family/community member or Elder. [Anonymous respondent to Indigenous patient survey]

Every time I go to the doctor I am told to take a pill for something and that any other medicine, holistic or natural, cannot be counted on to help in any way. [Anonymous respondent to Indigenous patient survey]

Have indigenous traditional healers information available to those who request it. Be open to working with indigenous peoples to find a way to provide for their requests – not hiding behind bureaucracy to state that needs can’t be met – make allowances. [Anonymous respondent to Indigenous patient survey]

This respondent to the staff survey stated the same.

If patients choose an alternate treatment to what our staff recommends, they may be dropped from the service or spoken of in a derisive manner. Patients have told me that they will not tell some staff members about treatment choices they are making because of this concern. This can lead to interactions between treatment choices that could be risking the health of the patient.
[Anonymous respondent to Staff survey]

One patient we interviewed explained that a loss of trust in the health care system, for example due to discrimination and marginalization, can lead people to resist western biomedicine in favor of traditional healing practices.

The common medicine, yes, you know for a common cold, or for a cut, or burn, I've used them myself. [Describes condition] and I used turpentine to close [a wound]. I boiled turpentine off a tree and I closed it. I was in camp; what could I do, you know, I didn't want to go out. I didn't want to lose my hours, so you know I did it myself. It was the way I was taught, right. Little simple things like that, but you know, people are willing to jump out of that and make the effort [to use western biomedicine], but if you're going to be pushed in the wrong direction they're going to try the old medicine again. [Indigenous patient 3: Inuit woman – patient and patient supporter]

The lack of accommodations made for traditional healing practices can be considered one expression of the much larger topic of anti-Indigenous racism and marginalization, which is developed below.

5.4 RACISM AND MARGINALIZATION

We heard stories of explicit racism being exhibited by health care providers within Eastern Health.

I heard a lady about a month ago got called a savage ... It's hurtful, it's hateful, and as you I'm sure you know this as well as anybody else, we're outnumbered big time and they choose their own ways and that's it ... It's almost like we're told *"Either you shut up or put up and whether you like it or not this is how we're going to treat you"*. [Indigenous patient 3: Inuit woman – patient and patient supporter]

When my child was admitted to the Janeway, the admitting nurse was speaking very loud and slow at my mother who was there with my child and I. It was very condescending, and the admitting nurse was acting like my Mum was deaf and stupid. It was insulting to be treated that way. Cultural competency training should be a requirement by all eastern health staff.
[Anonymous respondent, Indigenous patient survey]

I had an allergic reaction and was broken out in hives while at the Psychiatric Short Stay Unit. The doctor accused me of being a sex trade worker because I am an Indigenous woman. She said *"Many women like you are sex trade workers"* – I'm a university educated woman who has been working with [names field of employment] for the last 6 years. She accused me of having herpes all over my body due to working in the sex trade. I explained to her that I am a [names field] employee, happily married in a monogamous relationship, and she said it's probably herpes all over my body. I asked for a second opinion and the next doctor confirmed what I had believed – that I had allergic hives on my body. It was insulting to be accused of being a sex trade worker because I am Indigenous. This is just one example of how some staff at Eastern

Health have treated me like an inferior person because of my ethnicity. [Anonymous respondent, Indigenous patient survey]

Health care workers have assumed alcoholism and drug use as the primary reason for emergency visit when symptoms did not warrant such an assumption. They also did not see the value or would not allow additional family members to visit in support although this was a part of our values. (This was not a personal experience but one I had as a caretaker of a family member in both emergency and surgery department). [Anonymous respondent, Indigenous patient survey]

I've had multiple experiences of being discriminated against due to my ethnicity. One time a doctor accused me of being drunk and on drugs when I was sick with a bad flu (it was the H1N1 virus). [Anonymous respondent, Indigenous patient survey]

[We] were being discriminated against by a professional doctor saying that my brother couldn't come in every time he drinks and be put on oxygen or life support because, the way the doctor was saying, "*The life support is so expensive*". What about the life of my brother, you know what I mean? ... That, to me, was discrimination ... Because all my family were there and, well, the doctor even saying that to a recent patient is – [a doctor is supposed to be] a professional right?! To say that to my own brother, who was lying dead there on life support, you know, to talk about your machine that is so expensive – what about the life of my brother, and his wellbeing? That to me was discrimination. [Indigenous patient 1: Innu man – patient, patient supporter, and interpreter]

The event described above had taken place 6 years prior. This family member described how they had written a letter to the doctor asking her to apologize, but there was no follow up and no apology:

Well in a way she got away with it. She got away with it ... So that to me was discrimination. How many people have died in the hallways across Canada? An Aboriginal person on a wheelchair – he died on a spot there [referring to recent news coverage of a death in another province] ... That was discrimination. They don't look at the wellbeing of an Aboriginal person – they look at us as drunks, assuming that you're lazy, that's the kind of language they use here. To me the doctor was saying that to my brother. It's powerful. That was hard to swallow. It wasn't a nice thing to hear from a professional ... All my siblings were there – my brothers, sisters and my daughter – she lives here and attends college, and was well educated. [Indigenous patient 1: Innu man – patient, patient supporter, and interpreter]

This Inuit patient supporter had this to say about a nurse she had encountered at one of the Eastern Health hospital sites:

A lot of them I find are still ignorant about Aboriginal people ... I was here for an appointment, and when buddy was there talking and talking to me he said "*Don't mind me talking missus*", he said, "*I can talk a leg off an Eskimo*". And I said well "*We're not called Eskimos no more, we're called Inuit and Innu*" ... That was here at the Health Sciences [Centre] not even a year ago probably And [the man] didn't say sorry or "*Oh my gosh*" or didn't feel bad about it at all. Then I went out the door and he told me to go one way and I went the other way and he said

“You don’t take directions very well either”. So I mean there’s still racism going on [Elder, Advisor to project]

Patients and supporters we spoke with were frank and forthcoming in their descriptions of marginalization, systemic racism, and explicit discrimination. The words of one patient captured their collective anger as she explained how she now actively resists being treated in such a manner:

I don’t beat around the bush. No, I can be pretty sarcastic. I don’t let them [people who work in health care] go over me no more. I did for a few, you know, for a good few years, and I said you know – I’m not doing it no more. They can do it for a “normal” as I call them, sorry, Qallunaat²⁰ – if they can do it for Qallunaat, they can do it for me, sorry! [Indigenous patient 3: Inuit woman – patient and patient supporter]

In terms of solutions, most patients and supporters suggested mandatory training for health care provider; but in addition, this person recommended an anonymous means of reporting racism:

I think every patient should be given a questionnaire, a private questionnaire to put in a ballot box for when they are getting mistreated, so that they can keep track of it and note it and give to the liaison officer for them to read and discuss about it and get it fixed ... Because not everyone wants their names or just have saying the dates they were there and what room they were in and they don’t need to put down their name but state that this nurse or something did this to me or said this to me and needs to be taken care of by their supervisors. [Indigenous patient 4: Inuit woman – patient, patient supporter, and interpreter]

Anti-Indigenous racism can be expressed in many ways. In addition to the above examples, we also heard about other forms of marginalization, described below.

5.4.1 Marginalization

Aside from explicit discrimination, we heard stories of marginalization. Here, we use the concept of “marginalization” to describe the process of social exclusion in which individuals or groups are denied economic, political, or symbolic power and are treated as outsiders. Marginalization can be enacted by a dominant group treating members of another group as if they are not there or as if their opinion does not matter. Marginalization is a form of discrimination that may be unnoticed by those who have not experienced it. When asked for specific examples to explain discrimination in the hospital system, the APNs explained the subtle ways in which discrimination can be manifested:

It’s just the way that they act ... Like you just know by their actions and the way that they speak to you, the way they look at you. [APN]

The experience of being discriminated against through marginalization was explained by this patient supporter:

There were four patients in [the hospital room] including my husband, and I was there and this doctor came in ... My husband was the only patient that was there from the north coast and the

²⁰Qallunaat (singular: Qallunaaq) is a term originally used to describe white Europeans – a reference to their galluit, the bushy eyebrows that the Inuit saw as the distinctive feature of Europeans. The term is used to describe non-Inuit Canadians.

other three patients were from Newfoundland ... And the first patient he went to see – he was there talking to him good, and asking him how he was and telling him whatever, and then he went to see the patient across from him and the same thing, like, you know, just asking him questions, being really nice and stuff like that. And then when he came over to the section where my husband was, it's like his attitude changed, I noticed that ... We could tell right away his attitude was different toward us. He was speaking to us but he wouldn't let us speak, something like that. Like when we tried to ask a question he would just, like, ignore us, he wouldn't listen to us, so I noticed that right away. So what I did, I tried to, like, I butted in and tried to ask him a question and he wouldn't even hear me or, like, he wanted to like shut me up or something ... And my husband got really, what do you call, discouraged or felt really bad and he just wanted to leave the hospital. He didn't want to stay there and stay at the hospital anymore because of how he was being treated. [Indigenous patient 6: Inuit woman – patient, patient supporter, and interpreter]

One patient/supporter referred to the size of the APN office as an example of the marginalization of the APNs and of Indigenous peoples in general:

I mean, two of them are in one office and I mean like when you got sit down you're – there's very little room, I mean you got three people in a tiny little room, and I bet you the room was probably no more than 8 x 8 probably, or 8 x 7, it's not a very big space ... I could be wrong but I think the reason why they're shoved in a little closet – I would say they're supply rooms or janitor rooms – and I could be wrong, I mean I'm not a person to put anybody down, but I think when it comes to the Indigenous people, like we're looked at abnormal when it comes to the higher offices ... In the other office rooms in [Health Sciences Centre], I mean [staff are] out in the middle with glass doors and this and that – they see everything. What Katie and Sol is in, they don't see nothing. [Indigenous patient 5: Qalipu man – patient and patient supporter]

The office has since been moved to a larger space in a location that it is more easily found by patients.

A second patient/supporter also made reference to the APN office space in his comments on systemic racism and marginalization within Eastern Health and the province in general. He referred to the lack of windows in the APN office, the fact that the APN office is out of the way and hard to find, and the province's ongoing practice of removing children from Innu communities and fostering with white families, as examples of ongoing systemic discrimination. He referred to the entire system of discrimination as a "big blanket".

The big blanket, you know ... How do you tear the blanket? You can't do it. There's a lot of change to be done and we don't have [Innu] police officers, that kind of thing. We have social workers whose hands are tied because they got to go by the system. We have RCMP go with [i.e., side with] the social workers when they apprehend kids or go to people's houses. The justice system because ... the judges, right, we aren't looked at as well educated. Because that's the system they've created, we're assumed to be criminals, and looked at in all sorts of ways ... [It's] racism by the police, by the government, you know. [Indigenous patient 1: Innu man – patient, patient supporter and interpreter]

He went on to explain that the blanket is actually made out of paper, which is so powerful that it is stronger than canvas.

Well, we have this paper in the system, there's all kinds of words written: [for example] where you got to look after your grandchildren – *"If you don't follow [this authority figure's rules], I'll take your kid"* – it's covered, it's not canvas, it's paper. A canvas tent is much more stronger now; but their paper is much stronger than that, you know, that's why I'm saying – the health system needs to be changed and justice has to be well educated with the doctors or judges or you know – that's how I could see the system ... That's what I meant by blanket because that's *their* system, that's *their* policy, that's *their* policing, that's *their* judgment, that's *their* doctors. [Indigenous patient 1: Innu man – patient, patient supporter and interpreter].

Marginalization was thus experienced in many ways, from subtle microaggressions to systemic prioritization of settler norms and values. This relates to how the resourcing of programs specifically for Indigenous patients was understood, as is discussed in the next section.

5.4.2 Patient perceptions of under-resourcing of the APN program

Apart from the comments by patients and patient supporters about the APN office space as a symbol of the marginalization of Indigenous peoples in general, resourcing of the APN program was *not* raised as a problem to us by the APNs or by other frontline staff or decision makers. However, we were struck by the number of comments we heard from patients, patient supporters, health care providers, and EH decision makers about how the APNs were going "above and beyond" and "far beyond" their duties. While this language was meant to positively convey how very committed the APNs are, this praise also signaled, for us as outsiders, a likely need for greater resourcing of the APNs.

My perception is they're doing a lot more than navigating – like, they're going to the airport picking people up, that was never the intent of their job but they are working way outside the scope of a traditional navigator. People really rely on them because of cultural, not even language barriers, right, and their roles obviously weren't meant to do that kind of thing. The Native Friendship Centre [First Light], that's more their role because they provide a phenomenal support and because they have transportation vans that come back and forth. I mean there's not an hour of a day I'm sure they're not parked in front of the Health Sciences [Centre] picking up and dropping off people; but because I think Katie and Sol are so integrated into acute care, people really rely on them very strongly. They're very busy. [Participant and another EH Decision Maker] worry about them a lot actually. [We] monitor and help support them in any way we can. They're awesome people. [EH decision maker 3]

[Describing how the APNs go above and beyond in their support of patients] I mean it's their job to do paperwork, but I mean it's not their job to stop in and see how you're doing, or how you're feeling. But like they'll come up and they'll ask you – like when I was in my room like they'll come up and be like *"Do you need anything extra? If you need anything we'll try our best"*. Like, I mean, it's like a friend stopping in to see you ... They are strangers, but it almost made you feel like they were almost like family to you the way they treated you. I think they're doing way more than what their job qualifies them for, because I mean I've never seen that before in my life ... You only got the two workers there and I mean they – it's got to be stressful for them to deal with everybody and try to make everybody feel at home and try to help everybody every day, because they're pretty busy. Like, I don't know how they do it but, I mean they go out of their way, so they must get around to everybody. [Indigenous patient 5: Qalipu man – patient and patient supporter]

While the APN program was not described as explicitly under-funded, it is clear that the needs go beyond what the current staffing and scope was intended to be. While the fact that the APNs go “above and beyond” clearly demonstrates their commitment to providing compassionate care, acceptance of/praise for this extra labour can also be understood as a subtle enactment of power. The next section explores power relations in more detail.

5.5 POWER RELATIONS

Patients identified one aspect of power relations that requires special mention and discussion outside of the context of discrimination and marginalization. A common and very compelling narrative that emerged from patients/supporters was the critique of the way that Indigenous communities are categorized and understood. One aspect of this was the critique that the province’s Indigenous groups were being categorized and hierarchized, with differential access to services of the APN program. Another aspect was the critique that health care providers tend to lump all Indigenous communities together, failing to understand the important geographical, cultural, historical, and other differences between them.

5.5.1 Categorization and hierarchy

According to the Newfoundland and Labrador Indigenous Administrative Data Identifier Standard (2017)²¹, there is a “need to identify the records of Indigenous persons within regional, provincial, territorial and national health information systems” (pg. 1). According to the Standard, the rationale for implementing an Indigenous identifier data standard is that having a record of Indigenous persons within various health information systems is beneficial for the health of these populations. The document identifies priority systems for Standard uptake, including the MCP (particularly the Beneficiary Registry) system, NLCHI Live Birth System, and Provincial Cancer Registries. The Standard asserts that an identifier record supports “health service planning, delivery, evaluation and research related to Indigenous health issues” (pg. 1). Without the use of this kind of record system, other identification methods have been used²². These have largely been methods that rely on “postal or geographic codes to identify individuals from communities predominantly populated by Indigenous persons” (pg. 1). The supposed limit to this current system is that postal signifiers are much less useful in identifying Indigenous people living in urban centres. The document notes that the implementation of the Standard opens the doors for many different uses of Indigenous identifier data, including (but not limited to) demographic analysis, health services evaluation, chronic and communicable disease surveillance, as well as health related funding requests. It states that adopting the Standard could be done in a number of ways, but “the preference is to collect the information through the MCP application, renewal and update processes by including the self-report questions on the forms” (pg. 9).

²¹Department of Health and Community Services Newfoundland and Labrador Centre for Health Information. (2017). Newfoundland and Labrador Indigenous Administrative Data Identifier Standard. Retrieved from <https://www.mmiwg-ffada.ca/wp-content/uploads/2019/05/40-NL-Indigenous-Administrative-Data-Identifier-Standard-FINAL-2017-12-12.pdf>

²²Some individual departments or programs do have their own identification systems. For example, we were told by health care providers that Long Term Care does collect identifiers of Indigeneity as part of their client/patient intake. There are categories for First Nations, Metis (the former name for the Southern Inuit) and Inuit, in a yes/no format. The form can be skipped and often is, so it is not reliable.

From the perspective of health decision makers, having an identifier on MCP cards to flag patients as Indigenous is seen as a positive move, in terms of mobilizing resources for increased programming:

One of the things that we learned in cancer care is that when we went looking for incidence of cancer in our Aboriginal populations ... without an Aboriginal identifier how could we actually tell [what groups were getting certain kinds of cancers?] So in the cancer world, it would be important for us because the types of cancers in this group, some of them are very different – they're in younger generations as opposed to older. Sometimes the elders spoke very articulately about cancer: *"We don't understand what this is? Where is it coming from? It's coming from your [southern colonizers] polluting our lands and our water"* and, interesting, because the earth as you know and the land is very important and they see people dying of cancer, young people, and they really don't understand [EH decision maker 3]

But Indigenous knowledge holders describe important downsides to the health care system identifying and categorizing Indigenous patients.

For the Aboriginal there is no benefit [to labelling medical card with Indigenous identifier], none whatsoever and that's bluntly putting it. Because we're Aboriginal. We're just numbers to them. They [health care decision makers] don't care. We're not a person that we're considered to sit up and talk to ... When you're put down and being picked on or categorized they [Indigenous patients] don't want to do it [engage in the health care system] – they'd sooner die. They'd sooner let their self go, because, and I see it every day, every day they're categorized and they don't want it. [Indigenous patient 3: Inuit woman – patient and patient supporter]

Primarily, the practice has the feel of perpetuating colonialist methods of surveillance, and there are nuances to this sentiment that are important to learn about in further discussions with Inuit, Southern Inuit, Innu, and Mi'kmaq leaders, elders, and community members. It was clear from the interviews with Inuit, Southern Inuit, and First Nations patients and supporters that the politics of how various Indigenous groups are able to obtain land claims agreements, and the way the funding from the federal and provincial governments gets channeled, have created inequities – whether these are real or perceived was beyond the scope of our inquiry.

The northern Inuit are self-governing; costs and permissions related to patient and escort transport and support while in St. John's are the responsibility of Nunatsiavut. For the First Nations communities, it is the federal government that pays for costs related to care, with local Indigenous political organizations having their own discretion about whether to provide additional funding for, for example, additional family members to accompany the patient and escort.

The history of differential colonial interference with the various Indigenous populations of the province is complex and continues to shape perceptions of differential relationships between federal/provincial governments and community leaders in terms of Indigenous rights to land, amongst other rights. The politics of recognition in terms of Indigenous group identity get played out in patients' perceptions of injustice with respect to who gets access to what through the APNs. At the time the research was conducted, the two APNs were both Inuit, something that was apparent to the APNs and to EH decision makers as occasionally problematic in terms of the perception of injustice. (And in fact, plans to hire an Innu APN were in progress at the time of data collection).

They [the APNs] are Inuit, both of them are Inuit, right, they're not Innu so we don't have [a navigator] ... We don't have somebody. Sometimes there's a language barrier. [Some] people don't speak English at all, so there's a problem that exists ... There's no Innu there [in the APN office] and it's all an excuse for saying – it's all Inuit, you know what I mean, because usually because if you have a problem at midnight here in the hospital, we want to call right, but nobody speaks Innu, here it's only Inuit. So there's all kinds of problems you know ... I got nothing against [the APNs] [they're] doing a good job I don't want to be racist or anything like that but whoever is running the Friendship Centre [First Light], they're all white and Inuit. So who's me, you know what I mean? I'm an Innu person and I want to be treated exactly the same But I mean you got to be treated equally. [Indigenous patient 1: Innu man – patient, patient supporter, and interpreter]

According to one of the EH Decision makers, there was, in the early years, a misunderstanding on the part of both patients and providers in acute care that because the APNs were northern Inuit that only that population was being served.

We heard when we went there, *"Oh, there's no one for us people on the south coast"* – What do you mean? Katie and Sol are! But they may assume because they were [northern Inuit] that they would only be serving that population. So we've really improved access to that service. [EH decision maker 3]

The perception of unequal access to service was widespread amongst patients we interviewed, across all groups. Some Innu patients expressed a feeling of disadvantage of being denied transportation while Inuit patients were not – but according to the APNs, these would be cases where authorization for transportation for extended family members hadn't been arranged in advance, or where patients had priority over extended family members. By contrast, some Inuit patients expressed dissatisfaction that Innu patients were allowed multiple escorts, approved by their band council, whereas they were limited to one escort²³; and this dissatisfaction was occasionally attributed to the APN system (for example, in terms of access to transportation), when in fact it was not an APN cause.

5.5.2 Second escort support perceived as example of settler stratification of Indigeneity

Typically, only one patient escort is paid for by Nunatsiavut Government or Health Canada via the Band Council. However, at the discretion of the decision maker (that is, Nunatsiavut Government or the Band Council), a second patient escort could be approved. For example, if a patient is on life support, typically a second escort would be approved by Nunatsiavut and Health Canada for support to the substitute decision maker. An Inuit patient supporter explains why it is so important to have a second escort in some cases:

You know, like if you're out there for a long time it's gets really tiring ... Being in the hospital going back and forth to where you're staying, going back to the hospital, and it really gets tiring and really drains you out as the escort. Then sometimes this escort needs some help, you know, like needs some support, maybe taking turns being with the person who is in the hospital who

²³With Nunatsiavut Government, if a patient is having surgery or some other procedure that requires support then they would be allowed to have an escort with them. With Health Canada the same rule applies; however, First Nations band leaders are sometimes very supportive in paying for additional family members to accompany the patient (for example, in the case of a dying patient), leading to the perception of unfairness.

may be in critical condition or whatever ... I was spending a lot of time at the hospital and by the time I would get home, like late in the night, I would be drained, exhausted and then the next thing I would get up early in the morning and go back up there again; like it's almost like you need two people you know especially if there's critical conditions. [Indigenous patient 6: Inuit woman – patient, patient supporter, and interpreter]

Advance Education and Skills [AES] (“income support”) clients are not given a choice of accommodations, but rather are booked into one of the other cheaper hostels or motels. If the patient happens to also be a beneficiary of Nunatsiavut, then their expenses are first paid by AES, and only afterward does Nunatsiavut Government support begin. Patients in this category have difficulty understanding the unfairness of them staying in cheaper accommodations with no choice, whereas as a patient under Nunatsiavut Government they would have had a choice of a variety of accommodations.

Finally, no matter what type of payment was being provided for patients relocating to St. John's for medical care, the APNs also had to maintain a triage approach to providing support, which causes additional confusion for patients.

So every patient is different, so it depends on what they need ... Some really need a lot of TLC, like they actually need you to go with them to the appointment, to be there to listen to the doctor, to be there for the preparation for their surgery, to take them to the EKG, to take them for blood work, to take them to X-Ray or whatever it may be, so you could be with them all day. ... Or some will just say “*Okay, I don't know where to go for my appointment, can you take me there?*”, and then they'll say “*Okay, I'm fine I'll see you later*”. [APN]

Most often differences in services provided by the APNs are related to how proximate or distant to the St. John's site a patient is in terms of geography, social and cultural context, and English-speaking ability:

Yeah, if it's from the [northeast] coast it's usually ... the whole nine yards. Like we have to meet patients sometimes at the airport, they're often scared ... We can go meet them at the airport. Take them to their accommodations and then discuss meeting with them the next day about their appointments and then we'll just go from there As compared to somebody coming from Stephenville, they're pretty well on their own or just looking for help with paperwork. [APN]

Various factors contribute to perceptions of unfairness between the supports offered to different Indigenous groups. On the other hand, many people experienced the assumption that all Indigenous peoples are the same, with these additional problematic consequences described below.

5.5.3 Assuming all Indigenous patients are the same

Categorizing and labelling on the basis of community identity poses challenges of exacerbating already problematic perceptions of a hierarchy of care. Yet there are equally grave problems with lumping together all communities as if they are one homogeneous group (“Indigenous”) sharing identical values, beliefs and experiences with respect to health and health care.

They think that we're all one people. That we all speak one language ... Like I went to the emergency room yesterday and they said “*Oh, you're the interpreter*”. I said “*No, I'm not an interpreter*”. She said “*Oh, well we're looking for one*”, and I said “*Well, I'm trying to find you an Innu interpreter ... Ours is not available*” and she said “*Oh no, I thought you were the*”

interpreter””. I said “No”. So, she thought I was able to speak a hundred languages because I’m Aboriginal [This came from an assumption of] thinking that we’re one people. [APN]

In summary, while adopting the Indigenous Administrative Data Identifier Standard (2017), introduced earlier in this section has obvious benefits from the perspective of health decision makers and administrators, judging the appropriateness of this system requires further consultation from Indigenous knowledge holders to assess the community implications of using a “blanket” Indigenous identification system.

5.6 CONCLUSION

In this section, we reviewed some of the main challenges facing Indigenous patients, patient supporters, and staff, focusing on: the logistics of travel from Labrador posing undue hardship on patients and their travel escorts; communication barriers posing risks to patients in terms of care as well as informed consent; cultural differences exacerbating the lack of trust by patients in the health care system; racism and marginalization shaping the experience of care; and settler-Indigenous power relations more generally shaping mistrust in the system.

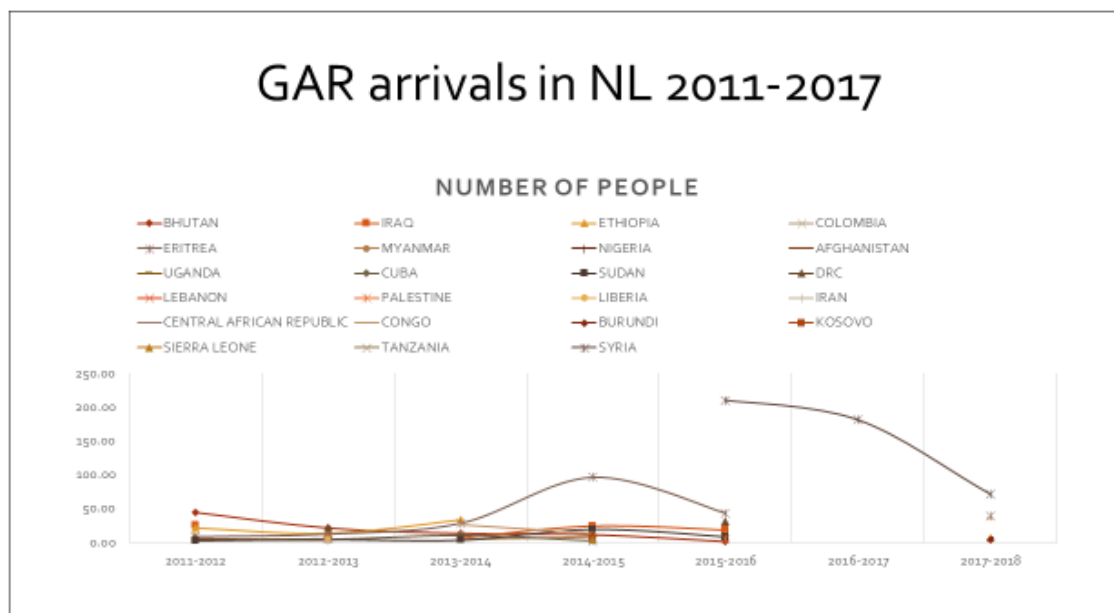
In terms of the logistics of accessing care, the key concerns were related to errors or miscommunication at the Labrador side of things, and continued lack of awareness by EH staff about the realities of travel within and from Labrador. We found overwhelming support and praise for the APN program, which goes a long way to ensuring that patients’ experiences while at Eastern Health are positive. With respect to communication, aside from the very pressing need for Innu interpretation—a situation that is currently placing Innu patients at risk—there is an ongoing role confusion of interpreters, travel escorts, and informal patient supporters. This is leading to challenges with respect to justice in pay for interpreters, and is potentially leading to errors with informed and legal substitute decision making. Cultural differences were somewhat of a concern, with the key challenges being visitor restriction policies and the incorporation of traditional healing practices into health care. In both of these areas, patient perceptions of intolerance on the part of health care providers is exacerbating the lack of trust in the health care system. We heard many stories of racism, marginalization, and discrimination, and we relayed some of the experiences that had been conveyed to us by Indigenous patients. We concluded this section by discussing power relations more generally, focusing on the perception of settler stratification and hierarchizing of Indigenous communities through health care policies and programming, which is experienced as a form of ongoing oppression.

In this section, we report on our findings related to access to care for newly arrived refugees and visible minority patients. We are very grateful to the patients and patient supporters who took the time to discuss their concerns so frankly with us. We begin with a brief overview of the demographics and health status of newcomers to the province. We examine the structure of health care for newly arrived refugees to St. John's and the surrounding area, focusing on the key role of Memorial University's Family Practice Unit and Refugee Health Clinic in providing care to Eastern Health patients. We examine the key logistical barriers to accessing care; language barriers and interpretation challenges; challenges posed by cultural differences; discrimination; and mistrust with care and its associated nonadherence to treatment. This is a lengthy account of the challenges faced, particularly by non-English speaking refugee newcomers to the province. The stories told to us point to the overwhelming desire of health care providers to understand and appropriately respond to the needs of these groups of patients. The stories also strongly convey a message, by both patients and providers, that there is a felt lack of infrastructural support to assist staff who are struggling to do the right thing.

6.1 DEMOGRAPHICS AND HEALTH STATUS OF NEWCOMERS

There has been historically very little immigration to Newfoundland and Labrador. People arriving to Canada to find a better life have tended to settle in cities like Toronto and Vancouver, or Montreal for the French speakers from Haiti and French speaking Africa. In 2018, under 3% of the population of the province were immigrants. In the past decade, with the world's population of refugees rising dramatically and with Canada's commitment under Prime Minister Justin Trudeau, the numbers of refugees arriving to St. John's has escalated dramatically, from being virtually nonexistent, to about 300 arriving each year. In a provincial population of 500,000 people this is significant. The primary countries of origin for this recent wave of arrivals are Syria and Eritrea (which each constitute about a third of the government assisted refugees arriving the NL) followed by Sudan and the Democratic Republic of the Congo. Languages spoken by the newcomers include various Arabic dialects, Tigrinya (spoken by newcomers from Eritrea), and multiple Congolese languages.

Eastern Health is facing new challenges with the provision of care to refugee patients. Linguistic, cultural and religious differences from the province's mainstream population, combined with unique illness experiences and care needs, are creating an urgent need for diversity programming across all program areas.



Health problems that newcomers experience range from war injuries, to undiagnosed chronic medical conditions and lack of preventive health care related to lack of consistent health care, to infectious diseases, all on top of the “normal” health concerns experienced by any Canadian.

A Refugee Health Clinic (RHC) physician described the kinds of problems they were treating.

These are people very vulnerable, many, many health concerns not treated, not identified. I mean you're talking about people with arms and limbs blown off from bombs, lots of people with amputations, bullets in places where there shouldn't be, children with all kinds of congenital issues you know. We found a number of diabetics who didn't know they were diabetics. Women who were pregnant who had no prenatal care. Women who were pregnant that we found were actually diabetic who didn't know they were diabetic and pregnancy, far advanced pregnancy, people with all kinds of medical problems, Hepatitis B, Hepatitis C, other issues many medical problems ... We found lots of people who were had severe vision problems. We had children who we found through screening had congenital deafness. [Physician1].

Concerns for pediatric patients were particularly pronounced.

A lot of growth and developmental ... expressive speech delay ... growth and nutrition is a big concern ... Associated with nutrition is iron deficiency ... kids with hearing problems, kids with neurological diseases, seizures. So they needed to be linked up with supports and care providers here. [Physician 3]

These health conditions are largely associated with nutritional deprivation in children who had been in refugee camps or living in other precarious situations where access to foods was limited. However, one newcomer participant commented that there are ongoing concerns with children's health related to nutrition due to the lack of availability of culturally familiar nutritional foods in NL.

I know something refugees really, really, struggle ... There's not enough offered in terms of ethnic foods, it's very limited and even if it is offered it could be much more expensive. They might not be able to afford it So either they sort of cut down on their nutritional behaviour – so they'll really just stop eating meat which might have been a very essential part of their cuisine – or they just resort to you know junk or in some cases I've noticed no food at all. [Immigrant patient 7: woman, economic immigrant, student].

An important aspect of the health of newcomers is mental health. Care providers made special note of the needs of those who had lived through trauma, in both the adult and pediatric populations. The trauma team in mental health has received specialized training, through a social worker who took it upon himself to receive additional expertise to respond to the gap in knowledge that existed in the province. [Social worker 1]

The unique needs of refugees have prompted the development of several health care units and facilities dedicated to this population. The next section outlines these various projects and programs and how they came to be.

6.2 THE STRUCTURE OF HEALTH CARE FOR NEWLY ARRIVED REFUGEES TO ST. JOHN'S AND AREA

6.2.1 The Key role of the Family Practice Unit and Refugee Health Clinic

The informal collaboration between Memorial University's Family Practice Unit (and its affiliated volunteer group of medical students through the MUN MED Gateway Project), the Public Health Nurse, and the Association for New Canadians (ANC) has been key to ensuring access to health care, in particular for government assisted refugees (GAR). The story of the herculean task that the Family Practice Unit (later, the RHC) and the Public Health Nurse undertook in response to the influx of Syrian refugees between December 2015 and March 2016 is remarkable, and is foundational for the Recommendations arising out of the research to be fully understood.

Prior to 2005, the ANC health resettlement workers were solely responsible for matching newcomers to family physicians, not an easy task in a context of a shortage of family physicians. One family physician associated with the Family Practice Unit of Memorial University, Dr. Pauline Duke, took a particular interest in the plight of the increasing numbers of refugees arriving who were not accessing health care, and began working informally with the ANC settlement workers to ensure that newcomers were receiving care. In collaboration with ANC, the Public Health Nurse, and the MUN Med Gateway Project (see below), Duke along with a small handful of other supportive family physicians with the Family Practice Unit (most notably Drs. Christine Bassler, Francoise Guigné, and Petra Joller), has managed to conduct medical screenings and provide a family physician for virtually every government assisted refugee to enter the province between 2005 to present. By 2015, just in time for influx of nearly 300 additional refugees between December and March of 2015-2016, the ongoing effort to find community physicians willing and able to work with the newcomers had been exhausted, and the small handful of family physicians found themselves taking on the vast majority of the new arrivals.

What was happening is we were just finding it more and more difficult to find family doctors in St. John's for our refugee newcomers and it would be me pleading or [Gateway Coordinator] pleading, [Public Health Nurse] pleading for family doctors and we did have a 100 % match rate but it was getting harder and harder. We also found that some people were getting absolutely wonderful care but a lot of people were getting what I call sickness care which means: come and

see me if you're sick, and very little in the way of preventative health services and screening and so forth. So without any funding or any extra clinical help or clerical help or secretarial help our Family Practice Unit took that on, with no funding from Eastern Health, no additional funding beyond what you know we have for our regular clinical activities at the Family Practice Unit and Torbay Road mall²⁴ Ever since then [September 2015] we've been seeing all of the refugee, government assisted refugees, coming to St. John's. It's about 200 people a year. [Physician 1]

For the family physicians who were working with refugees prior to and immediately following the "Syrian influx" of 2015-2016 (described below), an important part of the story of health care for government refugees up to 2016 was the lack of attention to a crisis in refugee health care on the part of Eastern Health.

We did ask for help from Eastern Health. I wrote the VP of medical services at the time and spoke to him. He realized I guess the need but said there was no funding and nothing they could really do to help us. So in my naivety, our naivety, we just hit the ground running and did it. We didn't wait. We couldn't wait. What initially happened was, as soon as we knew what was happening I wrote a letter to him urgently, the very beginning of January I think, asking for help and met with him. He said there was very little they could do because they had no money to provide any kind of care and he had checked with the Department of Health and said there's no money available and then he said that the best thing he could do was to ask me to present at a meeting at all the vice presidents of Eastern Health who met monthly or something and so that was arranged [for January 2016, but delayed and then held in March 2016].²⁵ I said at that meeting with Eastern Health, *"Look we've dealt with all of these people [Syrian refugees] with these huge numbers of massive problems. Eastern Health has not had to spend one dime or had to make one telephone call because we as a group at family practice took care of this for you and did not give us any help from above."* [Physician 1]

The physicians were well prepared for the meeting, armed with statistics and stories to illustrate the extent of what was essentially a crisis in care provision to refugees, and explaining what exactly their small group of professionals had been doing to respond to the crisis. Eastern Health leadership at the meeting reacted just as the physicians had hoped they would.

²⁴At this point in this history, it is important to note the changes that eventually came about. At the time of these interviews, the Refugee Health Clinic that operated out of Memorial University's Family Medicine Clinic was completely separate from Eastern Health, operating without support or funding from EH. It eventually transitioned to an Eastern Health fully-funded clinic in April 2020, after successful lobbying efforts by this group of family physicians. During the transition to the new clinic, intake of new patients was suspended for the period of April 2019-April 2020, with the new clinic reopening as an EH clinic in April 2020. The new clinic ("The Refugee Health Collaborative") avoids the fee-for-service model and enables salaried physicians to take the time needed to appropriately care for non-English speaking newcomers. The clinic is a transitional one. Once newcomers have effectively resettled they then transition into the mainstream health system, spending no more than two years with the Refugee Health Collaborative.

²⁵The timing is important. It was between December 2015 and March 2016 that the 265 Syrian refugees arrived, all requiring medical attention. The account of the family physician efforts at that time is detailed below.

I think people were aghast at what we had done because they didn't know perhaps, and [CEO of EH] to his credit said *"Tell me what you need"* and I told him we needed more frontline staff. [Physician 1]

Six months later, they received support in the form of a full-time nurse practitioner, which reportedly was a tremendous relief for the physicians and continues to be key to the success of the Refugee Health Clinic.

Around the same time that Dr. Duke came to be involved with championing access to health care for newly arriving refugees, the Public Health Nurse recognized a gap in care with respect to vaccinations and other public health needs for newcomers. At the beginning of her engagement with the ANC, this Public Health Nurse would visit the ANC two hours a week. However, it was clear that newcomers were not accessing the public health programs; children were not being vaccinated, and pregnant women were not receiving prenatal support. Resources were sought, under the Public Health Nurse's leadership, to expand her presence at the ANC's English language school. She started coming to the ANC language school to do vaccinations, "because this is where the parents are".

Whenever I reflect back I think it's remarkable how the Association for New Canadians staff welcomed us. There was never any question that they always wanted public health here from the beginning and they at one point, in order for me to start vaccinating people who were unvaccinated or had things we needed to take care of, they stored all my vaccine in their boardroom office and locked it up for years and we did flu clinics here in their boardroom. We did prenatal classes upstairs. They just made room just a bunch of us the staff at the ANC, my husband we came in and we cleaned it and painted it, Eastern Health put in some shelving, a computer and away we went. [Public health nurse 1]

The program expanded, and by 2018 there were weekly child health clinics; pre-school health checks; school immunization programs; tuberculosis screening; mental health services; parenting programs; and prenatal support and education. During the Syrian arrival (described below) under the leadership of the Public Health Nurse and Duke, there were 15 refugee mass clinics during the flu season. It was a huge project involving about 20 interpreters and many volunteers and all of the Public Health Nurses in the area.

6.2.1.1 The MUN MED Gateway Project.

A major challenge was finding family physicians to take on refugee patients and families. The physicians with the Family Practice Unit had been taking on increasing numbers of refugee patients themselves, unable to find sufficient support from community physicians. The MUN Med Gateway Project, based in the Faculty of Medicine, is a medical student initiative that partners with the ANC to provide health care for new refugees to the province. It is a joint project of the Discipline of Family Medicine and the Division of Community Health and Humanities with logistic and financial support from the Memorial University Faculty of Medicine. The Gateway project adopts the model of student-run clinics, but rather than providing medical care to a disadvantaged population, the goal is to connect refugees with the existing mainstream medical system.

The project was initiated by two medical students in 2005 under the supervision of Drs. Duke and Brunger. For the first several years of its operation, the project paired 1st and 2nd year medical students with newly arrived refugee patients, and worked under the supervision of Dr. Duke to match newcomers

with family physicians in the community. The medical student volunteers, under the supervision of a family doctor and working with an interpreter, would conduct a medical history interview and summarize it into a report which would be sent to the matched community physician. The ANC followed up by booking the first appointment and making any necessary transportation and interpretation arrangements. Screening was introduced in 2010 and included blood pressure, vision and hearing, height and weight, growth charts for children, and dental screening. Tuberculosis skin tests were added in 2012. The Evidence-Based Preventative Care Checklist for New Immigrants and Refugees²⁶ was included in the information provided to the family doctor. Patients were referred directly to dentists, optometrists, ophthalmologists, otolaryngologists, and other health care providers as necessary by the Gateway project.

Other non-clinic initiatives to promote the health of newcomers were introduced over the years. These have included the vitamin D program, whereby community pharmacy donations of vitamin D drops are sought and distributed to families through the ANC's Public Health Nurse; the car seat project, whereby students fundraise to purchase new car seats when are donated to families; health fairs, held at the ANC language school premises; and well-women clinics, among others. The Gateway project has been hugely successful in filling a much-needed gap in care for newcomers.^{27,28}

With the 2015 creation of the Refugee Health Clinic, Gateway's primary role of matching family physicians to newcomers ended, but students continue to take a medical history and conduct the health screening.

6.2.1.2 The "Syrian influx"

St. John's receives over 150 refugees from around the world each year. But during the peak of the Syrian crisis, Canada provided safety to 25,000 Syrians, and that meant that in December 2015 to January 2016, the number of government assisted refugees increased to 265 with very little notice.

A family physician with the RHC describes the workload associated with the "Syrian influx".

We kept our heads above water but then the Syrian influx happened and we had 320 Syrian newcomers come from about December 31st until early mid-March of 2016. And so we had 320 people to see with lots and lots of medical issues. So what we did on our own, we did go to Eastern Health. We wrote letters explaining that this was – we expected that we would get a lot of Syrian people coming, but we didn't know how many ... We did go to the NLMA to ask for help in the sense of asking physicians to help with organizing some kind of clinics to be able to do all of the medical care and screening for the Syrian refugees and the NLMA were really kind, certainly behind us and they put out information in their communiques to family doctors and others to say we're expecting people and you know would people contact us and we would help

²⁶www.ccirhken.ca/ccirh/checklist_website

²⁷Note that the Gateway program was temporarily suspended under the pandemic restrictions of Memorial University, but continues to engage with the community (and, in particular, the ANC) in terms of patient advocacy and preventative medicine projects, such as smoking cessation.

²⁸F. Brunger, P. Duke, R. Kenny, (2014). "Matching physicians to newly arrived refugees in a context of physician shortage: innovation through advocacy". *International Journal of Migration, Health and Social Care*, 10(1), 36-51; F. Brunger, P. Duke, (2015) "The MUN Med Gateway Project: Marrying medical education and social accountability", *Canadian Family Physician*, 61: 81-87.

them from then on. We didn't get much reply. We got about five or six physicians who said they would help. So what actually happened is the Syrians came through the Christmas and New Year period when our clinic is sort of downsized during that period of time ... So what happened then was I did house calls for anybody who was sick and needed immediate care or saw them in clinic at our clinic. And all the children were sick. Most of them had respiratory infections and so I did a lot of house calls at Torbay Road apartments where people were housed until their permanent housing was gotten. Used Google translate, used all kinds of things to try and communicate with people. Saw them in clinic for people who were sick. I saw them at the public health office – all kinds of places. And then we had to design some kind of way to be able to see people, to do all of the health screening that's needed ... Specific guidelines were written in 2011 by Canadian physicians and health care providers specific for Canada, for medical care and screening of refugees and newcomers and so we adapted those to here. We adapted those for the Syrian population who came and we collaborated nationally online through phone calls. It was a lot of work. [Second Family Physician at RHC] and I did it by ourselves. We wrote protocols; we did all this very quickly. We spent most nights working We recruited physicians really from our four clinics, the Discipline of Family Medicine clinics²⁹, so all of them helped and we ran clinics throughout the weeks. I think we saw eventually 32 families, and these are large families, none spoke English well, so we ran all these clinics and all of our other clinics, of course regular family medicine clinics had to happen at the same time. We had one Saturday which was January 26th where we had a full day from 8:00 in the morning to, I think [Public Health Nurse] and I left at 8 in the night, where we had medical students, residents, physicians, the ANC, Public Health Nurses – we did a full day sort of mass intake. We found that that didn't work very well, it worked but it was hard to organize and replicate and we didn't see enough people during that time because it's so comprehensive to be able to get through it effectively because we were doing immunizations, hearing screening, vision screening, then they were coming to us for all of their medical history and physician exams and so it was too much in one day. So then what we did was half day clinics where there were half days throughout the week, every half day of the week where two or three of our physicians would take a whole family and take care of, do all of the intake for that family. So by intake I mean a full history, a full physical you know getting all the lab tests that needed to be done, any x-rays, anything that needed to be done, making a problem list and then getting follow-up arranged through the ANC and so forth. [Physician 1]

The physician went on to emphasise the enormity of what she and her colleagues had taken on.

It was a massive undertaking It was massive and massive and we had to organize a lot of protocols. We had to have lots of meetings with lab and x-ray and people like that to sort of, you know, make it organizationally work because you're dealing with our newcomers who don't speak English, they've just landed, they've come from very bad situations We were working 12 hour days, 14 hour days ... So you know we just we did the best we could and I'm very proud of the work we did. I think people got extremely good care but you know it was at the price we paid was our health and you know it was extremely stressful, extremely stressful. [Physician 1]

²⁹Note that Memorial University's Discipline of Family Medicine clinics are now three clinics. The Torbay Road clinic has amalgamated with the formerly known Family Practice Unit, to form the Family Medicine Clinic.

Everybody was seen and taken very good care of. All medical issues were sorted out. Urgent things, semi-urgent things, future care was sorted out, immunizations were taken care of, all screening was done, any medical issues that were found were dealt with and then we did find physicians in the community who would take in the end took 12 of the 32 families and after we had done all of the medical care. So that could be a month or six weeks out because we followed up on all the blood work, followed up on everything More than urgent, like you know everything that needed to be settled was done; children who were anemic, all that investigation was done. Everything was done until they were ready to be able to be transferred to other doctors in town. So we have five or six doctors in town who wanted to help. So what we actually did was I packaged up, and our secretary packaged up, all of the information for each patient and a family. I wrote a cover letter for every single patient in their family and we sent all that information. We sent all of the explanation and cover sheet for each family so that every doctor would know what the issues were for each person, all their lab work, everything. And we sent it by courier to each family doctor and arranged family doctor appointments for each of them and then the rest of the families – which would have been what 21 families, something like that – remained with us in our four clinics ... That's just the Syrians of course, the other patients kept coming as well, patients from other countries, and we continued to see them. So it was massive. [Physician 1]

The Family Practice Unit and Refugee Health Clinic (now, the Refugee Health Collaborative), spearheaded by several dedicated individuals, plays an important role in NL refugee care today. Other individuals have also worked within EH to address the needs and challenges of refugee care. The work of these “diversity champions” is discussed below.

6.2.2 Individual “diversity champions” within Eastern Health

“I’m trying to make this up – I’m flying the plane as we’re building it” [Nurse 2]

A number of informal initiatives have been adopted throughout Eastern Health, by individuals whom we term diversity “champions” who have creatively found solutions to challenges with the provision of health care to newly arrived refugees. In the absence of clear direction with respect to diversity programming, they have been independently educating themselves on particular topics and providing informal peer training for other staff, in an effort to ensure that refugee patients are being treated in a manner that is culturally competent and culturally safe.

We heard many stories of health care workers going “above and beyond” their normal responsibilities in order to ensure that care was being provided. One of the Public Health Nurses shared with us a story of how a pediatrician, concerned about the health of children who were not being brought to appointments, decided instead to go to where the children were at the ANC language school:

They [children] were losing weight, just not thriving, sick all the time and she’d be trying, she’s a pediatrician up at the Janeway, she’d be trying to get them up there for clinic and they weren’t coming and so we’d be phoning back to each other and I’d be trying to give the appointment and she said, *“You know what – are they there? I’m coming.”* So she came. [Public health nurse 1]

They described the frustration of trying to understand what to do, and how to do it, with respect to care of the newcomers. This nurse manager explains this, using the example of her struggle with trying to access the telephone interpretation service:

It's always a challenge, and the problem with the logistics is the way Eastern Health goes about things: [Staff A] got to go and figure all that out by myself and then [Staff B] got to go figure that out all by herself and then [Staff C] got to go figure it out all by herself. We don't have a coordinated effort to say, *"This is what our translation services are; if you have an issue go to [staff point person], [staff point person] knows all of what we do with translation services and he will get you set up. He will make sure you know what it is. He'll make sure you have the right equipment. The equipment you need might be different than the equipment someone else needs and we will have everything all set up for you, he knows"*. I'm a manager. I'm trying to do staffing, I'm trying to get patient flow going, I'm trying to deal with – do I have to know what kind of phones Bell Aliant has? – yes, apparently I do. It's my job to know how many phones Bell Aliant has and what I need. That's not an appropriate way to do it because I might be foolish enough to keep at it for two days ... So if we want to be able to provide a good service for translation we need to have it centralized, to know what is that is available, who is my go-to person that knows all this information. I'll buy it, I'll organize it, I'll get it done but don't make me figure out what phone I got to buy and what pod I got to buy and what number I got to call and who the person's name is, because sixty managers in Eastern Health have to do that! It doesn't make sense. We need a central point for that. [Nurse 2]

They describe the practical ways in which increased staffing or material supports could assist them in their daily work.

I have lots of people from Eastern Health that phone me to tell me to remind people in this school of their appointments More clerical support is needed to help with that communication piece. Like if I had a clerical person they could be phoning everybody and reminding everybody of my appointments; like I get people missing my appointments. I don't even really give out appointments anymore, I just go grab people, just find them. If I do have to phone someone at home that's a challenge getting them in Resources, I think is a big piece we could build on at Eastern Health for our newcomers ... We've all kind of built our own, I have things that I built myself just in my spare time, information that I can give out – but I need a lot more ... I don't mind doing it but I could use the help. I could use someone working beside me. [Public health nurse 1]

It's hard to execute on everything that you need to do for the patients because they do require a lot of follow-up and consultation – so it's the paperwork piece that gets challenging after you've seen them. So seeing them is the easy part and that's the fun, but then it's the paperwork piece that you know I don't think I have a solution for that If I had dictation access that might streamline my workflow a little bit right. [Physician 3]

Another physician described needing help to provide care to newcomers at the height of the influx of Syrian refugees. When no volunteers were forthcoming from Eastern Health's pool of volunteers, she recruited her own family members to come in to assist with the care.

We've tried to get volunteer help through Eastern Health. It hasn't worked out that well, so what we did is actually found our own volunteers ... [They] went through the volunteer policy you know, the screening and everything, and [they] worked at our latent TB clinic every Wednesday morning for two semesters. You know, so we've sought out things like that ourselves. [Physician 1]

Several individuals pointed out the importance of the informal "refugee health interest group"

In 2010 we formed the refugee health interest group ... It's a group of everybody involved trying to work with this population to come together. We come together four times a year with the purpose of building resources, increasing health equity, dealing with discrepancies for our population. So it's physicians, social workers, nursing probably 25 members. [Public health nurse 1]

In some cases, these individuals pointedly critiqued the lack of support by Eastern Health, making it clear that they wanted their words to be heard by leadership. This social worker described the crucial need that existed in the province for specific mental health expertise on trauma for refugee patients. He enrolled in a program at a U.S. medical school in order to ensure the need for effective trauma support was filled in our province, and describes the lack of support for his initiative at that time.

I took two weeks. I had three days education leave; I took two weeks off to do this – time without pay, and Eastern Health didn't pay for this – so this was an initiative that wasn't particularly supported by Eastern Health. It wasn't obstructed, but it wasn't really supported either; you know I don't think refugee mental health was on the radar very much at that point, so that was my take on it, it was interest of mine but there wasn't much discussion like there is now with the new VP. [Social worker 1]

Since receiving his training, he has collaborated with ANC, the SWIS workers (Settlement Workers in Schools), and the school system, with the aim of developing a network of community groups and professionals to respond to the mental health needs of adolescent youth.

These diversity champions had identified specific needs within the refugee patient population, which they had attempted to meet, often successfully. But what was missing, they reported, was accountability and oversight, a structure through which various concerns and challenges and solutions could be brought forward and addressed in a systems-wide approach. The contribution of these diversity champions, and the insights gained by hearing of their individual concerns and strategies for promoting the health of refugees, is key to shaping the Recommendations arising from this research.

Community groups and non-profits have also played an important role in refugee care; the contributions of these groups are outlined in the next section.

6.2.3 Community organization support

Community organizations and groups have been consistently key to any successes noted by Eastern Health. Most visibly, the Association for New Canadians (ANC) and First Light (SJNFC) have been actively engaged in providing advice, support and training. But various other community agencies, including the Refugee and Immigrant Advisory Committee (RIAC), the Multicultural Women's Association, and other

cultural community organizations have been engaged over the past couple of decades with support and advocacy for culturally competent health care³⁰.

The Association of New Canadians. The ANC is a non-profit, community-based organization dedicated to the provision of settlement and integration services for immigrants and refugees in Newfoundland and Labrador. The ANC's Settlement Health Counsellor acts as a link between immigrants and health-related service providers in the province, including the MUN Med Gateway Program and the Refugee Health Intake Clinic, as well as an array of additional health-related supports, including a Healthy Baby Club (delivered in partnership with Daybreak Childcare Centre), Public Health Nurses, Optometrists, Dentists, specialists, and other health professionals. In addition, the Settlement Health Worker provides eligible immigrants with specialized information, orientation, and/or assistance with navigating the Newfoundland and Labrador health care system, finding a family physician, using pharmacies and understanding prescriptions, facilitating medical and dental appointments, and securing interpreters.³¹

Refugee and Immigrant Advisory Committee. At the time of this research, RIAC was an important non-profit community agency serving the needs of the region's immigrants and refugees. It was established in 1983, and was funded primarily through private donations and staffed primarily by volunteers, although provincial funding was also occasionally granted, including salary subsidies for the paid positions. It operated for 36 years until its closure in 2019 due to financial constraints. During its existence, RIAC's mandate was to support refugees, immigrants, and other new Canadians of diverse origins – particularly those who fell outside the mandates of other organizations – in establishing themselves in NL. RIAC was guided by a non-paternalist approach, encouraging independence, autonomy, and choice among members. Their programming included Immigrant Community Clinics, entrepreneurial skill development (sewing and tailoring), and informal conversation classes. They also offered system navigation to connect members with information and services related to family reunification, ESL classes, and other pertinent supports. RIAC had a public education mandate as well, and sought to raise awareness of important refugee and immigrant issues and to encourage greater acceptance and cultural safety among the host population.

Coalition on Richer Diversity. One key grass-roots community-based initiative deserves special mention – the Coalition on Richer Diversity (CORD). Starting in 2007, coinciding with a new provincial immigration policy at that time, a number of people from a wide range of interest groups representing education, health, housing, justice, employment, faith communities, and others formed an umbrella group for information exchange and collaborations to strategize for improvement in the lives of immigrant and refugee newcomers to the province.

The initiative was led by MUN education professor Barbara Burnaby. The Steering Committee for CORD hosted its inaugural meeting on September 29th and 30th 2007 at Memorial University. The focus was on

³⁰Key resources created in NL the early 2000s include: Women's Health Network (2002) Health care and immigrant women in St. John's, Newfoundland: A cross-cultural training and resource manual; St. John's Native Friendship Centre Association [now First Light], Building bridges: Innu and Inuit Experiences of Urban Health Services in Newfoundland and Labrador (2002) A project of the St. John's Native Friendship Centre Association and the Division of Community Health, Faculty of Medicine, Memorial University of Newfoundland; and Seniors Resource Centre of Newfoundland and Labrador, Building Bridges: Health Care for All: Seniors in Multicultural Canada. Final Report; Seniors Bridging Cultures Club, Seniors Resource Centre of Newfoundland and Labrador (2002).

³¹<http://www.ancnl.ca/services/settlement-and-orientation/settlement-services/health-and-wellness/>

strengthening partnerships between immigrants and long-time residents of Newfoundland and Labrador, and between immigrant-serving agencies (ISAs) as well as government agencies and organizations serving the community at large, in order to better identify and address diversity issues present in Newfoundland and Labrador. Over 70 participants from across the province came together to discuss a number of themes. Under the theme of “health”, the discussion concluded that: there is a need for unity of services; language barriers are an issue; certification of foreign trained health professionals needs to be addressed; courses on diversity need to be offered in professional programs; and a team of health care providers needs to be struck to address newcomer needs.³²

CORD was very active in the community for years, and was instrumental in the early years of diversity programming within Eastern Health.

The Red Cross Patient Navigator Pilot Program. A group of concerned activists, including the Public Health Nurse and the Faculty of Medicine’s Global Health Coordinator (in her role as Gateway faculty advisor), along with representatives from a vast array of stakeholders including the English School Board, The Department of Public Health, the ANC, and Gateway were concerned very early on with the need for a navigator to assist with the growing influx of refugees. They applied twice for a Lighthouse Grant to fund a pilot project but were unsuccessful both times. Fortunately, the Red Cross had reached out to the ANC and Gateway to inquire about what they could do to help. Discussion ensued, and a committee was struck to design and implement a one year pilot project. The project was jointly hosted by the Red Cross and the ANC. By all accounts the project was excellent in its intent, but a number of challenges made it difficult for the vision to be effectively operationalized. These challenges are described in more detail in the Recommendations section of this report.

Office of the Child and Youth Advocate. Along with these governmental and community organizations, it is useful to draw attention to recent work by the Office of the Child and Youth Advocate. That Office produced a case-based report demonstrating the necessity for professional cultural competence training. The case in question involved a family that had relocated to NL from another country. The Department of Children, Seniors and Social Development authorized a removal of the children from the home after receiving a report of physical abuse. The removal ended up being traumatic and upsetting, for reasons including the necessity of a forced entry, language barriers that led to confusion over the purpose and authority of the visit, a failure to debrief the children post-removal and failure to ensure they could attend religious and culturally relevant events while away from their parents. The findings of this report stipulate that frontline supports and assistance, as well as formal policy, must incorporate relevant understandings of language, culture and religion. It also recommends concurrent development of policy and protocol for all stakeholders (e.g. RNC, Department of Children, Seniors and Social Development, etc.) to create comprehensive guidelines for any interventions and to also ensure frontline staff are substantially trained in these guidelines.³³

³²Coalition on Richer Diversity (CORD) Diversity Fall Event Summary, [2007] n.d.

³³The Office of the Child and Youth Newfoundland and Labrador. (2020). The Case For Culturally Responsive Services. The Office of the Child and Youth Newfoundland and Labrador. Retrieved from https://cwrp.ca/sites/default/files/publications/nl_culturallyresponsiveservicesreport2017.pdf

In addition to the formal support of community organizations and projects, a wealth of support for refugee care comes from the unpaid and informal advocacy of community support workers, who will be discussed in the next section.

6.2.4 Informal patient supporters

In this report, we use the terms “informal patient supporter” and “community support worker” interchangeably to describe non-professional community-embedded volunteers who assist refugees in resettlement. Sometimes they are independent individuals; sometimes they are affiliated with, or have developed, informal groups with websites or Facebook pages to assist with outreach.

Informal patient supporters work primarily with privately sponsored refugees (PSRs), who they report are often un-supported, as they are assumed to fall outside of the jurisdiction of the ANC³⁴. They report that they help individuals to find a family physician, assist newcomers with navigating the health care system, work with the sponsors of PSRs helping them to learn how to navigate and access health services, assist with making health appointments, and assist with transportation to appointments.

Some informal patient supporters become involved because a friend has sponsored a refugee family and are looking for extra help. For one such community support worker, what started out as offering a woman a ride home from a social gathering snowballed into a full-time volunteer role, with a Facebook group of over one thousand individuals also participating in the work of resettling newcomers, and a second-hand furniture bank that she started in her own home and has since expanded. She describes the role with respect to health care:

If they can't do it themselves because of the language barrier they would ask me to do it. I would call the secretary and then make the appointment and then through the interpreter let them know when the appointment is and that would be medical appointments and dental appointments as well. The other thing that I've done for some families is like transportation to the appointments. So helping them find where they have to go and then sometimes depending on the person they will ask me to go to the appointment with them to just sit there and be there with them. Sometimes there will be an interpreter provided for the appointment but we come into situations sometimes where maybe the interpreter didn't get booked so the interpreter doesn't show up or the interpreter misunderstood the location or whatever, so we're there without an interpreter or they don't qualify for the services of an interpreter through the Association For New Canadians, so then my friend will often do it on speaker phone in the doctor's office. [Informal support worker 1]

We heard stories of informal patient supporters being available 24/7.

³⁴ANC advisors to this project reported that it is not the case that they only serve government-sponsored refugees. However, an individual or group who sponsors a refugee privately is meant to take on the responsibilities associated with resettlement. Therefore, the only time that the ANC would be approached to help with a privately sponsored refugee would be in cases where that private arrangement has not been working as it should. Recently, exceptions to this default assumption that privately sponsored refugees will be resettled by their sponsors who had agreed to do so have been made for “second generation” refugees who are settled and then sponsor others. In those cases, the ANC has seen a need for their assistance and has been providing it.

It's daily. I mean some days maybe it's just 1 hour and then other days it might be 6 or 7 or 8 hours. It could be more ... One of the children was sick they called me, it was very late at night. I stayed all night at the hospital until she was admitted. [Informal support worker 1]

Formal organizations such as the ANC are concerned that such attempts to do good are in fact causing harm to newcomers in the long run, by being inappropriately paternalistic. Informal patient supporters, however, feel that more official groups interfere with the good work that needs to be done for individuals who have no other support, and describe the reaction by formal agencies as a kind of turf war.

They jump up and they say "*We do that and anybody else doing it is duplicating and repeating*" ... They have said that to everybody and they said that to my face. "*You don't deal with my clients. You don't touch my clients.*" [Formal support worker 6]

Another community support worker, commenting on what she described as a tension between informal and formal refugee advocates, had this to say:

I do find that the best organizations are the ones that are open to dialogue and open to critique not necessarily criticism but critique – How can we do things better than we do? So my impression is that their attitude is, you know, "*We do the stuff we do, other people shouldn't be doing it; and don't criticize us for the way that we do things*" I think. [Informal support worker 1]

Patients also described the role of informal patient supporters as necessary:

[Describing the difficulty of finding a family physician] I have one of the most kind friend, actually she's from here, from St. John's, she said "*I will ask my family doctor if she can accept any new patient*" and just happen, you know, she asked [doctor] and she [doctor] said yes okay and I got with her [i.e. became a patient of that doctor] [Refugee patient 5: man, Arabic speaking]

Informal patient supporters feel they are not given the respect, authority or credibility that the formal organizations are given by health care staff.

I end up going to emergency rooms for a variety of things several times a week ... I have to unearth [an interpreter] in the middle of the night ... And I have to go along with them because the interpreter is not acknowledged as an interpreter until somebody with some authority is present ... Often times it happens that the family, knowing that the doctor is going to do the rounds at any moment, they reach to us early in the morning and say if we can have some interpreter you know at the bed so when the doctor comes in then some service is going to be provided. [Formal support worker 6]

This story of a privacy breach due to care being provided informally rather than through the ANC settlement agency illustrates the harms that can result when well-meaning sponsors of refugee families fail to tap into health care resources effectively or correctly. Importantly, in this scenario, it was health care workers themselves, advocating for a patient outside of a clinical context, who led to the breach of privacy.

One reason I'm really, really concerned ... I got an email from – I think I got it from [Colleague 1 at Memorial University/Eastern Health] and it was [Colleague 2 at Memorial University] who had

sent it to [them]. [Colleague 2] had got it from [their partner] who got it from someone in their church community, providing all of these details about this child's health and how, you know, we needed to pray for this child and we needed this and this and this and isn't there something that we can do and you're a doctor and can't you find somebody to help this child ... I was horrified. So [Colleague 2] sent this to [Colleague 1] because I think it was [medical condition] and [Colleague 1] then sent it out to anybody that [they] thought was able [to take on the person as a patient] and so [Colleague 3 at Eastern Health] and [Colleague 4 at Eastern Health] respond and say *"Oh well maybe I could see the patient, I could do this and this and this"* and I wrote back and said *"Can they please respect this family's privacy because I don't think this is-!"* I just couldn't believe it. This is the privately sponsored refugee groups. They need to know that just because someone is a refugee it doesn't mean they don't have privacy rights By the time I responded to it, like when I saw and responded, it had been responded to by at least three doctors. So anyway I talked to [Refugee Health Clinic] about it and [they] knew the family and [took over the care] [Formal support worker 3, affiliated with the Medical School]

The problem with informal patient support groups liaising with the health care system is also the inability to navigate privacy concerns to act as effective advocates for patients they are supporting. It is important to note that there are no privacy concerns related to the ANC, as the government resettlement agency, acting on behalf of patients.

Informal patient supporters sometimes fill the role that is supposed to be assumed by private sponsors. Private sponsors commit to certain tasks when they agree to sponsor a refugee. Some of them rely on informal patient supporters to take on these tasks. This informal patient supporter explains:

The woman [patient] contacted me and I said okay you know get all these things together the MCP cards and so on and we will go there tomorrow. When I went to the house to pick her up the private sponsor was at the house and [the patient] was getting ready to go to the appointment and I was taking her; and she introduced me to the private sponsor and I was saying like, I didn't say anything to her but it's like, *"Why am I doing this?"* ... So it was no understanding on the part of the private sponsor that this perhaps was something that they [sponsor] should have done. [Informal support worker 1]

Informal community support workers play an important but at times controversial role in the refugee healthcare landscape. Another contentious program that was developed to support new Canadians was the Red Cross pilot program, discussed below.

6.2.5 The Red Cross pilot program

A group of concerned activists, including the Public Health Nurse and the Faculty of Medicine's Global Health Coordinator (in her role as Gateway faculty advisor), along with representatives from a vast array of stakeholders including the English School Board, The Department of Public Health, the ANC, and Gateway were concerned very early on with the need for a navigator to assist with the growing influx of refugees. They applied twice for a Lighthouse Grant to fund a pilot project but were unsuccessful both times. Fortunately, the Red Cross had reached out to the ANC and Gateway to inquire about what they could do to help. Discussion ensued, and a committee was struck to design and implement a one year pilot project. The project was jointly hosted by the Red Cross and the ANC.

By all accounts the project was excellent in its intent, but a number of challenges made it difficult for the vision to be effectively operationalized. The vision that the Red Cross and the ANC had for a long-term and sustainable navigator program did not map neatly onto what clinicians needed, which was more urgent and crisis driven.

I think they [Red Cross and ANC] understood that the navigator would be about building capacity, volunteer capacity, and we were trying to provide some and also working within the system to try to find some efficiencies within a system that would enable refugees to get access faster and better. But I think the clinic people had a very different perspective. They really wanted the navigator to be somebody who could be instantly responsive to the needs that emerged from the clinic. [Formal support worker 3, affiliated with the Medical School]

The navigator in fact ended up attempting to respond to both visions – to build capacity in a sustainable way, while servicing the urgent and immediate clinical needs, primarily patient transportation to appointments and translation.

I think the navigator was trying to get volunteers who spoke the same language as the patients and that's very difficult to find because you're talking about students and people who have jobs and other things, and it just didn't work out I think. You know I think if you're going to look at a volunteer system it has to be people who have time on their hands, like retired people, and not rely on them to be the interpreters as well. I think it was done from a bit of an angle that didn't work out. [Physician 1]

The intent of the navigator from the perspective of the Red Cross and ANC had not been to hire an individual to be “the” navigator, but rather for a system of patient navigation to be developed, based on a network of volunteers. But when it quickly became apparent that this task was very difficult – particularly given the drive to find volunteers who could be matched in language to patients – the individual hired to create the system found herself drawn into the role of navigator herself – a position that was unsustainable for a single individual.

They hired one person and her job was not supposed to be the navigator herself but she was supposed to create a pool of navigators. So she was supposed to create a team of volunteers ... And she went out and met people in the community you know the different health groups and community groups had a fair, you know, did presentations, had a fair number of people interested but she said that after people would do it once or maybe twice they didn't want to keep doing it and I think the impression was that it was maybe more intense than what people were expecting or they found it harder than what they were expecting ... So in the end I think the last few months she was basically doing the navigating herself. She was picking people up and driving them, which is obviously not sustainable for one person to try to do that. [Physician 2]

Listening to the stories of this program, it appears that two factors dove-tailed to make the program unsustainable. First, the lack of availability of volunteers who could be matched to patient languages meant that very often there was no one available when the need for assistance arose. Second, the particular individual hired was by all accounts an extremely caring and giving individual who was highly committed and motivated to ensuring that patients received help. She was also highly skilled, was adept

at navigating, and spoke multiple languages. So, in an effort to respond to urgent clinical needs, she took on the task of sole navigator, an unsustainable role.

The Red Cross Patient Navigator Pilot program served to highlight competing models of what a patient navigator program could look like. For some, the vision of the pilot project for refugee patient navigation was to build an infrastructure that would support the goal of having patients learn to navigate the system themselves. For others, by contrast, the vision was to have a navigator available for patients when there was an urgent clinical need, whereby patient navigators would assist patients to do what they need to do in relation to health care – for example, driving them to appointments and providing interpretation.

What I would love is somebody who would be able to take people to booked appointments, not just to meet them there but to meet them at their house. To be able not to just accompany them to the appointment, but to help them at the 11th hour if they need to cancel or to make a phone call to delay. So to be able to contact the office if they need to and then to physically go with them up to the actual appointment. [Physician 2]

That model of having navigators on call to assist individual patients is the one employed by both the APN program and the Cancer Care patient navigation program. In both of those cases, support workers (paid, in the case of the APN program; volunteers in the case of the Cancer Care system) accompany individual patients when required, assisting them individually and personally with attending an appointment and providing or arranging for interpretation when required. That model works for those two programs because in both programs, the assistance is of limited term duration for a specific health crisis.

The “support to learn the system” model, by contrast, establishes a framework whereby patients are supported to navigate the system as any other member of the public would. That support model focuses on two aspects: first, helping patients with learning to navigate the system, rather than navigating patients directly; and secondly, creating changes in the Eastern Health system in order to make health care more accessible to a diverse patient population.

It was about navigating the *system* ... Going to the blood collection and finding out, *“Is there something we can do to make this a little simpler for people who don’t speak the language?”* ... Maybe doing a little bit of education with people about, you know, here’s the needs of a newcomer ... It was much more about getting the system prepared, helping the system become navigable. [Formal support worker 3]

There are, then, competing visions for how to proceed. One model (which we refer to as the “support to learn the system” model) emphasises independence. This model advocates teaching patients how to become fully functioning members of society, by training patients how to navigate the system themselves. The competing model (which we refer to as the “navigate individual patients” model) emphasises full patient support with navigation and interpretation. A third model is to have on-site navigators for assistance with finding appointments for all patients, regardless of whether they are non-English speaking or newcomers to the province. We return to the question of whether and how to initiate a patient navigator program for refugees in the Recommendations section of this report.

Now that we have laid out the various players in refugee health care in NL – how they came to be and the challenges they face – the next section delves into the barriers that refugee patients experience when trying to access care in this system.

6.3 LOGISTICAL BARRIERS TO ACCESSING CARE

We heard numerous stories of the difficulties faced by newly arrived patients physically accessing their medical appointment. This included navigating complex public transit to access a family physician far from home. This challenge, related to the lack of access of family physicians, is important to appreciate when considering the reasons why patients are late for appointments. This patient's story captures the difficulty:

The time we spent with Dr. [X], it was horrible actually because he is a family doctor and walk-in clinic at the same time, so you can take an appointment or you just go there; and we didn't have a car at that time, so always we had to take three buses if I want to go, and wait for two hours at least to see him, and you know with five children ... It's not easy to travel with [2 babies] with a stroller and you know three buses to go to the doctor. [Refugee patient 6: woman, Arabic speaking]

The St. John's public transit system has been identified as a major challenge for patients, as busses do not necessarily arrive or depart at the scheduled time. For patients from countries with sophisticated transit systems and where there are no wait times for physician appointments, it can be very frustrating to miss an appointment and then have to wait weeks or even months for another appointment, and possibly also pay a fee (which we were told may be as high as \$50 for a missed visit – onerous for newcomers with limited resources).

A greater challenge reported by patients was locating particular clinics and navigating through complex systems of registration once on site. Below, we hear from two health care providers who described their experience of the challenges faced by newcomer patients.

So people have to get to appointments by using buses or taxis often with small children in tow, through bad weather which they may be terrified of, never seen before or having to walk down slushy, sprayed on streets to get somewhere. Then they get to the Health Sciences Centre and how do they find where they're supposed go? They can't read the signs, there's nobody to help them. So that breaks my heart ... I mean, to see a specialist say, *"At St. Clare's you don't just go to the office, you have to check in somewhere"* where it's really not clear; you have to take a number but it doesn't tell you [where]. To see a specialist there's actually four or five steps before you actually get to see that person, and it doesn't actually tell you anywhere of where step number one, number two, number three, or number four is. So I can imagine if somebody were to show up to see a booked specialist appointment for 2:00, and they show up at 10 to 2:00, how it will be very difficult quite possibly to see that person actually at 2:00 because of all the pre-check-ins and the number taking ... And there's no help desk, there's nothing, right. [Physician 2]

To register at Eastern Health, right?! ... Even me, like it took me a while to learn that I could use that machine. You know, you can register yourself now But that's impossible, that system, unless you have someone with you. I always say take somebody. Who have you got to go with

you? If you got a volunteer from the church, if you got a friend, you know take somebody with you when you go ... I've seen things, like as an example, I was [at the Health Sciences Centre] for a meeting ... So I'm walking in, out of the corner of my eye I see the van from the ANC drop off a family who I know were supposed to go see Dr. [X] in MUN Family Medicine. Guess where they went? – because I followed them, I just had this feeling Well there they are all sitting in Emerg you know, right inside Emerg they sat down ... I think stuff like that probably happens all the time. [Public health nurse 1]

The implementation by physicians at the Refugee Health Clinic of the “yellow card system” has been a successful innovation in enabling patients to find their way to an appointment once within a site.

Now the ANC [it was in fact the RHC] did implement something that I thought was brilliant. They implemented a system with a yellow card where somebody, if a newcomer was coming to the hospital and ... this yellow card would just say very basically what department they needed to find. So if they got lost in the hospital they could hand that yellow card to somebody and it would just say “*I need to find this place*” and someone could direct them. It didn't have any information about why they needed that place, it was nothing breaching any confidentiality. It was just this yellow card that was a signal that they needed some direction and anybody who worked in the institution could then direct them³⁵. [Formal support worker 3, affiliated with the Medical School]

The logistical problems of accessing appointments is a key consideration for patients as well as providers, as it is directly related to what some providers see as a chronic problem of missed appointments within the refugee patient population. We turn to the issue of missed appointments next.

6.3.1 Missed appointments

This health care provider explains the implications of missed appointments for patients:

Plenty of [patients/families] are telling me about missed appointments, or getting a letter saying you know, you could never see this doctor again because you missed two appointments Oh yeah, if you miss two appointments at Eastern Health, you're done ... You have to go back to the family doctor, yup. You miss your specialist's appointment, you're done. [Public health nurse 1]

Missed appointments are a major problem for health care providers. In 2018, the Refugee Health Clinic's nurse practitioner was reportedly having a no-show rate of over 75%. At that time, one of the physicians with the RHC estimated her own patient no-show rate to be 50%. In this section, we share what patients told us about their experience with missing appointments. Common reasons for missed appointments included: administrative error, and letters being sent to the home of non-English speakers.

³⁵The yellow card system was since replaced by a new system. Now, reminders are placed on the patient's electronic medical record, asking for patient appointment information to be sent directly to the Refugee Health Collaborative or to the Family Medicine Clinic (for former refugee patients still facing language barriers years later). Family physicians who regularly work with refugee patients have a practice of ensuring that their patients are also given a paper copy of their appointment information, for use in hospital when seeking assistance. The patient's copy of the appointment reminder thus serves the same purpose as the “yellow card” had.

6.3.1.1 Administrative error

Administrative errors occasionally happen for all patients. But for a patient whose command of the English language is limited and who has therefore not been completely informed about the nature or location of a specialist appointment, an administrative error may not be noticed until the time of the appointment. We heard a few stories of patients whose letter gave incorrect details or incomplete details, so that the patient went to the wrong site and therefore was late to get to the correct appointment site.

[Patient participant is asked whether he had ever missed a clinic appointment; translator paraphrases the response]: Once it happened, but it was an accident. He received a letter that his appointment is at the Health Sciences [Centre]. When he showed up here they figured out that it's at St. Clare's Hospital, so he had to go there. So the receptionist over there told him that *"You're late now, I can't do anything"* but then he said *"It's your mistake, it's not mine because I have been in the Health Sciences [Centre]"*. So she called them and they figured out that this is the problem so they let him enter. [Refugee patient 1: man, Arabic speaking]

Names that are unfamiliar to administrators but common within a community can lead to administrative errors, with implications for privacy breaches. In the case described below, two women with the same first and last names had also been assigned the same MCP card; to complicate matters, both women required the same procedure in roughly the same period of time, leading to mass confusion.

We had an incident a few days ago, it was two clients both of them are newcomers, both of them with the same first and last name, and I'm not sure about the middle name but the same first and last name. There was a referral for one of them to do [names procedure] or something and the other one I think she also had [the same procedure] ... So apparently what has happened, it was switched, the appointment ... The notification of the appointment went to the wrong patient, and the other patient received the other thing. So I think she attended that appointment and in the middle of the appointment ... they found out it's not her. [Formal support worker 2, Interpreter, refugee patient]

Part of the difficulty, as the next section shows, is that information about specialist appointments is sent by mail, in English-language letters.

6.3.1.2 Receiving a letter at home, in English, and unable to read it

When patients with limited English receive information from a health care provider about the need for a specialist appointment, the fact that the appointment will be set by Eastern Health and mailed to the individual's home is sometimes poorly communicated. Numerous anecdotes were told about patients receiving a specialist appointment letter at the home, being unable to read it, and sometimes not even realizing that it was an Eastern Health letter of some urgency. This informal patient supporter explains:

Families will go to the mailbox and take out the mail and open it up and they have no idea what it is, and so then when I happen to go to their house they will come with a shopping bag of mail and say *"What is that?"* And this will be a mixture of the kids' school work, notes from the school, appointments for a specialist or a CT scan or whatever ... So that can be a real challenge for them. Sometimes they miss appointments, right I mean solutions can be difficult. I mean to say that if it were written in their own language this would help, but I mean, I don't know how

realistic that is when you're dealing with potentially hundreds of languages³⁶. I'm not sure how it could be addressed, but I do know that people have missed some pretty important appointments simply because they didn't know that piece of paper is any different from the note about the school lunch program. [Informal support worker 1]

For patients, not having full information about where to go for an appointment can result in emotional distress as well as all of the ripple effects and challenges of a missed appointment. An interpreter and a patient explain this.

Sometimes the patient will not even know where they are, where he or she is going. Like, I will ask, *"So why do you have to see Dr. [X]?"* and she's, like, *"I don't know, I don't know who is this person and I don't – I just received this by mail and I don't know"*. So it's really, like, you know when you're just coming to see a doctor that you're not sure – and it's also embarrassing for me as an interpreter ... The doctor will ask the first question, like, *"Okay why did you come to see me?"* and I'm like, *"I'm sorry but she's not sure who you are"* and [the doctor] will say *"Okay I'm the doctor who's, like, I'm a urologist"* ... So the patient will say, *"Oh yes I have this problem and I spoke about it at the Gateway or at the family clinic and maybe my family physician referred me to you"*. So, I feel like it's kind of a misunderstanding between the family physician [and the patient] [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

I think that's where a lot of this falls down, is people get into the system and they just don't know where to go and people will show up sometimes ... *"I know I have an appointment somewhere today, sometime, but I don't know where and I don't know with who"*. And they remember they were referred from the refugee health clinic to some specialist ... So then the refugee health clinic is trying to figure out, well, *"Who did we refer them to and, you know, where do they need to be?"*, and it would be some Major's Path or somewhere else that they needed to be and the appointment would be past. [Refugee patient 2: woman, Arabic speaking]

For this nurse, the solution is not that difficult: simply don't send letters to the home.

You know what's a real big barrier is those letters from Eastern Health you have an appointment on it – they can't read them. If you miss them, you're toast ... I think [the solution] has to go back to the referring office, like you can't just send a letter, please let the person know; or maybe contact the ANC directly would be the best ... They should communicate it to the ANC because they have a health settlement team and they would make sure that that person knew about the appointment. [Public health nurse 1]

This issue was raised at a research team meeting, with vehement agreement that the process is faulty, as this conversation involving a clinician, a settlement worker, and a community support worker indicates:

Community support worker: And you go and there's a Dominion bag full of papers, mixed papers, what's that; oh my god, like –

³⁶To clarify, there are unlikely "hundreds" of languages. Tigrinya and Arabic are the main ones; and many of the Africans arriving also have French as a language.

ANC settlement worker: And a lot of our clients will they come into our office with a bag or an envelope and they leave it, and they just leave it.

Physician: They don't know what's important.

ANC settlement worker: And they walk away and we open it up and our settlement people go through it and they call them back and let them know what it is.

Community support worker: Sometimes it's the last tenant's cable bill. [Research Team Analysis Meeting]

ANC's specific recommendation was to have all such letters also linked to the ANC.

The RHC, when making a referral to a specialist, will indicate on the letter to the specialist's office to contact the RHC with the appointment date and time once known, and the RHC will then notify the ANC to contact the patient.

We actually have a stamp or we handwrite at the top of the letter, *"Please contact our office with appointment date and time and we will notify the patient as the patient does not speak English"*. Otherwise, Eastern Health central bookings from x-ray or specialists' offices or central bookings for specialists' offices will send a piece of paper in English to the patient for an appointment that is meaningless. So the patients don't know what it is. So we put this on everybody's. Sometimes it's done; like we've worked hard at that and so it's getting better. So the secretary will contact our secretary at the office, our secretary will contact the health worker at the ANC verbally and send the confirmation of the appointment with the date and time and organize an interpreter. [Physician 1]

Accessing specialist services has its challenges for newly arrived patients. The lack of access to family physicians, however, has been a serious impediment to newcomers receiving basic health care, particularly prior to the establishment of the Refugee Health Collaborative. The following section explores this issue.

6.3.2 Access to family physicians

The shortage of family physicians means that finding physicians to take on newly arrived patients and families has been one of the main challenges. The MUN MED Gateway program was originally established as a way of dealing with that challenge, by matching patients to physicians recruited via Gateway to take on new patients. When finding sufficient numbers of physicians became impossible for Gateway, that system was eventually replaced by the new RHC. Recognizing that there simply was never going to be a sufficient number of physicians in community, the RHC was designed to ease the burden of the shortage of physicians by focusing on refugee care in one location, under the direction of a small number of Family Medicine specialists from the Family Practice Unit, working with medical residents.

One reason given for why family physicians are unwilling to take on newcomers is their lack of familiarity with working across languages and cultures. A goal of the faculty working with the RHC and Gateway is to train a new generation of physicians who are comfortable doing this³⁷. A second reason that family physicians are unwilling to take newcomers, we were told, is the lack of familiarity with and expertise in

³⁷Research to establish whether Gateway alumni go on to work in cross-cultural settings or to routinely accept patients from other language groups is in planning.

some of the diseases that are being seen, including particular parasites, infectious diseases, and other medical conditions that a family doctor in Canada rarely encounters. As one physician put it, “Family doctors are scared. They don’t know what’s going to walk in the door – I mean, I see all kinds of diseases that I hadn’t heard of in the past 20 years since medical school”. [Physician 2]

Another key reason that family physicians do not accept newcomer patients is the fee-for-service payment system. Even if physicians are comfortable with and willing to take on patients who require interpretation, the strong sentiment amongst physicians is that by doing, so they are losing money. We describe these sentiments in the next section.

6.3.3 How fee-for-service leads to barriers to accessing care

One of the most obvious and most discussed challenges with working across languages and cultures is the enormous amount of time it takes to be effective in a clinical setting.

Fern: If you could have a wish list of extra skills or extra support, what would that wish list include, where you could feel that you are better serving families?

Participant: Time. There’s not enough hours in the day. [Physician 3]

Community advocates expressed frustration with how the structure of family physician visits meant burdening newcomer patients with multiple clinic visits and wait times. This informal patient supporter recounts the story of her frustration in one case, when a prescription renewal meant a separate doctor’s visit for a patient – an unfamiliar process, when in much of the world pharmacists can renew prescriptions and no doctor’s visit is necessary.

So, like, [mimics doctor speaking] *“I can’t see three of them together”* [that is, each family member required a distinct appointment]. So I was like, *“Okay, I know that you can’t see them together when there’s something that really, let’s say, urgent or something ... [But to renew a prescription], you know it’s nothing – you’re not going to examine the patient!”* [And the doctor said] *“She needs to book another appointment”*, and then so I was like *“You know what, you can help her; it’s not going to– it’s nothing! you know.”* [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

This informal patient supporter said that in her experience, specialists *do* take an adequate amount of time with patients.

With family physicians usually, maybe because they want to see more patients you know they just want to end, but the specialist will have his time or her time and they [patients] can speak, you know ... When they have an appointment with a patient I feel like they put all their efforts to just, you know, give the patient his time or her time and speak with the patient. They let the patient feel that yes, they are with them, or even in a way, like sometimes they sit beside the patients, some of them. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

The fee-for-service system means that interpretation is tricky, in a context where medical appointments are simply not long enough. This community support worker explains this, and recommends finding some way to create a system where longer appointments can be made for non-English speaking patients.

So what can happen is that an appointment that they schedule for 15 minutes they may actually need 30 minutes ... So allowing time for the interpretation and, you know, requiring them to do it in increments that the interpreters can handle would be very, very helpful ... I really think attention needs to be drawn to that issue. [Informal support worker 1]

Physicians expressed frustration at not being adequately reimbursed, under the fee-for-service system, for patients for whom language differences and multiple health concerns mean extremely long visit times for refugee patients.

It is fee-for-service, you know, it probably costs [the doctor] to see these patients because it takes a huge, you know, it takes an hour for each patient. I mean it doesn't pay at all if you're a fee-for-service physician. So [names physician working with refugee patients] did this really out of the goodness of her heart and so did the others, [other doctors] who were fee-for-service – because they felt it was the right thing to do, but they certainly didn't get paid for it. [Physician 1]

When this topic was discussed in the context of a research team meeting, this was further explained:

A family doctor makes \$32.00 for an appointment whether it takes 10 minutes or an hour, okay ... If it takes an hour you can't pay your secretary, you can't pay your overhead in \$32.00 – it's ridiculous, right. [Research Team Analysis Meeting]

One physician and an advocate for refugee health care has lobbied for changes to the system:

I'm actually working on a proposal to Eastern Health and to the Newfoundland Medical Association to try to change billing codes to have sessional rates for certain refugee related care, and have an add-on billing code for community physicians. [Physician 2]

She went on to explain that if this proposal to the Newfoundland Medical (NLMA) is successful, then that would increase the likelihood that family physicians would take on refugee patients³⁸.

Some feel that support in accessing family physicians can differ depending on whether newcomers are privately sponsored or government assisted. Perceptions of such disparity are discussed below.

6.3.4 Perceived inequities: Support for PSRs compared to GARs

Private sponsors are supposed to provide health care resettlement by finding family physicians for those they sponsor as well as navigating them to health care more generally. The bulk of ANC clients are GARs, but the ANC will also assist some PSRs when the need arises and resources permit. Gateway was originally designed in collaboration with ANC and accepted GARs only, but at the time of the interviews had just begun accepting those refugee patients who are themselves sponsored by former Gateway refugee patients.

Some health care providers, patients, and patient supporters that we interviewed were unaware of this complexity, and believe that PSRs and other types of newcomers are not receiving the level of support that GARs do and that they are relatively disadvantaged. To compound this confusion, some are unaware that the mandate of the ANC is to empower newcomers to be independent with navigating the system, including encouraging them to not depend on resettlement services once they have obtained

³⁸ This effort remains underway today.

language and other resettlement skills. Inevitably some individuals will be “resettled” quicker than others, depending on the quickness of their acquisition of skills, which could give to outsiders the impression that there is differential access to resettlement support.

Sometimes there’s a difference in the services that are offered to privately sponsored and government sponsored in my experience I’m not sure why there is a gap. I mean the way that they do things, it seems to me to vary from time to time ... I don’t know if it’s as the ANC becomes overwhelmed or they change their policy or whatever and then they will tell the people “*After one year you don’t qualify for this service, that service*”, and so on. [Informal support worker 1]

One health care provider stated unequivocally that ANC “is not funded by Citizenship and Immigration Canada to provide any settlement services to privately sponsored refugees” [Physician 1]. A second health care provider explained that ANC has a worker who is responsible for PSRs [Physician 2].

According to ANC staff, they have a mandate to help settle and integrate newcomers to the province no matter what their status.

So in St. John’s that tends to be a lot of the time government assisted refugees, because they tend to have greater need to, say, international students or economic immigrants. But we do provide – our services are available to all newcomers We tend to have the most contact with [GARs] because we’re the agreement holder right. But certainly we touch all kinds of different groups. [Formal support worker 4]

Both the Refugee Health Clinic and Gateway were originally only supporting GARs, but recently changed their policies. We were told that this practice began at a time when there happened to be no GARs arriving and the clinic was slow. The medical students were organized to see refugee patients, but there were none; those who were booked kept cancelling and so a decision was made to see some PSRs just because there was clinic time and students available. That then led to a trial run of seeing PSRs who are sponsored by another refugee family (that is, refugees who are sponsoring their families to come).

I begged [RHC physician] to take some privately sponsored families for me when we had a bit of a lull and then because of that we revisited the notion of seeing privately sponsored at Gateway [Public health nurse 1]

This had led to additional confusion.

So I think there’s some confusion there about how – so there may be privately sponsored refugees coming there now. Anyway, what’s happened is a lot of families who have come here as refugees are now sponsoring family members to come, so there’s privately sponsored refugees who are being sponsored by refugee families. That’s who is being seen by Gateway. [Formal support worker 3, affiliated with the Medical School]

One rationale for supporting this change of policy is that PSRs who are sponsored by former refugee families may not have the resources necessary to flourish; but a second rationale is that PSRs fall outside of the purview of the ANC (which is not actually the case).

Because they have presumably less money, they don’t have a community group of 20 well-connected people to support them right. Arguably maybe the best support because this one

person [sponsor who was also a refugee] knows about all the challenges and knows how to get around things, but I also see them as higher risk because they don't have the ANC supporting them whatsoever right. [Physician 2]

By all accounts, there are some PSRs who do not receive adequate support from their sponsors. There can be enormous variation among private sponsors in their understanding or their willingness to take on responsibilities. Whether GARs or PSRs, and regardless of the available supports, most newcomers experience language barriers when accessing care. The next section explores these issues.

6.4 Language barriers and interpretation

There were about 200 interpreters representing 62 languages on call by ANC at the time of the interviews. For newly arrived GARs, the ANC would arrange an interpreter for the initial clinic visit, which, for GARs, is always in the context of the medical history and screening appointment with Memorial University's Family Practice Unit/Refugee Health Clinic and the MUN MED Gateway project.

When a patient is told, in the context of a medical appointment, that they require a follow up appointment, then the interpreter will generally contact ANC to inform them of the date and time of that upcoming appointment and that an interpreter is required. However, occasionally the interpreter will not do so because they assume the physician or patient will contact ANC. In cases where each of the three parties assume someone else has contacted ANC, a patient will present to a medical appointment with no interpreter having been arranged.

Patients who receive a letter at home indicating the date and time of a follow up appointment will contact ANC themselves to seek help with understanding the contents of the letter and/or to arrange an interpreter for the appointment. For recent arrivals with limited or no English language skills, ANC streamlines that process by having EH send such letters directly to the ANC office, where the health resettlement worker will arrange for an interpreter to notify the patient of their appointment and make arrangements for an interpreter to be present.

Interpretation for privately sponsored refugees or other non-English speakers who are not ANC clients will be arranged by the sponsor or an informal patient supporter. These individuals may contact ANC to receive a list of interpreters. Informally, family members or friends who accompany patients often act as interpreters.³⁹

6.4.1 Telephone interpretation

There is strong support in the literature for the use of telephone interpretation as a way of ensuring professional (trained) interpreters, and avoiding the pitfalls of the loss of confidentiality that comes with community based interpreters, particularly in smaller centres where communities of newcomer

³⁹Interpretation for French language speakers has its own process. French language services have been long available for patients, as part of the responsibility of EH to service patients from the French islands of St. Pierre and Miquelon, with two full –time workers and an on-call system for afterhours [EH decision maker 2]. We heard many critiques relating to a lack of availability of French interpreters. We did not ask specifically about this service, but the many impromptu statements about the problems lead us to believe that separate evaluation of challenges with that system is advisable.

populations are very small in size. This was upmost in the minds of some of the staff and community based interpreters we spoke with.

The person who is doing the interpreting may already know the person who needs the interpretation done and that kind of I guess anonymity can affect either the way that that person expresses themselves to the interpreter, or the way the interpreter interprets what that person is saying. So that can be a challenge and in a health care setting especially it can be important to take into account. [EH decision maker 4]

The good thing is there's generally accessible through phone interpreters that Eastern Health does provide and that's actually a good service and some of the problems with interpretation within the community is you know if you have a small community and you have people within the community interpreting then you know people are worried about being judged, people are worried about confidentiality all of those things are problematic. [Social worker 1]

Eastern Health has made use of a telephone interpretation service since about 2005. Following the initial EH diversity survey and establishment of the original diversity steering committee, this system (along with the establishment of the APN program) was considered to be of highest priority. The system is available for use by anyone working with Eastern Health. By all accounts, the system is not used effectively, for a number of reasons.

One issue we have is that a lot of the employees in Eastern Health won't use CanTalk⁴⁰. The Janeway emerg and Janeway, they will certainly use CanTalk. A lot of the adult system will refuse to use CanTalk It's just they refuse to use it. They say, "*No, we have to have an interpreter in person.*" [Physician 1]

[ANC settlement worker has] tried to encourage CanTalk and she's come up against wall after wall after wall, just in talking to the people with appointments and saying, "*You know you could use CanTalk?*"; "*No, we don't use that here*". Like, just a blatant "*No, we don't do that.*" So it really creates challenges for us because we're going, well, we know you [EH] have that service and we can't have more interpretation funding because that service exists, and that's why it's there. [Research Team Analysis Meeting].

Despite the fact that the telephone interpretation service has been in use for well over a decade, with the phone number instructions apparently provided at every nursing station in the system, many staff are not aware of its existence.

I find within Eastern Health a lot of departments or physicians either aren't aware of it or don't have portable phones or don't like to use it, they find it burdensome. I don't understand why it's not being used more because Eastern Health as far as I know has a mandate, I don't know if they have a mandate, but they have this agreement to provide it when needed because interpretation is the medical standard of care of course, right ... It should not be optional. [Physician 2]

⁴⁰The original service was since replaced by RIO (Remote Interpretation Ontario) in 2018. The use of RIO is reportedly markedly superior to the original service.

A second reason for its under-use has been the lack of available speaker phones, including the lack of portable speaker phones to take to the patient's side⁴¹.

They don't have speaker phones. You need a speaker phone right, so a lot of the specialists' clinics offices don't have any phones. So it's a simple matter of somebody in Eastern Health saying "*Okay take care of this*" so it's actually practical that the obstetrician who's seeing a patient, or the cancer specialist or whoever, can actually talk to the patient. Because none of the clinics have phones. [Physician 1]

[The problem is] the presence of portable phones ... There should be certainly several portable phones on each unit as a minimum. If people don't have limits on their cell phones numbers they could use their own cell phone. [Physician 2]

I haven't heard any problems with the program as much as its problems with our technology and inability to have a sensible conversation – Either a doctor is pulling out a cell phone, or you've got to move them into another room that has a speaker phone or the speaker phone is far away from one person and the person on CanTalk is saying "*I can't hear what you're saying*" ... So it's more of the technical problems I think there needs to be some type of a wireless telecom pod that we could bring to the bedside ... Telecommunications tells me I'm nuts when I ask for some things! So what we've ended up doing is, we've ended up replacing our older land phones with a better land phone that has a better speaker phone on it. And they'll change that out for us easily enough and they do that very quickly We have to move the patient into that room [where the phone is located] That's not the best but it is still a private area and it's still set up as best we can get it in some of our areas, but it's always a challenge. [Nurse 2]

Moreover, the current service can only be used in an office environment with the patient alongside the physician; it does not allow third party calls. This does not solve the problem of EH needing to contact a patient at home through an interpreter.

[Discussing an alternative telephone interpretation service] I can call the patient at home to ask a question, to remind them about something ... To be able to use the third line to give instructions, to have discussions, is going to be very helpful. [Physician 2]

An additional problem reported by staff that do regularly use the system is that the quality of interpretation is substandard with the particular company under contract (at the time of the interviews—a problem that no longer exists with the new RIO system).

There's often background noise, babies crying in the background, street noise. Often the volume is not big enough. There's often discussion back and forth between the interpreter and the patient, which always concerns me a little bit instead of a straight back and forth interpretation. In addition, at times we cannot get languages that we need. [Physician 2]

Additional problems include wait times for interpreters, and availability of languages.

⁴¹With the adoption of the RIO system, staff are able to use their own cell phones and dial the toll-free number, enter the Eastern Health ID code and a department specific access code, and be connected. This has alleviated many of these original reasons for refusal of the telephone interpretation service.

If you call CanTalk you don't necessarily get an interpreter right away. Sometimes you have to wait. Up to 20 minutes you may still be waiting, and then be told they don't have that language available ... If somebody presents to the emergency department with a third party it may be quicker just to ask that other person what's going on and get the history from that person, I would suspect, so that there may be a time crunch. As well if you're booked in a specialist's office they have this precious time for them to wait for a half an hour it's not acceptable, they have to get going, right. [Physician 2]

An additional problem that compounded the ineffectiveness of telephone translation was the inability of staff to know which language to ask for. Telephone translation is ideal for use in an emergency or when a patient suddenly presents and no interpreter has been arranged or is available. In these cases, it may be difficult to establish which language or dialect to request.

So let's say the patient is from Syria or Iraq and then you have an interpreter that is from Sudan. So, they [interpreters] speak Arabic, but there's sometimes a lack of understanding that the dialects can be quite different. So I've seen a situation of the patient sitting there, just kind of trying to take it all in, and then leaving and saying "*I didn't understand anything*". So then the doctor doesn't know that the patient didn't understand, right, so I mean this is critical information. This could potentially be quite serious ... So how does the patient who's sitting there communicate to the doctor that "*I can't understand, you think I understand – I can't understand what this person is saying to me*". They tell the interpreter – is the interpreter going to tell the doctor they can't understand? It doesn't happen, right. [Informal support worker 1]

An informal patient supporter told us the story of a woman who returned home from a prenatal visit that took place using the telephone interpretation service, and immediately had her friend contact the clinic to explain that the patient had understood almost nothing and had had no way to explain to the doctor that she was not fully understanding. The medical staff had held the clinical appointment from start to finish without ever realizing that the woman had not understood what was going on. [Research Team Analysis Meeting]

One patient supporter explained that it does happen that even when the language is appropriate, the speaker may have a heavy accent, either because of regional differences in accent, or because the speaker is a second-language speaker of the language, making the interpretation difficult; the client will often not complain because the language is, in fact, correct. She explained that face to face interpretation with an interpreter who has a heavy accent does not pose the same challenges because of the use of body language cues, and the interpreter and health worker are more likely to be aware when there is a lack of understanding. [Research Team Analysis Meeting].

Finally, physicians who are not aware of cultural factors related to modesty may be inappropriately using telephone interpretation and not aware that the system has failed because of a patient's inability to fully express themselves.

It is generally accepted, and reflected in the literature, that anonymous telephone interpretation provided from outside the local context is superior to interpretation by family, friends, or community members for reasons of patient confidentiality and interpreter moral distress, among others. It is also well publicized in the refugee health literature that women of certain faiths or cultural backgrounds may defer to male authority figures (e.g., husband, son), presenting a concern amongst physicians that

women may not be enabling their autonomy to be exercised in medical decision making. However, our study revealed that the well-meaning concern of physicians that women should speak for themselves, (and that using telephone interpretation rather than having a male relative interpret will support women's autonomy) may have the effect of silencing women, rather than enabling them to enact their autonomy. That is, the fear that women's narratives may be skewed when interpreted by a male relative, and the use of telephone interpretation to avoid this scenario, has meant that women may not even discuss the health issue if the telephone interpreter is male.

[Family physician clinic] will use interpretation through phone. They do not want an interpreter to come with a patient, I don't know why. But sometimes it's embarrassing for patients, you know, because some women patients would not like to speak with a male [by telephone] even if this person would not know them – still it's embarrassing to speak about some sensitive stuff Some [family physicians] will ask the patient, “*Do you need an interpreter with you?*” but some others will just use the phone system and they do not accept any interpreters. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

Eastern Health bears the cost of the telephone interpretation service. In keeping with how diversity is structured within Eastern Health – with the intention being to have it integrated throughout all departments and programs, rather than having its own location – the responsibility for the service has been in flux over the years.

We actually had to – it moved around. So it originally actually sat with Ethics and Pastoral Care and I think it was because it didn't really have a home so it was there for quite a long time Then people, we lost track of it really, it was still being paid but who was actually paying the bill or which department was paying the bill was under some question and eventually it's with our Information Technology group So how it works though is, that's where the sort of the master contract sits; but whoever is using it – whichever department is accessing it – they get whatever the charges are that come in. [EH decision maker 2]

None of the decision makers and managers we asked could identify who has responsibility for the service.

For the first several years of use, the cost of the service was minimal; there weren't many non-English speaking newcomers arriving, and there also wasn't a great awareness that the service existed.

So as a very ad hoc thing, it was used for 20 minutes, you know, once a month. And also, because nobody knew about it then, it wouldn't have been a big cost. But I imagine it must be tens and tens of thousands of dollars that's coming out of the budget ... I think if it's not booked [in advance] it's a dollar something per minute; if it's pre-booked it's a bit less than that but it's still more than an in-person interpreter, significantly more. [Physician 2]

The cost of the telephone interpretation service is very high, compared to the cost of in-person interpreters. For languages that are commonly needed, many argue, it makes sense to invest the money into having interpreters within the Eastern Health service.

I think that Eastern Health should invest in having at the minimum several onsite Arabic interpreters. The cost of CanTalk to me is, it just seems unethical that they're even considering paying that amount when we have trained people in the community, you know, who have done

privacy [education], with medical backgrounds, who – if they were paid fulltime – it would still be less than me using one day of CanTalk a week. [Physician 2]

Discussion in our research team meeting led to the same conclusion:

But what Eastern Health should do, I think, is have paid interpreters on staff; at least Arabic, which is by far the most common language that we need. And the cost of CanTalk per hour, it doesn't take very long for a few appointments and you could easily pay a weekly salary for somebody just to wait and to go to the two or three appointments – it would be cheaper, right. So I think that would be a strong recommendation that we could consider and it would be a cost savings thing for Eastern Health. [Research Team Analysis Meeting]

Finally, to conclude this section on the use of telephone translation, it is important to note that changing technology may be resolving some of the challenges described above. In particular, with the increasing availability and sophistication of smart phone translation apps, some patients and staff are turning to their phones for quick answers to interpretation in emergency contexts and in the context of in-patient care.

We had a really challenging patient who was an in-patient in the hospital. So we did arrange for the interpreter to come at certain times so we could explain the care plan and be there when we provided medical information and that kind of thing, but there's 24 hours in a day. The interpreter can't be there for 24 hours, so the mom had the Google Translate App on her phone. That was really, really helpful because we were trying to explain certain things that you know, *"We need to do this now, or that now, is that okay?"* so it was helpful. [Physician 3]

Given the high need for interpretation services, it is imperative that all parties understand how interpretation works: how they are paid, how they are arranged, and so forth. The next sections discuss some common confusions and misunderstandings.

6.4.2 Misunderstandings of how payment for interpreters works

Our interviews demonstrated a fair amount of confusion about how payment for interpreters works, and some uneven distribution with respect to the rate of pay, depending on whether it is EH paying (for ANC-arranged interpretation on EH premises) or ANC paying (for ANC-arranged interpretation at a community clinic) or a private sponsor paying (for non-ANC clients who are privately sponsored).

When an interpreter arranged through the ANC does interpretation at an EH site, the interpreter presents a form which EH staff sign, indicating the location and length of time of the interpretation. The interpreter then presents this to the ANC. The ANC pays the interpreter and is reimbursed by EH at a set rate (at the time of the interviews, this was about \$20.00/hour). Prior to the most recent wave of refugees, many staff were not familiar with the interpretation payment process and refused to sign the interpreter's invoice, a problem that has disappeared with time and experience [Research Team Analysis Meeting]

Interpretation for health services in community (for example, community specialist clinics and community family physicians) is paid by ANC. Funding is through transfer payments from the federal government to the ANC, which must be budgeted and allocated across the ANC client population. The rate of pay for this interpretation is nearly half the rate that EH pays (at the time of the interviews, at \$12.00/hour).

Private sponsors are responsible for arranging and paying for interpretation for the individuals they have sponsored. They are understandably sometimes feeling under pressure to minimize the amount of funding spent on interpretation, relying on family members or community-embedded volunteer interpreters whenever possible.

A major concern expressed to us by patients, patient supporters, ANC staff, and family physicians associated with the Refugee Health Clinic was the confusion for interpreters seeking pay for services rendered when they had been hired outside of the normal (formal) arrangements used by EH and ANC. This group of interpreters includes ANC-trained interpreters who are contacted directly by community members to accompany a patient to an urgent appointment (such as a visit to an emergency department), as well as any other informal community-embedded interpreter who is recruited by individual patients, informal patient supporters, or private sponsors. The way the system is supposed to work is that if a patient requires interpretation, EH staff are supposed to call ANC to alert them, and if this is done, then the interpreter will be paid. However, occasionally it happens that an interpreter who happens to be professionally affiliated with ANC will be asked informally to accompany a friend outside of the formal ANC-EH arrangement process. The interpreter will assume that they will be paid.

While our research did not investigate the proportion of paid versus unpaid interpreters, it is clear that a great deal of interpretation is unpaid (and untrained, an issue that will be addressed later). This represents community-embedded interpreters recruited by informal patient supporters (that is, not the government affiliated settlement agency) and private sponsors.

The RHC physicians are very concerned about the lack of interpretation for patients.

RHC staff: We feel very strongly that there should be a community wide interpretation system ... There's a reluctance among community family doctors to take patients because they are very worried that people may show up with no interpreters or with inappropriate interpretation.
[Research Team Analysis Meeting]

In terms of a model for a more organized process for interpretation in health care, the RHC staff provided the example of another province where they have instituted a province-wide medical provider interpretation system⁴².

From the perspective of non-ANC interpreters affiliated with informal patient support groups, the lack of opportunity for interpreters outside of the ANC system to be paid by EH was a problem. The mandate of ANC does not extend to all those patients who require interpretation, and for those individuals, interpreters will not receive reimbursement by EH, and are also often not treated professionally within the health care system (that is, they are treated as if they are a friend accompanying the patient, rather than as a support worker). As this director of a community support agency explains,

Participant: And I have to go along with [the interpreter] because the interpreter is not acknowledged as an interpreter until somebody with some authority is present ...

Fern: And then you're able to bill them for the cost of interpretation if you're there?

⁴²This will be returned to in the Recommendations section of this report.

Participant: Don't ask me that question because we're in a serious interview and I don't want to laugh. [Formal support worker 6]

Beyond organizing if and how interpreters get paid, is the issue of ensuring an interpreter is even present when needed. This is discussed next.

6.4.3 Process of ensuring that an interpreter is present

An ANC staff member spoke to us about the huge variation and inconsistencies with when and how the ANC interpreters are requested. Family physicians with the Family Practice Unit and Refugee Health Clinic have a clear system in place: they will flag referrals to specialists with a note notifying the clinic that the patient is a newcomer who speaks no English and will require an interpreter. Some other physicians, she reports, arrange for an interpreter on the day of visit; others will call two or three days in advance to make arrangements. In many departments, staff do not plan for interpretation or assume that the client will always come with their own interpreter, or that the client will speak English. By contrast, some other offices will ask for an interpreter whenever they see a patient with a non-English name [Formal support worker 2, Interpreter, refugee patient].

The ANC staff member explained some of the frustrations she has faced and some of the creative strategies she has used to manage the complexities of finding interpreters when patients present to Emergency and EH staff are reluctant to use the telephone interpretation service (or have tried, with no success). On one occasion, for one of the rarer languages, the patient was unable to be understood by staff, and the patient took it upon herself to call ANC to request help. There happened to be already an interpreter for the particular language on site with another patient, and ANC asked that interpreter to stop in to the Emergency Department to do an interpretation if possible. However, Eastern Health refused to pay the interpreter because the appropriate arrangements hadn't been made (Eastern Health had not requested the interpreter; the patient had) and moreover, the interpreter was deemed to be a friend of the patient (which she was; it is a very small community). So, what could have been an efficient way to deal with interpreter shortages did not work well. That particular ANC worker never again attempted to resolve an issue using that creative and efficient strategy; instead, her response when a patient called from the ED requiring a translator was to ask to speak to the nurse, and to ask the nurse to arrange for interpretation, adding extra complexity and time to the interpretation process. [Formal support worker 2, Interpreter, refugee patient]

A nurse manager related her frustration at what she sees as a lack of centralized interpretation services in EH, and the resulting inconsistency of care that results.

Generally what we do is if someone has a translator with them we'll go with that; someone doesn't have a translator with them we'll call the Association for New Canadians or Native Friendship [First Light] ... But again it's only if you know [how to arrange for interpretation] and you care enough to keep it in your head. [Nurse 2]

In her call for a centralized and well-communicated interpretation system, she also expressed frustration at the extra work that the lack of a centralized and organized system places on individual manager.

If we want to be able to provide a good service for translation we need to have it centralized to know what it is that is available, who is my go-to person that knows all this information. I'll buy it, I'll organize it, I'll get it done. But don't make me figure out what phone I got to buy and what pod

I got to buy and what number I got to call and who the person's name is, because sixty managers in Eastern Health have to go do that when it doesn't make sense. We need a central point for that. [Nurse 2]

Physicians with the Family Practice Unit and Refugee Health Clinic also observed problems with patients arriving in various departments of Eastern Health and having no interpretation available or, in some cases, missing appointments because the letter from Eastern Health was sent in English. They initiated the process (described above) of flagging patient referrals to help ensure that this does not occur.

We actually have a stamp or we handwrite at the top of the letter, *"Please contact our office with appointment date and time and we will notify the patient as the patient does not speak English"*. Otherwise, Eastern Health central bookings from x-ray or specialists' offices or central bookings for specialists' offices will send a piece of paper in English to the patient for an appointment that is meaningless. So the patients don't know what it is. So we put this on everybody's. Sometimes it's done; like we've worked hard at that and so it's getting better. So the secretary will contact our secretary at the office, our secretary will contact the health worker at the ANC verbally and send the confirmation of the appointment with the date and time and organize an interpreter. [Physician 1]

It is sometimes difficult to match interpreters to patients where there is a scarcity of interpreters for the language spoken, particularly when modesty requirements mean that the interpreter must be gender-matched to the patient.

Sometimes we do have an interpreter but that interpreter is a friend or in a family relationship, then we can't use that interpreter to interpret for a medical appointment ... For Arabic we do have a good number [of interpreters] ... but for most of the African languages we have lots of difficulty, like Swahili, Tigrinya ... Especially when the client is a lady, I absolutely can't send a male interpreter with her ... Even if it's a dental appointment, she would prefer to have a female. The African languages are really difficult to get honestly. [Formal support worker 2, Interpreter, refugee patient]

In-person interpretation doesn't work very well because there isn't that sense of confidentiality because the community is so small, and you're not dealing with professional interpreters when you're dealing with the community interpreters. [Physician 1]

It can be hard for the very rare languages, that people often know everybody in a community, so the only in-person interpreters are, you know, their cousin or somebody; and so people sometimes don't want there to be an in-person interpreter, which I can understand. [Physician 2]

One solution to deal with the shortage has been to draw on the pool of international students at Memorial University; however, this too has its disadvantages because students' lives are so very busy. [Formal support worker 2, Interpreter, refugee patient]

Privately sponsored refugees (non-GAR, non-ANC clients) are supposed to have interpretation paid for and provided through their sponsors. The refugee supporters we spoke with emphasised that this process is not working as it should.

The topic of unavailability of interpreters was discussed at a research team meeting that included patient and health care professional advisors to the project. One informal patient supporter remarked that when there are gaps in the availability of paid and trained interpreters, then she is called for assistance with finding a volunteer from within the various communities of newcomers to provide interpretation.

Informal patient supporter: Another example, last week somebody messaged me from the Janeway, one of the volunteers [i.e., one of EH's volunteers] and she said *"There's a woman here and the nurse can't understand her, she can't understand the nurse, what should they do?"*

RHC staff: The nurse should have called CanTalk.

Informal patient supporter: And I said *"Well do you know who the woman is? I mean maybe I know her."* She said *"I don't know who she is"*. I said *"Okay just a second"* and I went and got the ANC number for the coordinator or whatever. I said *"Try giving this to the nurse, ask her to call now and see if the ANC can sort something out either over the phone or if they can send somebody or whatever."*

RHC staff: So there's two issues that come out of that, right: one is to make sure that there's the best communication between the patient and the interpreter, and the second issue is awareness among Eastern Health staff and providers with the over-the-phone interpretation. [Research Team Analysis Meeting]

This led to a discussion about why a volunteer unpaid and untrained interpreter would be used, rather than an interpreter provided by the ANC or the telephone interpretation service – a system that was set up for precisely the situation where a patient arrives for care, requires interpretation, and none has been arranged in advance.

The ANC representative at the meeting went on to explain the challenges posed by last-minute requests for interpretation from EH staff. She described the successes that the organization has with providing multiple languages, but cautioned that this doesn't mean that there will always be an interpreter available, particularly for some of the less common languages.

Given these shortages in appropriate and accessible interpreters, adequate training and support is essential. The next section looks at the various types of training and support – or lack thereof – offered to different types of interpreters.

6.4.4 Training and support for interpreters

Those who do interpretation have a widely divergent range of training and experience and level of English proficiency. Those who provide interpretation through the ANC are trained and paid, and within that group the range of skill was not so concerning to us. However, community support workers acting as interpreters varied widely in terms of their expertise and experience. At one extreme, one interpreter we interviewed is an extremely well qualified and experienced interpreter, having held professional positions interpreting for the UNHCR, Canadian Immigration, and U.S. Immigration; this individual is proficient in a number of languages spoken by refugees of African origin, and is highly proficient in English. Many of those who are paid and trained to do interpretation through the ANC also act as informal volunteer interpreters, called on by family or friends, or arranged through informal support groups (including private sponsors). At the other extreme, we learned of community-embedded

volunteer interpreters who were at the time still learning the basics of the English language, and who are called in to interpret – often in their second language – in the context of a shortage of interpreters for some of the rarer languages.

Our impression about this variability was echoed by one of the community support workers:

I have seen what appears to me to be remarkably proficient interpreters and then others that seem to me to barely be able to cope in English. They can speak their language, they can speak Arabic or Swahili or whatever perfectly but their ability to interpret it into English can be quite limited. So I would find this to be a serious concern and I've encountered it many times, many times. [Informal support worker 1]

In general, we are left with the determination that there is a great deal of inconsistency with respect to quality of interpretation. There is a heavy reliance on family members as interpreters, which is well established as substandard in quality and potentially morally distressing for those doing the interpreting. There is also a heavy reliance on informal patient supporters, called on primarily to assist privately sponsored newcomers (for whom interpretation is arranged by the sponsors, not by ANC). These individuals are sometimes providing substandard interpretation due to a lack of training. Moreover, the potential for real and feared confidentiality breaches may lead to lack of full disclosure by patients whose personal health information is being interpreted by members of the same small community.

The social and economic burden on these informal patient supporters may also be significant in some cases. In contrast to the Indigenous patient support side of things, where a quick call to the APNs could result in support and arrangements being made for patient supporters, on the refugee side of things this meant that occasionally volunteer interpreters were unable to fulfill their role.

Sometimes interpreters haven't come because they can't find a parking spot or we've heard of interpreters not wanting to come because they have to pay for parking, and that can significantly eat into how much money they get paid – they don't get reimbursed for parking. So that's just a little aside. [Research Team Analysis Meeting]

Regardless of how well-trained or not interpreters are, health care workers also need to understand how to work appropriately with interpreters. This is covered in the next section.

6.4.5 Physician inexperience with working with interpreters

Interpreters and community support workers reported that it is a challenge working with physicians, nurses and others who do not know how to work with interpreters. This community support worker explains:

I think training for the doctors and nurses in how to interact with an interpreter would be very helpful. So I have seen many situations where the doctor will come in or the nurse, and they will speak to the patient just as they would speak to any other patient who speaks English; and they may go on for 5 or 10 minutes and the interpreter is standing there waiting, you know. As someone who has done interpretation, 5 minutes of medical information is a lot ... What I have started to do now when I'm at the appointments, I assume maybe that the doctor or nurse hasn't worked with an interpreter, I just say *"Okay, as we're doing this could we stop every 3 or 4 lines and let the interpreter say that and then you say your next thing. Can we just slow this down a bit?"* [Informal support worker 1]

Another interpreter explained, “If they are trying to speak fast, I ask them can they reduce please – so that I may understand what they are [saying] and so that I am able to translate too.” [Refugee patient 10: formal and informal support worker and interpreter, woman, Swahili speaking]

Interpreters emphasised that this is a difficult balancing act, particularly with physicians; on the one hand, the interpreter needs to be directive with the physician and request them to alter the way they are conveying information; on the other hand, there is a very huge power imbalance between privileged physicians, who are often male and very often white, and newly arrived visible minority refugee interpreters, often female – and there is a reluctance on the part of some interpreters to challenge that authority.

This interpreter described her frustration with physicians who ignore the patient and speak to her as if she were the patient, and emphasised how challenging it is to address a physician with authority and have them respectfully listen.

Sometimes I feel like I’m the patient and they are just, you know, speaking with me and ignoring the patient, and I’m trying to just like pulling the patient inside the conversation in a way ... I find it easy with some doctors; but with others no I find it really hard ... And the doctor will not even listen to everything you’re saying as an interpreter – they just [listen to] a few words and then, “Yes, yes, okay, okay”. Like, they are so busy, or I don’t know – they do not have time to complete everything – so I [try to say to the doctor] “*I still have something to tell you what she told me!*” – and I can’t, like, stop, and I have to say something. So sometimes, I’m not saying I’ll be rude, but sometimes I’ll be like: “*No I’m going to tell you, you have to listen.*” [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

She went on to say that in her experience specialists are much better at working with interpreters than family physicians are.

An additional challenge related to physicians’ incompetency with working with interpreters had to do with the interpretation of complex medical terminology. Health care providers are supposed to be using lay language to explain complex medical concepts and terms – regardless of whether an interpreter is involved – but this is particularly important when working with an interpreter. Some physicians are not doing this, which has risks of leading to misinformation or missing information.

For example, in Swahili I have to find the way that I’m going to translate it, when there is a specific word in medicine that is difficult to translate ... So you have to tell the doctor, “*Let me try to explain it*” ... For me this happened many times. [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

One interpreter, described how she felt it was her own duty, as part of her role, to inform the doctor about how to alter medical terminology to make the process of interpretation flow easier. She implied that it is a collegial process of mutual assistance between physician and interpreter:

I’m the one who’s supposed to tell them [doctors] that this word is difficult so you have to help me, to explain to me how I can translate ... They [doctors] know how to make those names [medical terms] in an easier way, so they try to help me ... One day I brought my sister to a dentist and then some things they would tell me using medical names, and I was, “*No, I don’t understand that word*”, so they had to explain to me. That is the time I find it difficult ... I was

not able to translate to my mom [accompanying the younger sister] the name of that medicine in my language or in Swahili [their second language] so that is the thing which become difficult to me. [Refugee patient 10: formal and informal support worker and interpreter, woman, Swahili speaking]

Interpreters expressed to us that they feel a certain level of distress when working with a physician-patient duo where interpretation is difficult. They are concerned that if they do not accurately and effectively interpret what the physician is saying, that the patient may suffer.

You have to take responsibility, because there is a human being that is there, so you have to be professional. That's why if you don't understand, try to ask and the doctor has to, you know, find a different way to try to speak with you so you're going to understand ... If there is something wrong or something that I don't know, I will ask – because I know it's a human being. If you translate [incorrectly] you can even cause something bigger [worsen a patient's condition]. [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

One interpreter told us about a case she had heard of, where miscommunication between a physician, interpreter, and patient led to the patient suffering. The patient, accompanied by an interpreter, had seen a physician and received a prescription. At that time, the physician had said that the patient should contact him to have the prescription renewed once that prescription had run out. This need to re-contact the physician was either not understood or not communicated by the interpreter, or the patient had not understood the interpreter. The prescription was very essential and was for a serious medical condition.

It was a mistake, because the interpretation went really bad ... The interpreter didn't tell them that or even explain that well to the patient. So they went home and they didn't take this, like after like a week they ran out of the medication and they didn't contact the doctor And it was something really – like it was an essential medication because you know [names medical condition] is something really hard to deal with if you miss the medication, and she missed that medication for almost two months and she became really bad [sick]. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

Similarly, a nurse reported, “we have had incidents where we know the individual has received the wrong care but we don't know if the care was misunderstood or if it was maliciously or accidentally misinterpreted.” [Nurse 2]

One interpreter pointed out that there is sometimes limited opportunity to correct misunderstandings, because physicians do not allow that to happen. This interpreter described how the norms of interpretation are such that one should simply convey, in an objective and neutral manner, the information that is communicated between physician and patient, and if the interpreter suspects that there is additional information that is not being said by the physician that may be helpful to a patient, it is not the interpreter's role to second-guess what the physician is saying, unless the physician invites that.

I don't have any authorization ... Because when you're interpreting you can't do anything because you have to pass the information for someone who is speaking; it's not, you're – you're

not in his mind, so you have to do [communicate] what he [doctor] is saying ... But if the doctor allows it, to do some intervention, you can do it, or maybe if you see that there is something but they don't understand each other you can ask, *"Can I help?"* [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

This interpreter also emphasised that it is not professional for an interpreter to have a side conversation with the patient, prior to or during the clinical appointment, as a way of gaining background medical information that can then be conveyed to the physician, and that this restricted the ability to know whether there might be misunderstandings between a physician and patient.

You can't call him [patient]. You can't say, *"Oh you remember that day I was in?"* – no, no, no he's not allowed Even we are not allowed to share one transportation ... When I finish my service, I go ... So even if there is a misunderstanding between them you can't do anything. [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

Given that it is not the responsibility of interpreters to elicit additional information from patients, it is up to doctors to ensure that the full range of information is being asked of patients via an interpreter. A nurse manager explained how massive the gap in physician education about interpretation is, using the example of a physician-patient encounter she had recently witnessed:

I had a resident not too long ago, I was fortunately being a fly on the wall and she [resident] said [to the interpreter], *"Can you make sure that the patient knows she's going to get a PAP test and all that and understands what's going to happen?"* And I said, *"No"* – and this is a very sensitive, lovely, smart resident, until I pointed out – *"You can't have the interpreter explain things!"* You know, so very basic education about how to use the interpreter appropriately. [Physician 2]

A nurse manager discussed the lack of a centralized place within EH to go for basic information about cross-cultural care, including information about how to work with interpreters. She used the example of a nurse having a conversation with a Muslim patient for whom modesty may be an issue, in a situation where the patient had a friend as interpreter.

And then I got to say to [the patient], *"When was your last period? Did you have unprotected sex today?"* Like, and you're talking for your friend! And don't even start with the cultural issues. [Nurse 2]

From the perspective of health care providers, working with interpreters can be extremely challenging, even for those who are highly attuned to and experienced with working with interpreters. An obvious challenge for physicians locally and across Canada, is the reality of working within a fee-for-service system and in a context where a scarcity of family physicians and long wait lines for specialist appointments means there actually is not the time to take to double or triple the length of a clinic appointment to accommodate effective interpretation. But beyond those obvious logistical and justice (access) issues, interpretation is simply not as effective as communication in a common language. This social worker, with experience and expertise in cross-cultural mental health care, explains:

Most people, including myself, hate working through interpreters ... It can be really problematic and if you do work with families in particular you may have one generation that's very fluent and another that's not, and that causes some difficulties ... I find it really frustrating. I think

because it's intrinsically difficult to do, especially in something like psychotherapy where nuance is everything and it's easy to lose the nuance if you have an interpreter. [Social worker 1]

The social worker went on to describe the moral distress that so often accompanies working with an interpreter.

There's also the, *"Oh my God, did the client get the gist of what I was trying to convey or trying to ask?"* And it's really extremely difficult to do, because some of our services are not individual face to face service – some of them are group services; and it's really hard to ... I can't use an interpreter with a larger group, I think it's just too difficult ... So I think there are struggles with it but I think they are intrinsic struggles that are always going to be there and you persevere as best you can and try to have as many resources as you can. [Social worker 1]

Interpreters can also experience this kind of moral distress around their role in the health care exchange, as the next section shows.

6.4.6 Interpreter moral distress

Interpreters reported having moral distress when they have information that they know the physician should have, but the patient is not sharing it with the physician. One interpreter shared the story of a patient who had informed her, while they were waiting for the appointment, that he had been using traditional folk healing for a condition instead of the medication that the doctor had prescribed. She then noticed, during the appointment, that he had not revealed this to the doctor. The professional standards of interpretation, that the information is to be transferred between physician and patient without editorializing on the part of the interpreter, meant that she faced a moral dilemma about whether to reveal the facts, and moral distress at the decision to not disclose the additional information:

But, like, if the patient will not say it, can you tell the doctor about this – no, but And sometimes I feel, like, I'm guilty, like I should say something while I know I can't, because the patient asked me not to say it, but in this case like I should say it, you know. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

She told another story,

There was an emergency case, when I came to the hospital and a child was injured and they [parents] wanted, you know, the injury was really bad and the parents were really afraid because they felt that the doctors will ask them if they did something to the child, that that's why he's injured. So I can see the fear in their eyes, and I was like *"Calm down. Did you do anything?"* and he said *"No, no, no but they will ask but I don't want them to feel like we did something wrong"*. And then the doctor was like *"What is he saying?"* and I was like – what should I say? I can't – and then like he [father of patient] said *"Don't tell him, don't tell him that"* and I was like, *"Okay no nothing, they were saying about how it happened"* or something you know ... But I was not sure if they did really, they did something to the child or, you know. So in this situation, you will be in the situation that, what should I say, or should I, like I don't know [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

She went on to explain the complexities of resolving such ethical dilemmas.

Sometimes I feel like, if I feel like there is a risk to the person, or even there is a risk to the child ... in my opinion if something really, if I felt that something wrong is going to happen, if I didn't interpret that – even if the patient said do not do it – I'll do it anyway, because I'm afraid of something bad happening and then I will be guilty, you know, feel guilty, let's say somebody is going to harm himself you know like I can't, I can't – you should say it [tell the doctor] you know, even though if he said like *"I'm going to kill myself but do not say that to them,"* at least I will give them a hint that this person needs more you supervision because he said something; something like that, I'll do something like that; but not – but yeah, it's really tricky. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

These instances of moral distress relate to interpreters' ability to establish trust between themselves and the patients they are working for. Trust is described in the following section.

6.4.7 Trust and disclosure in the patient-interpreter relationship

Often the emphasis in interpretation is with how to ensure a safe and trusting doctor-patient relationship. But our interviews revealed the importance of a safe and trusting relationship between patient and interpreter. Interpreters report that sometimes patients can feel shy to speak, particularly on sensitive issues, and it is their role to establish a relationship of trust and safety with the patient, in order to ensure that the patient feels confident enough to reveal sensitive information, through them, to the physician.

There are also the refugees that are shy, you know. There are some, I think, that can't speak, so you have to do a strategy to feel them comfortable. [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking].

One of the ways to increase the feeling of trust and safety is for patients to have an ongoing relationship with an interpreter. Both interpreters and community support workers are aware that this enhances interpretation. This interpreter describes this:

It's really hard sometimes because, you know, like it's really sensitive ... Especially for medical appointments, they are giving you everything about their [personal health] so usually I prefer to stay with the same family. Not for me, but for them. Because if I was the person, the patient, I would prefer the same interpreter all the time ... even though they're not going to say anything outside [i.e., break confidentiality] but I'll feel unsafe, like, to tell my story to five different people. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

This was echoed by refugee support workers:

We try as much as possible, if we know that a relationship has been established between a client and a certain interpreter, especially if they have ongoing complex medical needs. We try as much as possible to ensure that they're assigned to that individual. But at the end of the day we have to work within a medical system that is very much driven by appointments and the ability to meet those appointments, and if that interpreter is not available we have to find another one, that's the other side of that particular struggle. It's not that everyone is insensitive to the need for comfort levels and all those sorts of pieces; but if somebody isn't available then they're not available. [Research Team Analysis Meeting]

As is next explored, establishing trust is part of a larger conversation around patients' consent to the use of a particular interpreter.

6.4.8 Consent to the use of interpreters

This issue of developing trust and rapport with a patient while using an interpreter is an obvious challenge. Other possible problems with patient shyness or modesty are not so easily remedied. One of the main ones raised by interpreters and patient supporters is the case of a patient working with an interpreter who is a good match for language (that is, there are no dialect challenges), but where the interpretation will be unsuccessful because for social or cultural reasons the patient is not able or willing to reveal information to that interpreter.

I have concerns sometimes with interpreters, if it's a male with a female patient: is she really telling me the true story? Because she knows there's a male interpreting. If we're talking about gynecological or, you know, contraception, that sort of thing especially and then I also wonder sometimes is the interpreter truly interpreting things correctly [Physician 2]

The challenge with these scenarios is that the patient may be unable (for the same or additional social or cultural reasons) to tell the interpreter that they would prefer another interpreter. This issue of how to obtain consent for use of an interpreter is underrepresented in the literature as a concern, yet poses enormous difficulties at times. This is most evident with respect to gender matches and modesty, but is equally problematic for power relations between interpreter and patient within small communities.

One of the big issues, and we brought this up with privacy and confidentiality recently in one of our meetings at [names specialization] because as you can imagine there's extreme intimate details being spoken about: sometimes both the couple, the man and the woman, don't speak English. So now you have a third party talking about every part of your [intimate health details] ... and we're getting consent for a translator. So the translator is translating the consent to the patient [about whether or not they consented to using a translator, or consented to using that particular translator]. [Nurse 2]

Similar problems arise with respect to the use of informal – particularly impromptu – interpretation where the patient is being reached by telephone. One nurse manager reported that her staff have expressed concern about sometimes not knowing whether a patient being telephoned is in fact okay with having personal health information discussed with a third party – there is no way of knowing whether the individual who is handed the telephone at the patient's home is actually someone that the patient would want to have certain health details relayed through. In this, case, the nurse developed an ethically sound approach that would meet standards of privacy and confidentiality. She instructed staff to collect, during in-person clinic visits, names and telephone numbers of individuals that had accompanied a patient (which would imply that the patient was comfortable with having that person continue to interpret). For phone calls, only those individuals would be contacted by telephone.

So my guidance to them now is: guess what, you can't talk to anyone that you've never spoken to in person with her ... Now [patient] can come in next week with Jane and I can write Jane's number down. [Patient] can come down next week with Sue and I can write Sue's name down; but Sue can't call me if I've never seen [Sue, with the patient]. But it's still tricky. [Nurse 2]

The interpreter-patient relationship and dynamic is very important, especially given how interpreters often play additional roles as culture brokers, health system navigators, and emotional support. The next section looks at these other roles.

6.4.9 Interpreters as emotional supporters, culture brokers, and navigators

Interpreters often do more than interpret. They can serve as enormous supports to patients and families, including helping to navigate the system and helping to “broker” the cultural gap between patients and providers.

A mother of a pediatric patient reflected on her horrible experience at the hospital where she tried to be independent and not use an interpreter when her small child was having surgery.

I will never make the same mistake. I will take [friend who is interpreter] with me or call the ANC or somebody who knows the system very well. [Refugee patient 6: woman, Arabic speaking]

Another support worker echoed this concern, explaining that even for those who do speak English, it is difficult to have conversations without a support person. [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking].

One interpreter explained that interpreting across cultures is just as important as interpreting words when it comes to asking seemingly “routine” questions about alcohol use and sexual history with Muslim patients.

They have to ask if you’re drinking alcohol or if you are having multiple sexual partners. Some client will think that’s not nice ... So I went back to the clients and tried to reassure them, try to make them aware of the Canadian culture and the questions, and you just need to answer it. But also for [the health care workers] I felt they, they were not, they are asking the question, they are very nice with the clients but they were a little bit hesitant. [Formal support worker 2, Interpreter, refugee patient]

She suggested that having the interpreter meet with the physician ahead of time to give an orientation would have helped to ease the awkwardness of the clinical encounter:

You know, if they had an orientation before they see the clients it [would have been] way better, I would feel them more prepared. [Formal support worker 2, Interpreter, refugee patient]

Interpreters also inevitably act as navigators, often meeting the patient at the entrance to the hospital, for example, and guiding them to the appointment, rather than meeting them at the location.

Given all of the complications to interpretation outlined above, an ideal scenario is, of course, to not require interpretation in the first place. This is expressed in the next section.

6.4.10 Ideal scenario: Access to services in a variety of languages

An ideal scenario is to have a physician population that matches the demographics of the patient population, so that patients can be matched to physicians who speak their language and understand their cultural and religious health accommodation needs.

This does sometimes happen in St. John's, where fortunately a number of local physicians are immigrants to the province, as this refugee support worker points out.

I know a few physicians ... their native language for example is Arabic. And I know someone, their native language is Swahili, or he can manage Swahili and French. So if the clinics, other than the Refugee Health Clinic, if any of the other clinics in the city can accept these patients ... that would help a lot, especially if we have a family doctor who speaks Arabic and English then it's going to be perfect – they will not even need an interpreter. [Formal support worker 2, Interpreter, refugee patient]

Some clinicians argued for resources to enable print documents to be available in some of the main languages spoken by newcomers. However, patient supporters also cautioned that clinicians should not assume that patients are literate in their own language.

The other thing is with written communication there are newcomers who cannot read and write in their own language, so then that adds another layer of difficulty with the communication. And, just as an example of that kind of problem, I once came to the Janeway with some children and their father. The two children were sick and the doctor was really, really good you know, in trying to understand what was going on and so on, and you know made some prescriptions and then printed off a lot of information. And she figured out how to print it off in Arabic, which, I mean – this is fantastic that you're able to do this, but I knew that the mother and father, neither one of them could read Arabic, they could speak but they could not read it. So I had to just kind of gently let the doctor know, *"Okay you know they're not literate in their own language."* So we can't make the assumption that even if it's written in their language that they're going to be able to understand it. [Informal support worker 1]

As has been alluded to, interpretation occurs around more than language but also around cultural differences more generally. Cultural distinctions can be a big large barrier to respectful, appropriate, and effective care. The next major subsection delves into the various ways that culture – both that of newcomers and that of the health care system – impacts refugee care.

6.5 CULTURAL DIFFERENCES

Cultural and religious factors were seen as posing challenges to access to care by both patients and providers. Themes included: prescription medicines in relation to religious prohibitions and cultural norms; modesty requirements; alternative conceptions of autonomy and decision making; child safety practices; visitors policies; naming systems causing confusion; the use of alternative healing modalities being hidden from physicians; and provider distress at wanting to be more culturally competent. Each is discussed in turn below.

6.5.1 Prescription medicine in relation to religious prohibitions and cultural norms

One patient explained how it is important for pharmacists and physicians to understand that some patients have dietary restrictions, and the ingredients in medications must be fully explained to patients. Patients may need to avoid specific medications that contain a prohibited ingredient, and be reluctant to ask the physician for an alternative. As well, if the ingredients in a medication are not fully explained to a patient, they may inadvertently consume a prohibited product. One of the most common errors is the prescription of pills that contain gelatin, which must be avoided by patients who do not consume

pork, including followers of Islam, Judaism, and certain Christian denominations; strict vegetarians will also avoid gelatin.

A lot of medications and supplements have gelatin in them and sometimes it could be very crucial for you ... I make the exception but not everyone will do. If they found out after consuming something that has had gelatin, what are the ramifications? Someone could be infuriated that they've been consuming a pork by-product for X amount of time. [Immigrant patient 7: woman, economic immigrant, student]

An additional problem with prescriptions for drugs is the lack of understanding that concepts like "lunch", "dinner", and "supper" are cultural constructs. Confusion over when to take medication can happen when health care providers assume that Canadian lifestyle norms are the same for others. One refugee support worker described this as a common problem they have observed with prescription instructions, whereby patients are told to take medication "with supper" or "with breakfast", but providers fail to appreciate that some patients will not know how to interpret that, when their own meals follow quite a different schedule [Formal support worker 6].

6.5.2 Modesty requirements: More than appropriate draping

Muslim patients reported that EH staff in general are very accommodating with, and respectful toward, a woman's need to retain her hijab or to be appropriately draped if the hijab does have to be removed. One interpreter commented that it is very rewarding to see how many Eastern Health staff have quickly learned to be flexible with respect to Muslim women's health.

Especially when we have ladies in labour they were super, super helpful honestly and I feel like they understand. When they call me, they say we felt she didn't feel comfortable even with the interpreter, so we said let's leave her, maybe next time we'll discuss ... I appreciate that they are flexible, they understand there is a cultural difference and they are flexible with that. [Formal support worker 2, Interpreter, refugee patient]

We learned that the impression amongst Muslim women is that EH nurses are particularly knowledgeable about modesty requirements and prepared for how to adapt their standard practices in order to accommodate women's needs. As this interpreter explains,

Let's say it's during the OR, you know, like you have to take off anything that you're wearing. But the nurses are much more familiar with that, like, *"Okay I'm going to give you a cap. You can take off your Hijab and just put a cap. Nobody will see your hair and I'll give you something to wear like a gown and I'll cover you, like I'll cover all your body with a blanket or something."* [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

She went on to explain that doctors are not as comfortable with how to handle a situation where a woman refuses to remove their hijab, and as interpreter she often also plays the role of culture-broker, explaining that the compromise is for the woman to wear a cap.

Patients and their supporters did express concern about the lack of knowledge amongst care providers about the importance of gender in relation to modesty requirements. One behaviour that was particularly troublesome – and yet easily remedied with some basic training of health care workers – was the habit of male physicians shaking hands with female patients.

This interpreter told the story of a well-meaning male physician who tried to shake the hand of a new patient. The woman was wearing a hijab, which should be taken as a sign that the woman's modesty may⁴³ prevent her from being touched by a male doctor in this context.

[The physician] wanted to shake hands with her, and I wanted to say [to the woman] that "*You can do it*", or "*That's okay*", but like I couldn't; like – it was so embarrassing, she was so embarrassed and she didn't do anything and her husband was with her. And this is also a problem, when the husband is with the wife it will be even more embarrassing you know ... So she kind of refused several times but the doctor didn't understand that she doesn't want to shake hands with him; like he didn't understand that, because he's not familiar with the religion. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

She told a similar story of a pregnant woman who had recently arrived at the hospital to deliver.

A doctor came and shook her hand, you know, and she was so upset, like she was the whole way upset, because he shook her hand Like, "*I didn't want to shake hands with him, I didn't want to shake*", and I was like "*Calm down, that's okay.*" [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

This interpreter explained that while the removal of a hijab would of course be even more traumatizing, this is actually much less of an issue because the modesty concerns related to the hijab are more known to health care providers.

A key concern for patients and their supporters with respect to modesty had to do with how to manage situations where the health care provider is male, and the frustration that patients experience with not being able to convey the importance of this to care providers.

One woman told a story of requiring an appointment with a specialist. The nurse who met with her was a man; the woman asked for a woman nurse instead, explaining her religious requirements with respect to modesty. They provided a woman nurse. Yet when the doctor came in, it also was a man. From the patient's perspective, it was obvious that if she didn't want a male nurse touching her, then it followed that also she wouldn't want a male doctor touching her. ("*Seriously, he's still a male, like, you know!*" [Refugee patient 6: woman, Arabic speaking]) In this case the woman simply did not even try to argue for a female physician. She asked for robes and covered her entire body and proceeded with the examination.

One informal community support worker shared with us that she had arranged for a couple to find a family doctor, and had matched them with an Arab physician so that there would be no communication difficulties. She reported being surprised when the patients told her, after the initial visit, that they were not interested in continuing with the physician. It was better over all, they told her, to have a female doctor and work through an interpreter rather than have a male doctor who spoke the same language,

⁴³This is not necessarily the case, as individual beliefs within any given culture or religious tradition may vary tremendously. However, the wearing of a hijab can generally be a signal to at least consider that modesty requirements may mean that touching is forbidden.

because often the husband would be unable to accompany her to an appointment [Immigrant patient 7: woman, economic immigrant, student].

For patients trying to convey to health care providers the importance of this modesty requirement with respect to gender, part of the challenge is the power differential – patient to physician; female (patient) to male (health care provider); and newcomer with no political “clout” to established Newfoundlander. One interpreter summarized this patient participant’s story. The patient and her teenage children were reluctant to see a male doctor, but didn’t know how to tell the doctor that. They were hoping to explain to the female nurse that they needed a female doctor, but were reluctant to even do that.

The family were going to him. They are sick. They don’t know what to say. They were saying they are waiting for the nurse, to talk to the nurse or to the lady there and explain to her, they tell her we don’t want, we can’t ... we don’t want to go to that doctor ... They would even be shy to tell her that. They said [to the interviewers], *“We don’t know what they will think of us if we say we don’t want the male. They will think we are not good or we’re not treating the doctor good,”* so they are saying, *“We were really, really reluctant from even telling the nurse.”* [Formal support worker 2, Interpreter, refugee patient]

For EH managers, there is a moral conflict between the desire to respect a woman’s right to have care that is not delivered in a traumatizing way and the need to work within the realities of limited staff resources while still meeting the ethical and legal standard of care. This nurse shared the moral distress that she and other nursing staff feel, in the context of Obstetrics and a woman’s refusal to have a male doctor. She explained that roughly half the staff are male, and even though there are female residents who can deliver the baby, the staff member is legally obligated to be present and if that is a male physician then there is no other option.

We’ve had men [fathers] yell at us, *“Get him [doctor] out of here, get him out of here!”* Well it’s either that or like the kid [baby being born] is not – the kid is coming anyway and he [physician] legally has to be here for us. So that’s the whole part of – we got to go both ways, right. So we got rules to follow as well, and asking us to breach our rules morally and ethically is only the start of it because professionally and legally comes right after it, and we don’t have the professional option because if something happens it’s on me and I’m the one hauled down and I’m not a nurse anymore and that is on a nurse’s mind all the time. So it’s very difficult when you don’t feel like they’re willing to work with you. [Nurse 2]

Different gender norms also become apparent in the expression of alternative cultural understandings of autonomy and decision making, as discussed next.

6.5.3 Alternative conceptions of autonomy and decision making

Another source of frustration for patients is the lack of knowledge about and respect for traditions in which decision making is done by a family authority figure. Particular sources of tension were decisions being made by a parent, in cases where the child had the capacity to decide, or by a man on behalf of a woman who had the capacity to decide.

One young woman described having been prescribed birth control pills as a treatment for a medical condition while in high school. She requested her father’s permission, as was her tradition and her own personal preferred course of action, and her father advised her to not accept the treatment.

I met [the physician] many months later, he asked me a question – *“So did you use it?”* I said no. *“Why?”* ... I said *“Well actually I come from a culture and from a religion where certain topics are taboo; this is one of them.”* I wasn’t able to convince and he was like *“Okay, if your dad’s making the decision”*, because he thought it was very odd that my dad would have a say in this, but culturally it’s accepted to have your parents also to be involved in your sort of health seeking behaviour. He was like, *“If your dad has any questions”* – and I think he kind of said it sarcastically, it was like – *“He can give me a call, I’ll explain it to him.”* [Immigrant patient 7: woman, economic immigrant, student]

An interpreter recounted the story of a mother and her 12-year-old. The girl had a gynecology appointment, and the gynecologist had recommended surgery. The mother had many reservations about it and did not immediately consent. The 12-year-old daughter, meanwhile, was silent and deferring to the mother to decide. The interpreter, imitating the mother recounting the story, said “the nurse told me, ‘well she’s 12 years old, she’s here in Canada, she’s free. It’s up to her whatever she wants to do with her body, you don’t have any right to say no’”. The interpreter went on to report that the mother said “I felt that’s really strong; and my daughter is still 12 years old, she’s not 18. Why would she [have the right to decide?]. And she [nurse] said, she said it in front of my daughter I totally know my daughter, she doesn’t understand even like all the things and consequences”. The interpreter went on to explain that the mother was looking at the negative effects of having the surgery, from a cultural point of view. The interpreter explained that gynecological procedures or exams are not done for a girl until she gets married or after 18 years old.

I understand the mom, she really wants the best for her daughter and she’s really scared about her when she heard surgery and she’s still 12 years old. She said ... maybe they don’t know in their culture that she can’t have any surgery or anything until she gets, unless it’s really urgent or it’s really affecting her life until the age of 18. [Formal support worker 2, Interpreter, refugee patient]

She went on to explain that such stories are rare in her experience.

I haven’t encountered something like that [before or since], to be honest. It’s the first time that I hear. I usually know, like especially the employees with Eastern Health, they really take care of these cultural things. [Formal support worker 2, Interpreter, refugee patient]

For staff, male-female power dynamics that do not map onto Canadian norms are deeply troubling, particularly when language barriers make it difficult to know whether coercion by a man may be happening.

That power dominance is very uncomfortable for everybody because that is not our culture ... So I’ve had English couples that we have the male/female power dominance and the nurse will come out and say, *“I don’t know – she don’t say a word. She lets him speak for her.”* I said, *“Well does she hear what you’re saying and does she allow him to speak for her?”* Because we can’t make that not happen; but when it’s a language barrier [the nurse] can’t say *“Yes, she knows what I’m saying and she’s allowing him to answer”*. The nurses can’t say that the patient knows what is going on and it makes them extremely uncomfortable. [Nurse 2]

She told a story to explain this:

The other day we had a couple ... The male was speaking for the female. The female was not speaking. We had a power gradient that was uncomfortable for everybody. She spoke minute words but, we knew, not enough to understand ... so the man was adamant that the male [physician] would not care for his wife ... To which the nurse very professionally went back and said, *"But you realize that when you came to our services you told us this [that the woman required a female physician] and we told you whenever we can accommodate you we will. So today there is only one physician here [a male]. If another physician was here I would ask her to do this but there is not. There is one physician here and you can either receive the care or you cannot receive the care, but if you do not receive the care here are the challenges"* ... And he spoke for her [female patient] to say *"We will not receive the care"*. She came away a little bit then, I guess she kind of realized that *"We're leaving and I didn't get anything done, what's happening here?"* ... And she came back right and anyway they worked it out that she would see the male and, but they left out one of the more intimate parts of the test ... The whole situation left everyone not feeling good because number one, he made a care decision for her and was leaving with something that she obviously did not agree with because when they walked away and he spoke to her in her language she was like, *"Hey that ain't not happening"*, so that was the male power gradient uncomfortableness. And then with the language barrier it was kind of difficult to maneuver what care could be provided if, like if I could speak to her in English I'd say *"Alright can we do this much and can we do that"* – but how do you do that, when the person that's translating is unwilling to translate to the patient. So that's difficult. [Nurse 2]

She went on to elaborate that it's not just concern for the woman's autonomy, there is concern as well that a procedure will be done on a woman that she did not want to have happen.

It's about the comfort level and the trust. We have a male partner who appears to be translating all the time who appears to be engaging the patient in her own care ... So as long as we feel like they're engaging each other, they're talking back and forth and she's agreeing, like if he explains something to her and she puts her arm out you know he just said they're going to do blood work you know what I mean so you can trust that the words are coming. But we've been burned a little bit too, right so you know it doesn't take long for word to spread that a male translator had a female agree to the wrong procedure to have a completely different ... outcome to what they thought the outcome would be. They were unable to discern whether or not the translation was an accidental or malicious translation but it was a dramatically incorrect care plan that we did proceed with. [Nurse 2]

She went on to say how very afraid the staff are that another error will happen because of cultural and interpretation issues:

That trickles through the ears of the care providers, *"Do you know what happened the other day, do you know what happened?"* You got to be careful, you got to be careful, you got to be careful, you got to be careful ... Is she allowing him to speak for him because she's good with it, or is she allowing him to speak with him because she's afraid? Is she okay with what we're about to do? [Nurse 2]

Family dynamics are culturally constructed. This is apparent in differences around child-rearing as well, as the next section unpacks.

6.5.4 Child safety practices

Differences in parenting have been a source of dissension between nurses and parents. A primary concern has been with visitor policies, where children accompany parents, and staff are concerned that children are not being appropriately supervised and are disrupting other patients. But concerns around child safety were also expressed by health care staff, who assume that the scientifically-grounded best practices of western child care practices are in the best interests of children.

One support worker told this story that had happened a few years previously.

There is this African lady that is pregnant and it comes her time and she has a baby and everything goes well and the nurses bring, happily, the baby to present it to the wife, to the mother right, and the mother goes “*No, no, no*”; in English she can say nothing more than “*No*.” So, according to the nurses, the mother is rejecting the child and if the mother rejected the child then child services has to be involved. And the mother was upset because [the nurses then proceeded to take the infant out of the room] and she was saying “*No, no*”, indicating that the child has to be in the room. So these people were really confused, you know, “*You don’t want it nearby, you don’t want it to be out, so what’s it going to be?*” And the situation heated up and so they had to call security. Security called the police. So we had the police, we had child services in place and somebody else – social services as well, a social worker kind of thing, and the mother. The last thing that nobody thought was to bring an interpreter in. Finally, mother of the child, the woman, the young mother of the child, managed to get one of the men of the house to confront the police and tell them in English, broken English, what was the issue. It is simple: the mother cannot touch the baby because the mother is going to contaminate the baby and the grandmother must clean the baby. So there is a little ritual that – nothing mumbo jumbo thingy about it – but the grandmother has to cleanse the child before it’s given to the mother. That was it. Now the grandma came in and cleansed the baby and mother took the baby with her, everything was supposed to be well? No! Because now we have the child services involved, the social services involved, the police has to file a report, and the poor woman in that was detained because she was “rejecting the baby”. [Formal support worker 6]

He shared another story in which the harms to the mother were more blatant. The mother was jailed for a week for child abuse because she was following her cultural custom of diapering the baby.

A mother was taken to jail because she was “abusing the child.” It was just a few days old child and the nurse said the mother was abusing the child ... In this family, this culture, they held the baby by the feet and they cleaned the baby and then they put the diaper Fortunately it lasted only a week. It lasted only a week because at that time there was a foreign judge who was replacing the family judge at the time, and that judge, she was saying, “*How is that abuse?*” [Formal support worker 6]

Differences in child-rearing practices were raised by nurses who work with parents of young children, and the concerns raised reflect the literature on cross-cultural health care: choking hazards related to jewelry, and risks associated with family beds were two common ones.

One nurse effectively captured the tension between wanting to respect cultural practices and worry about the safety of small children:

With the babies, you know, there's a lot that some of the nurses get worried about with the little chokers and the threads and the bells, the pierced ears, like they're all not recommended. I never say anything. I, you know, I just feel it's not my place, I just feel like it would be disrespectful I guess of what they feel needs to keep the baby safe – like the painting the red marking for safety. [Public health nurse 1]

She went on to explain that with some customs, such as using car seats safely, not using crib bumper pads, and not smoking around a baby, she draws a hard line and is insistent that these are too harmful to be warranted. Other customs, such as sharing a family bed, are more difficult to navigate.

There's a really fine line between, well I guess an example is you know we're not advocating bumper pads anymore, and smoking around a baby – like I'd be firm with that, you know, we know that that's very dangerous ... I see most people now they're complying with that but I hear a lot of reports out in the community about bed sharing, do you know what I'm saying – like babies sleeping with the mom, like that's what they do like when they're babies in Africa, it's so hot women would say we just go out and lay down on the cold ground with our babies it's so hot. Well there's a lot, well, you're not supposed to co-share your bed. [Public health nurse 1]

Similarly, another clinician on the topic of family beds stated “I would give them the Canadian advice but I don't discourage them to continue what they're doing, like I say that to all families” (meaning, not just to newcomer families) [Physician 3].

Another nurse emphasised the importance of ensuring information about Canadian health expectations for infant and child safety must be communicated effectively in order for health care providers to be meeting their duty of care.

All of our documentation is only in English so we have a document that you have to sign for safe sleep, that we've told you that this is how your baby can sleep safely. And it's a liability issue. You go home and you said “*Nobody ever told me that the baby could be strangled by bumper pads in the crib*”, and now we have an infant who has died and the family is like “*Nope, nobody ever told me*” but you signed an English sheet of paper and you don't speak English – that don't make sense right. [Nurse 2].

As in the section on Indigenous care, controversy over culturally-distinct family practices also emerged around hospital visiting hours and policies. This is discussed next.

6.5.5 Visitor policies

Nurses reported having difficulties with cultural norms about visitation policies that are different from the rules that the local hospitals have in place. This story makes it really clear how different sets of expectations and different norms around what should be expected in a hospital can lead to tension and exacerbate mistrust and distance across cultures:

One of the biggest issues that we have is that we find people in other cultures don't want to follow any of our rules. So the biggest and most important thing and we get in fights, people are ignorant, they're rude, they abuse the staff and but our visiting hours and our visiting rules are the most contentious issue That you tell them, “*Sorry, there are no visiting hours right now*”, and they clip your head off, yell at you and walk in through anyway and it's a – the girls [nurses] feel, and I'm speaking for them but I've heard it too, that it's complete disrespect and disregard

for them and I feel that the people visiting feel the same thing, but we don't, like, we don't let the Newfoundlander people in and we don't let the non-Newfoundlander people in; but the people that like, there's heated violence on times when we ask people to follow the rules and it's a blatant disregard for what that is So right off the bat you have a negative connotation and then how do you build positivity of cultural diversity and allowing cultural differences when you feel as a nurse that you are completely disrespected and disregarded. So it's a very, I don't know, it's very contentious. I would say that happens every second day. [Nurse 2]

She goes on to explain the complexity of visiting hours with respect to cultural practices:

So their support person doesn't have to be their husband or their partner, it could be their friend; but then their friend brings three children and the children are literally running up and down the halls of the hospital and you go in five times and say *"This is a hospital. There are people here that could trip and fall. There are babies that could be in danger. You don't know where your child is, your child is in danger. You have to parent your child."* And you do that three or four times and the child is out as fast as you leave the room the child is out again right. It's supposed to be one [visitor] and then sometimes you go in the room and there's 15 people in the room. This could be Newfoundlanders too You got to have consistent behaviour from the staff, but the staff get beat down so much with the physical, with the verbal abuse that they take that after a while they give up Does it mean because you're from [names a country] that you can have four females caring for you because you don't care for yourself or the baby in the first four days after birth? Not really, because I don't have room for four of ya's in a four-bed ward! ... And I fear we basically put it all in a cookie cutter. We don't care what culture you're from, follow the rules right. So it's not like we're anti- any particular culture right. We have our rules and you have to follow them. [Nurse 2]

Visitor policies are often structured by who counts as immediate family; for this reason, differences around how family names work in different cultures has also been a source of confusion, as described below.

6.5.6 Naming systems causing confusion

Related to confusion over visitor policies is the question of who is considered to be a husband or wife and is allowed to visit in cases where visitors are restricted. In the province of NL, it is the cultural norm for a wife to adopt her husband's surname at marriage, a custom that is not common in many other parts of the world. One community support worker expressed concern at the lack of appreciation for other naming systems, leading to immediate family members having to argue for visitor access.

The names of individuals are different [in some cases the wife doesn't take the husband's family name] ... and in an emergency situation something urgent then they're not going to believe that she's the wife They bring the MCP card and of course the two MCP cards doesn't match, so, *"You're not a next of kin of that person"; "You're not family members so you're not allowed to be in the room"; "You don't have a say with the health of this person."* When it comes to family doctors, they [spouse] are not allowed to be in the room because their information doesn't match; so the husband and wife either way cannot assist each other or as parents. Sometimes a father cannot assist their child because their name doesn't match ... and *"You're lying to us"* that, you know, you say you are a family member ... and it really hard to carry around birth

certificates and translated birth certificates and even certified and notarized birth certificates.
[Formal support worker 6]

As the next section explores, some of the most contentious cultural differences are those around alternative health practices that people use in lieu of or in addition to Canadian biomedical treatments.

6.5.7 Alternative healing modalities

Patients commonly use their own healing systems alongside western biomedicine, and reported to us that they are reluctant to share this information with physicians who, in their experience, are unreceptive to this. The translator paraphrases what one participant said about why he would never tell a physician about his use of specific herbs for healing:

They [participant couple] think that there's no need to tell the doctor since it's something really good. It will not hurt even if you take an overdose or a minimum dose so it's not going to hurt them anyway so there's no need to tell the doctor for this thing ... They are saying that sometimes it's better not to say it because the doctors here have a lot of fears about their patients in a way, so they will ask a lot about a lot of blood work or something or they will have a lot of concerns about what kind of herbs are you taking, like you know a list of questions or a list of bloodwork, so they prefer not to tell them because of that. Yeah but if something happened and they took something and if something bad happened for sure they will tell that this is what happened or we because we drank this thing. [Refugee patient 1: man, Arabic speaking]

Many other participants reported that they had difficulties finding some key herbs, but continued to use what is easily available, describing a range of therapies for sore throats, coughs, headaches, stomach cramps, and repair of fractures. When asked about whether they share this information with physicians, most stated emphatically that this is not something they would ever share with a physician.

In response to the question, "Have you ever held back from telling a physician about your use of natural medicines because you weren't sure of their reaction?" one patient participant stated that she had tried at times to share this information but doctors are not receptive.

[Giving an example of what she might say to a physician] *"You know in [home country] we tend to [describes treatment]"* – and as soon as I say it, you know, they turn back, like *"What?!"* and that kind of complete, like, unawareness makes you feel like, oh wait a second ... Oops let's not tell it again, you know because it was not something that was even like, *"Oh really, tell me more about it, maybe I should read up about it."* You know it's just kind of: *"What? Oh. Hmm"* Yeah I've withheld information I'd say, just because I know that there would be no acknowledgement of it. There would be no follow-up on it. [Immigrant patient 7: woman, economic immigrant, student]

This participant has the same perspective, that a physician would simply not accept it.

Participant: There's other traditional medicine that works good, but in real life, you know, doctors they don't believe in it ... You can't go to tell a doctor that I'm going to use this because for them how come? ... For me, no, I can't tell a doctor that I'm going to use this.

Fern: So you wouldn't just tell the doctor?

Participant: No I can't tell. I can't tell. I can't tell him because he not accept, he not accept.

[Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

Others relayed specific circumstances under which they would share – if it were something very “serious”, as this woman reports:

If the medicine I used is something I considered serious and he's going to give me another medication I need to mention it. But if this is just something normal, like drinking water and salt, I didn't see it's, like, so needful to tell him. [Refugee patient 9: woman, Ghanaian]

This interpreter, in the context of a discussion on moral distress when knowing that a patient has withheld information from a physician, recounted this story. A pediatric patient's father thought the doctor had terminated a particular prescription, but the doctor had meant that he wouldn't fill it again until they came back with the empty prescription bottle showing that it was used up, a mix-up that resulted in a child going 2 months without essential medication for a very serious medical condition. The father was quite angry because the treatment would have to be started all over again. He told the interpreter that that he should instead use traditional remedies for the condition:

He told me, *“You know what, I should do something ... I should just get out of the city and let her walk on the soil, like just on soil without any shoes, so that would help the [describes a physiological process related to her condition] and that's it”,* you know. And I was, like, *“Are you speaking seriously?”* and he was like *“Yes, yes she didn't need any of those medications”* ... and he was insistent that this was the proper thing to do for this patient, but he didn't tell the doctor. I was like, *“You can tell the doctor that”* and he was like *“I'm not going to tell him because you know he would kind of make fun of me.”* [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

Another interpreter and support worker is of the opinion that over time, as patients get more familiar with their physicians, they will disclose their use of traditional medicines.

When the clients are really new here sometimes they will refuse to take, not refuse, they will, they're not used to maybe to use the medication ... So they will say *“No, we'll do our traditional therapy for a while and then I will see”* ... When they have that good relationship with the family doctor after seeing her five, four times then they will not be hesitant to tell her, *“Oh we have in our home we use this and this.”* [Formal support worker 2, Interpreter, refugee patient]

One informal patient supporter described a patient who had recounted to her how a broken arm would have been dealt with in his country, explaining the importance of having physicians listen respectfully to learn what treatments would have been tried in the homeland.

I mean for the doctor to be able to acknowledge, *“Oh, okay,”* you know and to validate: *“Okay, that's what you did, that's interesting and if you want to also make the tea with the lemons, you keep doing that. But we also find that here, that taking this inhaler you know for asthma, or this antibiotics or whatever is very, very helpful”*. So just an acknowledgement that, *“Okay, we don't think you're crazy because you put bread and a cloth around your arm, it's what you did, and we have another thing that may be helpful here so can we try this.”* [Informal support worker 1]

By contrast, one health care provider, when asked about traditional medicines, responded to the question in exactly the dismissive way that patients had reported, in their description of how patients don't ever say what traditional medicines they are using.

I know that with a lot of cultures, there's beliefs about things that are medically inaccurate so we actually spend a bit of time trying to dispel medical myths, you know, people being ostracized for behaviours that have a medical cause, thinking of possession and that sort of thing, or that you know demons did this and this is a punishment for this or that, right. I can't comment on the use of complementary medicine – I'm not asking what else are [patients] doing and people aren't bringing it forward I ask what drugs or what medications are you taking and nobody has ever offered ... I haven't had people bring forward any traditional medicine.
[provider ID withheld in case of potential breach of confidentiality]

Despite some of these more dismissive attitudes, many health care workers are very interested in and concerned about providing culturally competent care. The next section discusses this worry among health care providers.

6.5.8 Provider distress at wanting to do better with culturally competent care

There were some stories of providers who had gone out of their way to understand and address the cultural or religious needs of patients.⁴⁴ This patient and patient supporter recounts with humour how a helpful health care worker actually got the culture wrong, but was highly appreciated by the patient and family for her efforts:

My mom for instance had to see a dietitian last week and she came back and she was very, very happy and I was like why and – we thought it was adorable – the dietitian probably had read my mom's name, and managed to figure out what part of the world she's from. I don't know how she did that, if it was a Google search or not, I don't know ... I thought that was very nice of the dietitian to do that and she was a little bit off – She assumed my mom was from [names a region of the world] ... And my mom laughed, she's like *"You're very close, I'm [names another region]"*. She [dietician] said *"I'm so sorry about that! You see I actually prepared a diet chart based on [incorrect region]"*.... My mom actually left the clinic with a realistic goal of what she should do in terms of food rather than have to change her entire routine based on I guess a North American diet, like you know mashed potatoes or like tea and coffee; but this dietitian went a step extra. [Immigrant patient 7: woman, economic immigrant, student]

We were struck by how often we heard patients express concern for health care providers who are concerned about "getting it right". Patients and patient supporters worry about the distress that health care workers feel when they do not know enough about culture or religion or have made a mistake in terms of providing culturally appropriate care. One support worker reported that she has received phone calls from physicians wanting to double check that what they had done was correct.

⁴⁴While patients shared small anecdotes, Eastern Health's Storyline featured a story that is a fitting example of staff going out of their way to understand another's culture. "Finding Lachhuman: Embracing change, culture and friendship" (EH Storyline, March 23, 2017) is a story told by Brian Pinsent, an LPN working in long-term care, who describes his experience in cross-cultural caregiving as he develops a relationship with a Nepali refugee resident.

I feel lots of them [health care workers] they have questions, they don't know where to go so they call me and they say *"We felt they [patient] are not really okay; can you check with them, were they comfortable with what happened?"* [Formal support worker 2, Interpreter, refugee patient]

She went on to say that in her opinion health care workers require additional emotional and educational support on cross-cultural care, because providers are feeling distress out of their concern that they are not providing culturally competent care. She referred to a specific case of a health care worker treating a Muslim woman, whose husband was becoming aggressive. The husband had been speaking very loudly to his wife, and became increasingly loud throughout the discussion so that even the physician herself was becoming afraid:

They [providers] have lots of questions during the appointments and even after the appointment: *"Was that okay? So was it okay if he speaks loudly with her?"* ... They are doing really good with the clients and they are, like, really accurate and they want to, they are really trying to take care of the cultural differences, but at the same time you feel they need something to support or just to touch base with. [Formal support worker 2, Interpreter, refugee patient]

She went on to explain that it is clear that many health care workers are trying hard to understand about culture and religion and to be accommodating, but those who have had no orientation or experience are left floundering and unsupported during patient visits. She commented that eventually when enough health care workers develop experience working with patients from other parts of the world they will be able to provide peer support and this will alleviate some of the burden.

We asked one health decision maker about whether, in her experience, health care workers are generally accommodating or dismissive of cultural differences, and her response echoes the concerns of patients and providers – that, if anything, health care workers struggle with wanting to do more and not having the resources to support them in that endeavor:

I haven't heard anything really negative. I think the negative that I hear is the people wanting to do so much more but not feeling that they have the resources to do that and thinking that if they only had that, what a difference they could make, you know. [EH decision maker 4]

This social worker emphasised that health care workers are very, very concerned about cultural competency and not inadvertently causing harm to newcomers:

People are also interested in, *"How do I be respectful?"*, *"How can we develop collaborative relationships with clients?"* ... My feedback from people [health care providers] is – *"Oh my God we get these referrals, we read the history here, we're not quite sure what to do, we don't want to do any harm."* People are really worried that they're going to be inappropriate or insensitive, which is kind of the reason you know I think people maybe are even a little overboard about that, honestly; but it's kind of a good reaction ... There's always an enthusiastic bunch that want to learn more and do more. There's an interest in skilling up, there's an interest in becoming aware from a large number of clinical people who are just saying, *"God I'd really like to do some of this work I'm really interested in but I don't feel I know or I don't want to be insensitive"; "I*

don't want to be, you know, this type of culturally dominant blunder that's going to be stupid about it". [Social worker 1]

He went on to describe how patients are very forgiving of provider blunders.

My experience is most of the people [patients] I've worked with have been extremely forgiving of my stupidity, you know ... I've never felt judged by a patient. [Social worker 1]

Perhaps most importantly, he – like the patient supporters quoted above – pointed to the need for compassion for providers who are trying so hard to be culturally competent.

It's good that there's a sensitivity to power imbalance, but people can be a little hyper focused about it and it almost needs – it's like people need permission to make mistakes People need permission to say *"I don't know everything. It's impossible for me to know everything about any – every culture. I don't understand my own culture"* you know. But really what people need is permission to be respectful and curious and try to understand and try to figure out how that works. [Social worker 1]

This nurse and manager explains how nervous staff are about making an error:

The staff are nervous about the cultural [aspects of providing care to newcomers] ... It's the unknown ... Nurses don't like not being comfortable. They will not do it if they are not comfortable. The reason is because they feel like they're the last buck in a lot of places and they are the one that is then providing the care. They will be the ones that their association is going to come back and judge them by a standard if an error occurs or an occurrence or an adverse outcome happens. So they're very nervous when they're not comfortable. [Nurse 2]

One clinician felt it would be useful to have someone to check in with, to provide support to clinicians who are feeling afraid of inadvertently doing something wrong in providing cross-cultural care.

It's more the families that you're meeting for the first time that you're worried that you're not explaining it properly and wondering, *"Hmm, am I doing a good job? Am I providing, you know, complete care, comprehensive care?"* So it would be nice to have somebody there to you know validate how you're feeling. [Physician 3]

Many health care providers are very concerned with providing culturally safe, competent, and humble care. That said, participants had had many experiences of discrimination when accessing care. The next section looks at some of the major forms of discrimination that came out of this research.

6.6 DISCRIMINATION

We asked about the experience of discrimination – patients feeling like they were being ignored or treated poorly because of language barriers and/or because of being minority newcomers – and three themes emerged: (1) feeling unable to be assertive with respect to treatment because of the precarious residency status; (2) physicians assuming patients are ignorant about their own health, when it is physicians who are uninformed about global health; and (3) physicians equated being a “refugee” with being rural and illiterate and incapable of self-care. Each is now discussed in turn.

6.6.1 Feeling unable to be assertive because of the precariousness of residency status

One mother told the story of how she was not communicated with because health care workers found it easier to ignore her rather than try to explain what was going on with her sick child across a possible language barrier. The mother believes that the staff felt they could get away with not making an effort to keep her in the loop because as a newcomer she would not protest the lack of attention.

Her small child was having an operation. She was told that the procedure would take about half an hour, and once the child woke up they would come and get her and she could go to him. She was told to wait in the waiting room in the meantime. After two hours, she asked staff what was happening; she was told that the staff didn't know, and that she was to sit and wait for the doctor. A couple of hours later, she again asked about the status of the child and was again told that staff knew nothing and that she was to sit and wait. She continued asking, to no avail. After six hours of waiting, with other children coming and going all day for this routine procedure and the mother becoming increasingly frantic about the status of her child, a doctor finally appeared and explained that the child had had complications. The mom expressed her frustration at not knowing whether she should ask, whether it was her right to know the status of her child.

Participant: That's part of the problem. I say it twice [asking the front desk staff what is going on and why there has been no news about her child]. I don't say it the third time because I don't know the rules. I don't know how the system work I'm the mother and I have all the right to know what's happening in the surgery room I keep going forth and back like what's happening, I need to know, and she just give, like, send me back, like *"I don't know, just please take a chair. When we have any information we will call you"*.

Fern: Do you think she was being more dismissive of you because she didn't know how to tell – What do you think was going on?

Interpreter: Yeah since they know that she's not from here, so she's not familiar with the system, she's not familiar with the rules, she doesn't know what to do so then in this case I will not even make an effort, like as a nurse or a receptionist I will not make an effort and go ahead and ask what is going on, so I'll just ask the mom to get back to her seat and sit down ...

Participant: I remember I ask her like twice, like *"Miss can you call somebody or the doctor to come to meet me?"* and she said *"Okay I will call him. Can you go back and sit?"* but still I was crying all that time, actually every time I was come to ask her I was crying all the time ... She's a nurse so she can go to other room and check with other doctor or check for my child because she knows all his information. She can just go to the room and see what's happening and come to tell me all the details. I feel that she was actually very mean with me. [Refugee patient 6: woman, Arabic speaking]

Newcomers are in a position of relative powerlessness because of their precarious residency status, and also are grateful to the host nation, which may make it difficult to stand up for their rights in a health care setting. In this interview with a patient, the interpreter recaps what the patient participant has just said:

People who are fluent in English and can speak English, they usually yell at the receptionist, or they ask about their rights in a way, that they pay taxes. But with his [patient participant]

situation, he can't really yell or shout at people at the hospital to make it faster ... It's not like a fear of like being out, kicking him outside the country; it's just like a feeling that it's like, I'm a foreign person so I shouldn't do this because I'm not in my home country. [Refugee patient 6: man, Arabic speaking]

When the participant was asked his opinion on how long one would need to be in the country before feeling free to speak up, he said when the person is able to work and pay taxes and is no longer receiving help from the government, then they would likely feel freer to demand their rights.

Another participant, describing the feeling of being dismissed and not taken seriously, said:

They know I don't know the system and I don't know the rules so they just tell, you know, shooing me away like you know. I think this is the most [important] thing. [Refugee patient 6: woman, Arabic speaking]

When asked about her general approach to asking for health information about her child in the hospital, she stated:

That's part of the problem, I say it twice [asking for information], I don't say it the third time because I don't know the rules. I don't know how the system work ... I wasn't tell [told] anything. [Refugee patient 6: woman, Arabic speaking]

She went on to explain that she tried not to seek assistance from ANC and was trying to be independent. Given that her English is quite good and she is educated, she felt she should not burden ANC; and then, when she couldn't receive answers to questions about her sick child in hospital, she felt that it was her fault because she hadn't effectively asked for support in advance.

I'm trying you know to be independent and learn how to be by myself because you know they [ANC] have a lot of people to take care of, and I think it's my responsibility because I already speak English and I'm well educated, so I have to you know go through it and learn what I have to do since they [ANC] have other people, most of them they can't speak or they can't, you know, understand what they have to say. They have lots of people to help. I think this my problem. This my fault because I don't tell them first [i.e., doesn't ask for assistance from ANC when taking a child to the hospital]. [Refugee patient 6: woman, Arabic speaking]

In a discussion where she was relating how staff give her odd looks when she makes certain privacy requests, she emphasised the importance of being strong in the context of such relative powerlessness:

I don't care [about receiving "weird looks"], like I think I'm strong woman enough to, you know, push everybody away, so, she [health care worker] said *"You want to close [the door, for privacy, during bloodwork]"*? I said *"Yes please"* with strong tone, and she just turned to the door and closed it ... We are having a very hard time with the wars and running from the dead people, and you know we're survivors, so I can survive with this mad look – I don't care about this you know, it doesn't matter. It doesn't bother me at all. [Refugee patient 6: woman, Arabic speaking]

Patients sometimes struggle to assert themselves in health care settings. But as the next section shows, even when they do, physicians and other health care workers may treat them as if they do not know what they are talking about.

6.6.2 Physicians assuming patients are ignorant about their own health

Some patients/supporters reported that they believe that family physicians tend not to trust the opinions of patients and assume that patients do not have a correct understanding of their own health care. Sometimes, this was because family physicians were actually not familiar with global health issues, such as variations in the types of infections or parasites that an individual might have. Importantly, it was not the lack of such knowledge that was a concern for patients or supporters; rather, it was having the patient's own opinion dismissed as uninformed or uneducated that was the issue.

[When a patient presents to the doctor and reports that they likely have a condition that is common in their own country but not common in Canada] often times most of the family doctors simply says to the patient, *"No we don't have that here. It's impossible that you have worms in your belly because we don't have that here" "You can't have that type of infection because we don't have that here for years and years, we eradicated that so it has to be something else."* We've had that kind of conversation with patients, and it's mostly family doctors ... What happens is the patient, sometimes mother is diagnosing the child, right: *"But my children has that, and that's why we're looking for a treatment for that."* And the doctor is like, *"No, that doesn't exist, it's impossible that your children has that."* ... They don't consider it. They just disregard it. They don't consider the father and mother's diagnosis, [they dismiss it as] mumbo jumbo. [Formal support worker 6]

At other times, patients told us, physicians treat them as if they are ignorant because of the assumptions patients have about the Canadian health care system, because the physicians are not aware of how the medical systems of other countries work. They do not sufficiently appreciate that in the context of the world's countries, the Canadian health care system is rather unique; it is not the case that newcomers will know the unspoken rules. This is not because others are uninformed about how health care works; it is because the physicians are uninformed about how health care works in most of the world.

Let's say "silly questions" that the patient will ask; I'm not saying [that the questions are] silly but I mean like for here [Canada] it's silly to ask, like *"Can I buy this antibiotic without prescription?"* Like in our country that's okay, that's fine, you can buy it – but here like *"Oh my god that's so silly, like how could they think a person can buy an antibiotic without prescription?"* you know. I mean like they [doctors] can read more about the culture itself or the country itself, since there is a lot of refugees from Syria [physicians] can read more about the health care system in Syria ... and see what is the differences and then you will be prepared for those questions that the patient will ask and not feel and not letting him or her feel that they are really silly when they are asking these questions. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

One reason physicians might treat newcomers as ignorant about their health care needs is an assumption that all refugees are illiterate and uneducated. This is discussed next.

6.6.3 Physicians equating being a "refugee" with being incapable of self-care

Discrimination by family physicians was also experienced in the form of physicians making assumptions about what it means to be a "refugee", with patients and supporters feeling that physicians were

lumping all refugees together and assuming that they were rural and illiterate and that this “poverty of knowledge” was the reason why appointments are missed. This interpreter explains.

I don't feel comfortable when I'm dealing with a family physician [compared to] when I'm dealing with other specialists ... Rarely I find a family physician who is really friendly. I don't know why is that, but I went with several patients and I feel like they're always like so strict ... I have this feeling, I don't know, like, *“Oh those people do not know anything. Those people are coming from a new country”* – like I feel like we are, because I'm from [names country of origin] so I have this feeling like I want to tell the doctor, *“Hey, like see we're not still living in tribes and those stuff you know; we have technology, we have everything and we are good people – stop doing that”*, you know I don't feel that the patients here are really relaxed when they are meeting their family physician, while it should be the contrast. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

Issues of trust and belief are crucial to effective health care relationships. As the next section explores, there are various additional cultural reasons that physicians do not trust refugee patients, and patients do not trust the Canadian health care system or Canadian-trained physicians.

6.7 MISTRUST AND NONADHERENCE

Providers are concerned about patient noncompliance and particularly with the frequency with which patients miss appointments. On the flip side, patients report not fully trusting the Canadian health care system. They say they may ignore physician advice when it appears to be uninformed about the patient's experience of sickness. They are frustrated when they miss appointments and then face fees and long wait times for appointments. Patients commented frequently on how strange the Canadian medical system is compared to what they had been used to in their home land or in the other nations that they had lived in.

For patients, a key source of frustration is that Canadian health care providers do not seem to understand that the Canadian system is unusual compared to many of the world's health care systems. They find that providers fail to appreciate that patients' assumptions about the kind of care they expect to receive are well founded and based on long experience with multiple other nations.

The long wait times to see a specialist, the lack of access to medicines at a pharmacy without a prescription, the use of a “wait and see” approach rather than prescribing medicines or tests, and the rushed nature of clinic visits – all aspects of a socialized approach to medicine where stewardship of health care resources is a key consideration – were commonly cited as bewildering and unusual aspects of the Canadian health care system.

A patient shared this perspective:

There is a difference between Canada and my country. Here, if you're sick, say with a headache, you can go to the hospital and even if it's not all that serious you need a prescription to go to the pharmacy to get medicine. You can't go to the pharmacy and say *“I'm sick, I need this particular medicine”* – no, they aren't allowed to give it to you. That's the big difference. In my country, if you're sick and you don't have time to go to the hospital or to see a doctor, you can go and get the medicine and just see if you feel better, and if not then the next day you can go and see a doctor. You can just go to the pharmacy and say *“I have this type of stomach ache”*

and they'll give you medicine; and only if that doesn't work would you go to the doctor. You can wait and see how you feel and go to the doctor the next day if the medicine doesn't work.
[Refugee patient 11: woman, Swahili speaking]

A second patient had a similar observation:

Back home you can just go to the pharmacist sometimes and say to him that *"I have this symptom"* and he will directly like give you a kind of medication that will be good for you; or even going to the doctor who will prescribe something directly you know. But here they prefer not to prescribe a lot of medications, usually they will prefer, like, to leave the person to deal with it, let the body deal with it, while maybe if you prescribe something that will be easier, like that would take two days rather than taking 15 or 20 days to be good. So [I] found this problem with the system here. [Refugee patient 3: man, Arabic speaking]

This same individual gave an example of going to the doctor in his home country following an accident and injury to his hand and receiving surgery and recovering quickly, whereas in Canada he injured his leg and was told to go home and take pain medication. For him, this contrast is an example of how the Canadian system is not as effective as other systems are. He stated this as a way of emphasising that Canadian doctors who assume that patients have uneducated or unrealistic demands are themselves uninformed about how medicine tends to work globally. This patient/supporter had the same observation:

Of course it's a different health care system [in previous home nation] as well. You could call someone up and you see them within a week, maybe even less, and then whatever medications are prescribed to you, you can call for a follow-up just as quickly as well. If you try something out and it's not working for two weeks you can call your doctor up and be like, *"This medication is making me break out, what do I do?" "Come on in and let's talk about it"*, as opposed to here being seen by someone to just have that question clarified in another 4 or 5 months. That is definitely something that really sticks out here, really. [Immigrant patient 7: woman, economic immigrant, student]

One patient observed that the new generation growing up in Canada would be used to the Canadian system and would not see how unusual the Canadian system is: *"the new generation, they will adapt to this kind of medicine and to this way of dealing with patients or healing patients"* [Immigrant patient 7: woman, economic immigrant, student].

One of the different cultural expectations around medicine that generated the most confusion and frustration was that of missed appointments, which are described next.

6.7.1 "Missed appointments": Reframing as a Canadian cultural issue

In much of the world it is common and accepted that a patient may be late for a clinic appointment, or may not show up without calling to cancel; patients simply call and rebook and would get another appointment in the near future. For newcomer patients, the idea that being a few minutes late for an appointment could be a problem, is foreign. In countries where there are no wait times to see physicians, or where walk-in pharmacies provide much of the care that is restricted to physicians in Canada, it may not occur to patients that missing an appointment can have serious implications not only

for them as a patient needing care, but for other patients who could have availed of that appointment time⁴⁵.

For physicians we spoke with, missed appointments was seen as a significant concern, and was generally attributed to the “culture” of the patients – different cultural norms around keeping time, and a lack of understanding about the need to keep appointment times. Family physicians are reluctant to take on refugee patients because “the culture and ... sometimes the clients are late, they don’t show up, they call last minute and cancel the appointment” [Physician 2].

However, from patient perspectives, it is the culture of the *Canadian* medical system that is odd and is the reason for “nonadherence.”

In our country, we didn’t used to come exactly on time, like we are able to come 10 minutes late or 15 minutes late, that doesn’t matter; but here if you’re late for 1, 2 minutes ... you will be asked why you are late [Refugee patient 1: man, Arabic speaking].

I remember my case when I came I had a problem with my [names physical condition] and they give me an appointment [for 8 months later] ... I said I can’t wait until eight months ... This is different from the place that we come from. [In this case, the patient declined surgery and used You Tube videos to strengthen and heal the area of concern, rather than deal with the lengthy wait] [Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

In our country we just used to cancel appointments without calling or something ... It’s easier in our country to book an appointment with a doctor – you can just call his secretary or her secretary and just say “*I need an appointment*” and they will give it to you within two weeks, it depends on the schedule, or even sometimes like a day or two. So here, people do not have this idea that, okay, here to book an appointment with a specialist it might take months you know, so if you cancel this appointment or escape it so then you will not have the opportunity to book this appointment for like another six months. So they do not have this idea about how busy specialists here are. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

The ANC staff we spoke with reported that they make a great effort to impress upon clients the importance of not missing an appointment.

The clients, when they come in here, it’s a totally new health care system for them so it takes time. We do information sessions, we visit them, we explain a lot about the health care system. You can’t miss an appointment. It’s very important. If you have to miss the appointment you have to let us know, you need to let someone who speaks English know so they can call rebook or reschedule the appointment for you It takes lots of time and lots of information sessions and we’re explaining to them, and it’s working honestly. For example, the 300 who came in 2016, now they are way better. They know if they don’t want to miss an appointment, if they have anything and they get a missed appointment they contact me, they contact someone, just

⁴⁵The implications of the missed appointments for physicians in a fee-for-service system is discussed elsewhere.

try to rebook the appointment. But mainly it's interpretation, honestly, it's a big challenge.
[Formal support worker 2, Interpreter, refugee patient]

It is frustrating for patients to be treated as if they are lazy or ignorant because they miss an appointment.

I mean, those doctors have in their minds that, okay those people are or came from countries that there's no rules, they do not know anything about health system, they do not – just, like, they enter any clinic they want or even, you know, but we are not like that – but here the system is more strict ... the doctor's being angry with them or saying *"I'm not going to see you anymore because this is the third time that you cancel, or you even didn't show up in your appointment"*.

[Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

This interpreter went on to explain that this is particularly frustrating when the reason for the missed appointment is the lack of appropriate communication by Eastern Health.

6.7.2 Lack of trust that doctors are providing quality care

One interpreter explained that many newcomers do not put a lot of faith in Canadian doctors who seem to have no appreciation for the lived experience of sickness in the context of a life of political violence, unsettlement, and resettlement.

The newcomers that I've spoken to about, you know, they'll jokingly say *"Oh physicians here they'll tell us to do all these you know things, like, we never dreamt of, like we feel depressed for instance and they'll say 'oh go exercise'"*. And according to them [patients] that is not, there's no connection whatsoever or, you know, they [physicians] may say *"Go and sit in the park and be in touch with nature"*, for instance. For them [patients] these things don't register, so they're unable to see where the physician is coming from, and then they can draw their own conclusions that the physician is not qualified enough to serve them [Immigrant patient 7: woman, economic immigrant, student].

He goes on to speculate that patients in this situation will continue to seek care elsewhere, or will not show up to appointments where they feel they have not been appropriately cared for, and therefore put a burden on the health care system in terms of wait times.

Another interpreter emphasised that a long wait time to see a specialist is sometimes taken as a sign of inexperience or ineptitude on the part of the referring physician.

I remember, a refugee from Iraq she was explaining ... that sometimes you can come to the hospital, you see that your son is sick, and they just give you the appointment of three months, four months – and for a mom, she knows the thing that this is not right, you know. In the home country if someone sick and you come there so they have to treat you immediately; but here is different, you can come and they give you an appointment maybe two months after, three.

[Refugee patient 8: formal and informal support worker and interpreter, man, Swahili speaking]

This patient and interpreter, describing how patients often see Canadian physicians as poor-quality practitioners, theorizes that physicians in Canada may be reluctant to treat out of fear of making an error and being accused of negligence.

Most of the people, of the refugee people – and I’m sorry to say that – they have this idea about, like, Canadian doctors they are not good, they are not good and they do not have, like – Syrian doctors are better. They can prescribe whatever we want. They can find the problem directly, they can – you know. Here, people [doctors] will just do a lot of tests and go through a lot of things and ask several people, and I found this actually, because maybe in my point of view that doctors here are afraid about doing something wrong with the patient I’m not saying that they are, like, out of ethics or something; no they are not. But they will be, they are, strong enough to do something without this fear; so they will be able to say this is the thing or this is what I’m going to do but here they can’t do anything at the emergency. The doctor will come and then this doctor will ask another doctor and another doctor will ask another doctor so it will be a decision of, like, seven people. While in Syria, no, a doctor can come and say this is the thing directly you know; and most of the time will be that this *is* the thing because they have this experience ... So yes, refugees here, we all have this – that doctors here are not really, or even if you ask a doctor a question he will say *“This is not my speciality so I can’t answer it”*; but in Syria they can answer it, they have really wide view about everything. [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

These stories illustrate the need for doctors to explain to patients about why they are not prescribing or why they are taking no action but instead referring the patient elsewhere – in the absence of such explanations, patients will assume physicians are not effectively trained.

The lack of time spent with physicians, and the lack of prescribing medication to the extent that patients were used to at home, was particularly stressful in the case of one mother, whose experience led her to identify a physician who was, for her, too dismissive of her concern. Her two toddlers had been very sick with a high fever for a week. During that week, she had taken them to the ER on three separate occasions. Each time she was told that it would run its course. The mother reported that this was followed by three months of the children having fevers off and on, not eating, not sleeping well, having difficulty breathing and gaining no weight at all, with the mother growing increasingly agitated but recognizing that going to the ER was to no avail.

By coincidence, the children had an appointment for a hearing test around 3 months into this. That health care provider referred her to ENT. Two weeks later that specialist appointment occurred, and it was discovered that both children had very bad infections of the tonsils and adenoids.

Then the doctor [specialist] asked me, like, *“Why you didn’t bring them to the hospital because they have a bad situation!”* and I told him, I told him I actually did bring them here three times to the emergency and nobody give me anything, just tell me, *“Use that Tylenol.”* And they [specialist] said *“Oh it’s the [first] doctor’s fault and they have to give them antibiotics from the first time”* So I was like, have a lot yelling, screaming with the doctor [that is, the first doctor], you know. I tell them we bring our children from the war just to protect them and here they were sick for three months and nobody, you know, give me the right answer like what’s happened. [Refugee patient 6: woman, Arabic speaking]

She described the strain that it put on her to have the children so sick for so long.

I don’t want to see my child suffering every day ... You know especially sorry, you know it break my heart to see them – they want to eat but they can’t and they just keep crying and crying all the

day long or 24 hour they don't get enough sleep, they didn't get enough food they want to play but they can't because they don't have enough energy. It's killing me and I notice this affected for them development. [Refugee patient 6: woman, Arabic speaking]

A lack of trust in physicians means patients are less likely to adhere to the prescribed treatments, as the next section explores.

6.7.3 Lack of trust leads to non-adherence

Non-adherence to treatment plans results from this lack of trust in the health care system. These patient supporters explain:

When the clients are really new here sometimes they will refuse to take, if they're not used to using the medication so they will say, *"No, we'll do our traditional therapy for a while and then I will see."* [Formal support worker 2, Interpreter, refugee patient]

We'll come away [from clinic visit] with prescriptions, say it's a prescription for an antibiotic and an inhaler and something else, a pain medication ... So I'll make sure okay we got the prescriptions and so on and I'll bring it home with them and open it up and I'll get my friend [interpreter] on the speaker phone to say *"Okay now this inhaler, they're supposed to do it this way two times a day and they're supposed to do this tablets three times a day"* and whatever, whatever. So we get it really clear. And I go back to visit three days later – nothing. They didn't take any of the tablets, they didn't use the inhaler, and they didn't do any of it. So maybe the person is no better. I say, *"Okay, like why?"* *"Oh the doctor doesn't know what they're talking about."* Okay, okay so why does the doctor not know what they're talking about? *"Because in my country we would do this, this and this if they had this and now the doctor is saying do this."* So they're not believing that this is actually a good idea, right. [Informal support worker 1]

This informal patient supporter believes that doctors need to focus on building trust with patients. Building this trust is key to ensuring communication about the rationale for the western biomedical treatment being prescribed, in order to enhance adherence to the prescribed treatment. She gave the example of someone seeking treatment for a broken arm. In Canada, she explains, the treatment would be something like x-rays, a cast, and physiotherapy. By contrast, the patient may be expecting the treatment used in the home country, where healers would have applied a bread poultice.

You can see that it's two completely different things. So I'm not saying the doctor here can send the person home and say put bread and tie it in a cloth, I mean clearly this is not what we do. But if the doctor understands that the treatment that may have been recommended in their country was a lot different than what we're recommending here, how do we get the person to a place where they can trust and believe that what we're suggesting is likely going to be very helpful. [Informal support worker 1]

In her experience accompanying patients, the lack of trust is exacerbated by physicians' dismissal of, and lack of clarification of why, patients are declined treatment.

I think when it's the non-compliance and I will go back with the person two weeks later and the doctor will say, *"Okay, so did they go get the test, or did they take the medication?"* and I say no they didn't, and then it's like the eye roll ... People would be fairly reluctant [to explain why to the doctor] and they may tell me in their own home some of the things, but if they're here for a little

bit of time they make feel embarrassed to tell the doctor that we put bread [for the broken limb], like they would tell me and I would go okay that's interesting. But if they're here for a period of time they will know that telling a doctor here is not a good idea, that's not a good – the doctor may think that they're whatever. [Informal support worker 1]

She goes on to suggest that another way to ensure non-adherence to treatment is to encourage follow up visits so that the doctor can determine whether the treatment was followed, and to explain further the need for it, in cases where the treatment has not been followed:

My doctor gave my daughter, when she was young, an antibiotic for two weeks ... and that's it, she doesn't need to go back and be rechecked. And the doctor wouldn't ask us to come back, but in these cases if the doctor could say, *"Can you please come back in 3 or 4 days, I want to see how you're doing, can you please bring your medications with you?"* And the doctor will soon see that none of the tablets are gone, or there's two tablets gone, or the inhaler is not opened or whatever, and be able to talk to the person and so, *"Okay I can see that you haven't used this"* or *"You used it and you stopped"* or whatever, *"Can we see how you're doing and maybe see if we can get you to start using some of these things?"* [Informal support worker 1]

She emphasised the importance of the doctor acknowledging and validating the patient's own experiences and narratives around what healing means for them, as a way of building trust and therefore encouraging adherence to prescribed treatments.

6.8 CONCLUSION

In this section, we reported on the challenges faced by newcomers to the province, particularly for non-English speaking refugee patients. We focused on logistical barriers to accessing care; language barriers and interpretation challenges; challenges posed by cultural differences; discrimination; and mistrust with care. The stories told point to the need for support for staff, who are working hard to do the right thing in a system that, many feel, has left them largely to their own devices. For patients and patient supporters, the need to create a structure within Eastern Health that can more seamlessly align with existing community structures (such as the Association for New Canadians) and have patient needs driven by community experts, is key. Most importantly, for patients, patient supporters, and frontline staff, there is an urgent need for cultural competency training that emphasises, first, an appreciation for the lived experience of sickness in the context of a life of political violence, unsettlement, and resettlement; and second, an appreciation that the Canadian medical system itself is inherently political and cultural.

7 RECOMMENDATIONS

Eastern Health has done something that is important, timely, and brave, in entering into a partnership with patients to assess the state of cultural safety in its organization.

In terms of access to health care by refugee newcomers, there is a need for leadership, structured program and policy development, consistency and communication of practice, and direction and support for health care providers. For the most part, patients are feeling that health care providers want to help them. Front line workers are concerned that they are inadvertently providing substandard care. We found overwhelmingly that health care providers and decision makers want to help and want to do the right thing, but very often they don't know what to do and don't know where to turn for advice and support. The key theme in terms of access to health care for refugee patients was connecting various diverse pieces of ad hoc programming, and having a structure and leadership to implement and drive practices, policies and programs to support culturally safe care.

In terms of Indigenous patients receiving care at Eastern Health, the infrastructure, programming, and leadership within Eastern Health—experienced by patients primarily through the Aboriginal Patient Navigator Program—is by all accounts stellar. However, at the same time, the experiences of patients are strongly of being marginalized by, and having mistrust in, the health care system in general. Moreover, we heard repeated stories of patients being subjected to discrimination and racism by front line workers. It is difficult to locate the mistrust in the health care system *in general* solely within Eastern Health, as the experience is a pan-provincial experience of being resettled to receive care in the St. John's region. Therefore, some of the solutions will need to include pan-provincial strategies.

Recommendations for improvement within EH fall into five key areas of concern: (1) create an obvious governance and leadership structure; (2) educate health care providers; (3) carefully consider the vision for refugee patient navigation; (4) provide sufficient professional interpretation throughout the Eastern Health region; and (5) promote an organizational culture of cultural safety by emphasising cultural humility and relations of power.

This section contains general recommendations as well as specific guidance. References to the literature are provided in an Appendix, to guide EH with setting its priorities and directions.

We refer to quotes from health care providers and leaders in this section. This is not because this is solely where these ideas originated; the stories told by patients and providers, captured throughout this report, have culminated in these sets of recommendations. We apologize to all participants if we have missed something important to you.

7.1 CREATE AN OBVIOUS GOVERNANCE AND LEADERSHIP STRUCTURE

If the cultural diversity isn't owned by someone, nobody owns it, it dies. So who owns it? And if I own it, how do I keep my foot on my gas pedal that helps everyone else keep thinking about it? Because I got 180 gas pedals, I don't need 181. So what is it that we can do to support people to not have to figure it out themselves? [Nurse 2]

The value of connectedness is key to success for the kind of system-wide approach that is required with cultural safety. Connectedness is one of the core values of Eastern Health. Connectedness means “recognizing and celebrating the strength of each part, both within and beyond the structure, that

creates the whole of Eastern Health”⁴⁶. Yet lack of ‘connectedness’ in this sense was raised time and time again—by patients, community patient supporters, staff, and EH leadership—as being a significant problem with respect to diversity programming and cultural safety.

EH must provide clear leadership, governance, and accountability with respect to diversity. There needs to be a clear structure and programming throughout EH. The current system is scattered with no clear ‘home’, vision, or leadership.

Diversity programming within EH has been organized in a somewhat *ad hoc* manner, primarily based on which leaders have had a personal passion for the issue. HR is responsible for the Diversity and Inclusion Committee because the Chair (who had been involved in the early days of the Diversity Working Group of HCCSJ) happens to be staff in HR. Bilingual Services are under that same VP; but a different VP has Cancer Care (where the Aboriginal initiative, Big Land, was centered) and she also has Professional Practice and is responsible for the APN program. In terms of a mandate, it does make sense that the Cancer Care program’s Aboriginal initiative and the Aboriginal Patient Navigators both fall under the VP for Professional Practice, but this is by coincidence, not by design: the Director for Professional Practice happened to have an interest in Indigenous health, and the former VP in charge of those programs (who is herself Indigenous) had recommended that the particular individual should take it on.

Other areas within EH that formally address diversity (that is, beyond the APN program, Cancer Care, and HR) include the new Refugee Health Collaborative, housed under the VP responsible for Primary Care⁴⁷, and “client and family centred care” (which ensures appropriate access to services such as kosher meals), which is housed under Quality and Safety.

When decision makers were asked about the relationship between programming for refugee/racialized patients and Indigenous patients, no one was sure. As this health leader put it, “I don’t think there’s a relationship right now. I really don’t know, you know” (EH Decision maker 4).

When asked about the possibility of a purposeful design for where diversity programming would be located, one VP felt strongly that it does continue to make sense to have a decentralized approach, pointing out that everyone knows whose responsibility is where and that the pieces are easily connected:

I think we have a good sense of the tentacles that are out there and can connect them. So you know, sometimes I wonder, “*Should we have it all under one umbrella?*”. I don’t know, the spread I think would take longer then, and then someone owns it and it just becomes that program instead of being a corporate initiative, which I think it probably should be if we’re going to really work. [EH Decision maker 2]

When pressed on the difference between a program and a corporate initiative, this decision maker explained the importance of engagement with and sense of ownership over diversity:

⁴⁶Foundational Statements, Eastern Health, Core Values.

<http://www.easternhealth.ca/AboutEH.aspx?d=1&id=709&p=73>

⁴⁷Originally, the nurse practitioner position that had, since 2016, been funded for the Refugee Health Clinic was housed with the VP in charge of Emergency Services, and then moved to the VP for Primacy Care. Since 2020, the new Refugee Health Collaborative has also been the responsibility of the VP responsible for primary care.

If we have this kind of more decentralized, you know, I own a little bit, [names a VP] owns a bit, [names another VP] owns a bit of it, everyone feels that sense of ownership then. So I wonder if actually we wouldn't get more traction that way. [EH Decision maker 2]

This promotion of a systems-wide and decentralized approach reflects the recommendations that had been made by the original Diversity Working Group in their 2009 Framework for Diversity. However, also in that Framework had been the recommendation to ensure that accountability for the systems-wide approach be included in the governance structure of Eastern Health. A systems-wide, decentralized approach may be best; but such an approach requires connectedness and accountability.

7.1.1 Have centralized leadership and oversight of the system-wide approach

It needs to be somebody's baby. It needs to be somebody saying, "Okay what can we do to support this? What can we do to promote this practice? What can we do to evaluate what's happening? What can we do to empower the clinical people who are on the ground, in the field, to do more?" [Social worker 1]

What is clear from our interviews with physicians, nurses, and other health care providers was that the organic and piece-meal programming, led by various staff primarily not in positions of power, was a source of frustration for health care providers.

It's just the coordination piece, that is massive and there's a lot of players that are already doing a very good job with the resources that they have, with the pieces that they have, but there's an overarching piece that's missing. [Physician 2]

The feeling amongst health care providers is that it would be helpful to know *who* to go to for answers about the right thing to do. This nurse, like many of the health care providers and decision makers we spoke with, called attention to the success of the APN program as a model for leadership that works:

I had a patient from Labrador about two years ago, I called Katie [one of the APNs]. *"Katie, people are up here talking about plane tickets and getting such and such and so and so, Katie I don't know what they're talking about."* *"I'll be up in a minute"*. Done. She had it taken care of And then, how do we do that [care of new Canadians] using that model? [Nurse 2]

The question of where leadership would be housed had no easy answer; while a range of suggestions were offered, a general consensus expressed was that *which* person or group should be responsible did not matter as much as having a system that includes clear accountability and oversight.

This decision maker summarizes this need for accountability and oversight:

I'm not sure that it matters if it's with, say, clinical service delivery or if it's with [names another VP], or with any other supportive service, but we just need to make sure that everybody knows about it and they're supported to do that There's lots of things, though, in our organization that get siloed, right, but it's a matter of how do we make it acceptable for everybody and how do we ensure that the people who really need to have that background do have it as part of their work? I mean it's just a matter of making sure that people are informed, and I think that's part of our job in terms of, you know, managing it and communicating it. [EH Decision maker 4]

On the Indigenous side of things, it was clear who was accountable among leadership, and it was clear where within Eastern Health staff and patients could turn for assistance and support. The APN program

was remarkably successful in terms of profile within the health care system, and the two APNs were consistently held up as stellar examples of a well working system of advocacy and support for patients, and as stellar examples of how to access support and education. On the refugee health side of things, patients and providers we interviewed consistently identified the need for diversity programming in a context which was overwhelmingly perceived as positive with respect to *intention* with cultural safety⁴⁸, yet seen as relatively absent of intentional support and programming.

7.1.2 Enable community partners to guide EH decision making

A community-centred approach is key to success. Any visioning must involve formal and informal community stakeholders. A structure within EH must be completely inter-dependent with community organizations who assist with health care access for marginalized populations. A family physician explains:

I think whatever Eastern Health thinks might help – what they think they might want to do – what’s really, really important is they’ve got to do it in conjunction with us and the community partners like ANC, because we know what’s on the ground. Please. Eastern Health needs to hear this loud and clear. [Physician 1]

Similarly, this social worker involved with mental health and the refugee community emphasised the need for coordination between the clinic and the community to move toward better health outcomes.

It’s about building connections to the community and the larger community and it’s about efficacy within the systems that are out there This is not about going to an emergency room and treating a symptom; it has to be understanding enough of the story so that we’re able to build the future while understanding, validating, and knowing the impacts of some of the adverse experiences in the past ... How can we go out a little more, how can we work with the settlement workers, how can we work with the SWIS settlement workers in school, how can we take some of the things we do out of the clinic a little bit? [Social worker 1]

This VP expressed the same concern with ensuring that any programming is informed by and done in collaboration with community partners:

I think one of the benefits of a diversity committee, whether you’re talking about health care or in business or in government, is bringing people together who have different perspectives. Basically, you want a diversity committee to be itself diverse and reflect diverse sets of perspectives. So I think that having that kind of makeup in a body like that would be very useful. Because a lot of the time, we don’t know what everyone else is doing in the community and we can risk duplicating some of those efforts ... If you got a pretty representative body that can make that connection a lot more easily. [EH Decision maker 4]

She added that in terms of refugee health, a close partnership with ANC is key.

⁴⁸ Cultural safety is about acknowledging the barriers to clinical effectiveness arising from the inherent power imbalance between provider and patient. This concept rejects the notion that health providers should focus on learning cultural customs of different ethnic groups. Instead, cultural safety seeks to achieve better care through being aware of power relationships, implementing reflective practice, and allowing patients to determine whether a clinical encounter is safe.

7.1.3 Recognize and sanction diversity champions and initiatives

I think Eastern Health has no idea what kind of a gold mine they have in the sense of the kind of really fabulous work that's done. They have no clue. [Physician 1]

There are a number of “diversity champions” scattered throughout Eastern Health whose efforts are being done piece-meal, through self-motivation and self-education, and often above and beyond the duties that they would normally have to do. These individuals are often feeling unacknowledged, somewhat invisible, and unsupported in the work that they are doing to promote culturally safe care to newly arrived refugees. There is a need for leadership to recognize this work, to explicitly sanction it, and to commit to supporting it.

A key piece of feeling isolated and unconnected in such endeavors is the worry about not being sanctioned to do work that does not have a place in official programming and is being done without the authority of leaders within Eastern Health. This social worker explains this:

If you had, you know, permission and support to kind of coordinate some of the things, I think that would be big from Eastern Health. For someone who has an interest or people who have an interest in this to feel free to free up a little bit of intellectual space so that we can say, “Yeah let's do this, let's try that” ... It would have been nice to permission or sanction so, you know, the field of what you're doing is sanctioned and supported. [Social worker 1]

The notion of having one's efforts sanctioned and receiving “permission” to initiate a process or program to increase cultural safety, from someone who clearly has the authority and to whom staff can be accountable, is very telling in its message about the need for leadership and oversight.

A member of the EH Diversity Steering Committee commented on how important sanction from EH leadership is for momentum. She described having received a thank you email for her work on the 2017 diversity education day.

The little words, how powerful they can be, because that kind of gave me the permission to go and do more. When you don't feel you have the support it's really hard to be motivated to do something. [EH Decision maker 5]

Support includes ensuring that there is an accountability mechanism and support structure in place for staff who worry they've made an error or haven't done enough for a patient when working across cultures.

From the perspective of one of the EH decision makers, one challenge is that the work of diversity that is occurring has not been labelled as “diversity” and therefore hasn't been recognized as such.

I won't say that things weren't happening because I think they probably were still happening, but it was much more organic and we weren't necessarily naming it diversity So you know, I think we haven't called it that [diversity work] but I think we've been doing work around it for lack of a better way to say it. So where are we, I guess was your question. Um, I still think we're perhaps at the beginning, even though we've done some work in it. So I think we need to theme it and name it because I think there's work that's been done but it hasn't been named. [EH Decision maker 2]

In some cases, clear policies are needed rather than having decision making applied in an ad hoc manner. For example, cultural accommodation for modesty concerns has evolved into some excellent practices, but in the absence of clear guidance or policy, these are not uniformly applied.

7.1.4 Evaluate programs and measure success

Policies and programs need to meet national standards that have been well-established as best practice. Other provinces in Canada have a longer history of cross-cultural health care; some health authorities have long-standing programs and policies that have been examined and proven effective. Conducting research on what is being done well, and promoting EH's successes through research and dissemination, is reportedly missing at this stage – largely because those who are doing innovative work are doing so in isolation from official programming. The values of excellence and employee belonging intersect with this concern. While we heard many stories of great successes throughout Eastern Health, there is always a danger that ad hoc and isolated approaches to care can lead to uninformed care. Compassion is important and crises must be managed – but the goals of excellence and long-term sustainability are also important. Excellence requires sanctioned programming, with goals that are measured and reported to those who are accountable.

7.1.5 Communicate and coordinate services

An important gap raised by providers in terms of creating and sustaining culturally safe care is to ensure that policies and programs that do exist are made known to all providers. Approaches to care that solve some of the difficulties with access have been implemented in various places across Eastern Health – but as these are program- or site- specific with no links to an obvious leadership structure, the strategies are not known and shared and opportunities are being missed. The lack of oversight means that it is difficult for health care providers to know who is doing what; they are unable to access each other's knowledge and tools.

One obvious example is the approach to follow-up of non-English speaking patients who may receive clinic appointment letters in English at their home. The refugee health collaborative and the Family Medicine Clinic have a coordinated approach to this challenge (described earlier); but this is not universally known or applied. Similarly, cultural accommodation for modesty concerns has evolved into some excellent practices, but in the absence of clear guidance or policy, these practices are not uniformly applied. Coordination and communication across the system is not the responsibility of whatever diversity champions have developed an innovative strategy; but someone needs to take charge.

7.1.6 Support capacity building

We heard stories of diversity champions seeking out training outside of the province – self-motivated and self-funded – outside of their regular work schedule. This gap in accessible training and capacity building is an important one for EH to prioritize. This includes supporting peer training, by (1) having external experts come in to assist with developing supports; and (2) sending local health care providers elsewhere for training, in the spirit of a “train the trainer” model of peer education. This type of “train the trainer” model has already been implemented by some providers we spoke with, who have on their own sought out opportunities to go elsewhere in Canada or the US to receive training in particular aspects of refugee health care.

It was clear from our discussions with patients, supporters, and providers that many providers do in fact have an excellent grasp of the complexities of culture and how to provide culturally safe health care. I asked one nurse how it was that she had such a sensitive and thorough understanding of how culture shapes health care, and of how to provide culturally safe care specifically with respect to Syrian patients. She explained that she and her colleagues took time, early on in their first encounters with Syrian patients, to ask questions and to receive information about culture from the patients themselves. Those who learned were then able to pass this knowledge on to their peers, such that over time cultural competency grew (Nurse 2).

Similarly, the social worker who had independently sought out training in refugee trauma care (discussed earlier) did so in part as a “train the trainer” strategy, and was then able to teach others (Social work 1). This social worker is interested in setting up quarterly case-consultation style meetings to create a learning network across various programmes.

What I’d like to do is to really try and set up something a little bit, I don’t know if structured is the right word, but ongoing in terms of perhaps quarterly meetings, case consultations with people who are interested, so to develop some internal expertise, some internal knowledge around this issue. I want to have a little bit of a network set up so that the people who are interested in this clinically will have a place and maybe you know I can see maybe people from you know the adult system, the child system, people from ANC, perhaps people from the refugee health unit you know, being a core group, and so that’s kind of the goal for me. So I’ve been trying to stir up a little interest in the subject actually, and I have to say it’s been an incredibly easy sell with clinicians ... If I had a million bucks I’d hire some more staff but if we are working within existing structures it would be really building the networks of people that have this interest, it would be providing good ongoing support training. [Social worker 1]

The social worker in this case trained outside of regular work hours, in fact losing salary to do so by extending vacation into personal leave time. Resources to support a “train the trainer” model – in the spirit of the individual initiatives undertaken by this nurse and social worker – could be highly effective for advancing peer-to-peer teaching and learning.

One physician proposed a formal support group style peer learning process, with CME credit for physicians who participate. This model would require dedicated time and support for a physician leader to provide coordination and support to the training.

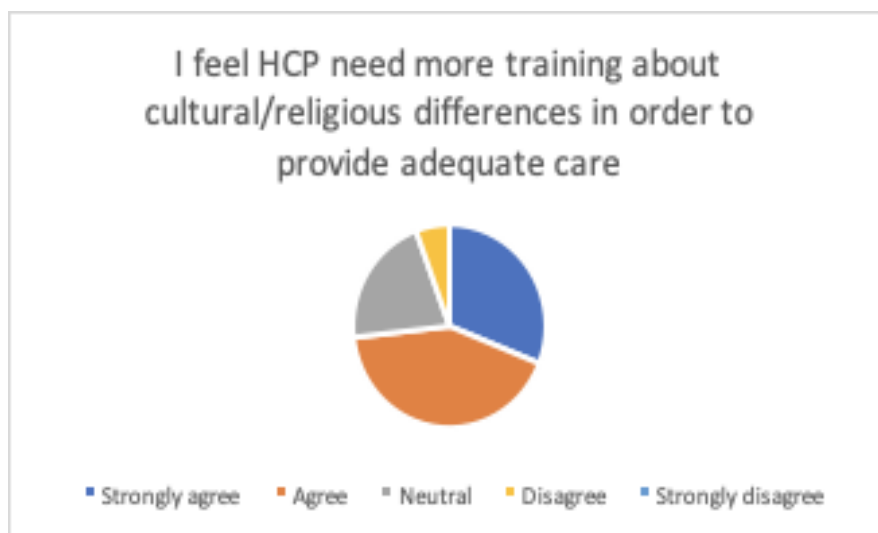
Right now people say to me ... *“Why don’t you train [family physicians]?”* and I’m like, well, that’s great, but when do I do this? At 11:00 at night? To have some support – if I had a protected day once a week and I could work on CME that would be great, you know, and if I had an administrative assistant who could help me, that would be wonderful; but working you know nine half days clinically a week and then doing training, doing other unpaid academic stuff – there’s just no time for it. But I think that we should have a core group of interested community doctors ... who we could connect with, maybe every six months, we’d say *“How’s it going? There’s this little update. Do you want to come to this talk? You can get CME credits, come for an hour, we’ll have some pizza”* – something like that, so they feel like they’re part of a group. [Physician 2]

7.2 EDUCATE HEALTH CARE PROVIDERS

There is limited training available. There is one diversity course about Aboriginal patients; however, it is really limited in terms of addressing sources of racism with this population. We need to speak to other health authorities in other provinces that have been doing this type of staff education for decades. [Anonymous respondent to Staff survey]

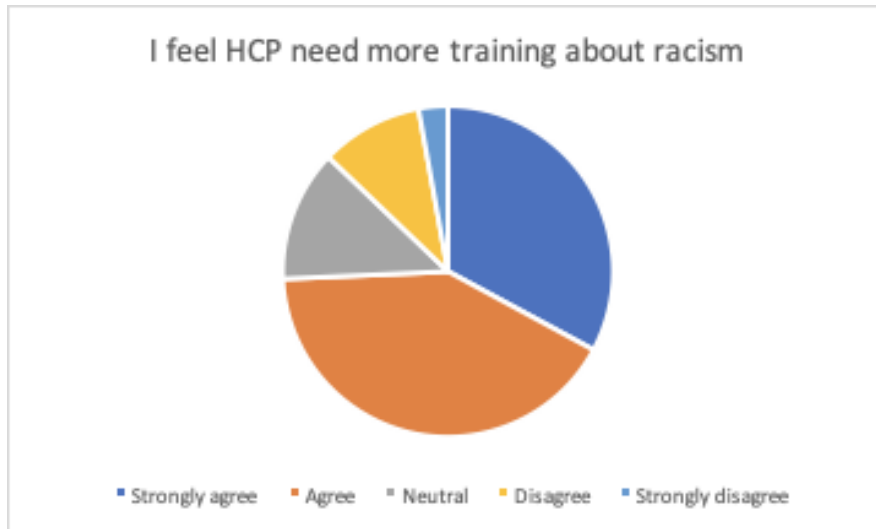
Diversity training is currently provided piece-meal. First Light provides training on Indigenous health, and has been invited in by Cancer Care and other programs to train staff. Cancer Care's "Journey in the Big Land" project created a series of training modules that staff can avail of to learn about Labrador communities and aspects of Indigenous health⁴⁹. On the refugee side, it is mainly the ANC that is responsible for staff education, speaking primarily about the experience of having to flee a violent situation and the health-related issues that may be associated with political oppression. Depending on the audience and the request, they may also provide education on culture in general in relation to health care. Other community organizations (most notably, RIAC) have also been invited in to educate specific groups or programmes. The Refugee Health Clinic (now, Refugee Health Collaborative) has provided information on the context of particular incoming communities, to family physicians seeing new patients.

Health care providers were asked, in the survey, whether they believe they need more training on cultural/religious differences. The majority of respondents to that question (52/71 or 73%) believed or strongly believed that training on cultural/religious differences is needed.

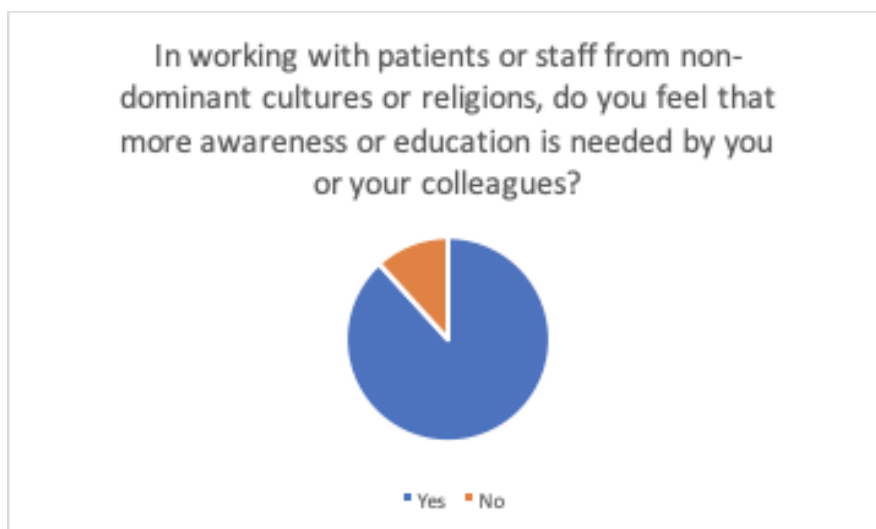


When asked about the need for training on racism, 52 of 70 respondents to that question (74%) agreed or strongly agreed in the need for training.

⁴⁹<https://storyline.easternhealth.ca/2016/06/22/navigating-the-journey-aboriginal-health-initiatives-at-eastern-health/>



Further, of 68 respondents to a question about the need for awareness training about non-dominant cultures or religions, 88% felt that they or their colleagues required education.



It is clear that training on diversity awareness, cultural competency, and cultural safety is needed for health care providers and decision makers. Five key recommendations for staff training emerged through our interviews with patients/supporters and providers: (1) information about patient populations must be easy to access; (2) information must not inadvertently lead to a “recipe book”-style essentialist approach of how to provide care; (3) cultural competency training needs to emphasise cultural safety and humility; (4) methods must be designed to meet staff schedules and time constraints; (5) community-based experts should be partners in providing training; and (6) training must be linked to a wider organizational cultural that promotes cultural safety, for patients as well as providers. We consider each of these in turn.

7.2.1 Make information about patient populations easily available

Easy access to information about specific patient populations can be helpful to health care providers. In the absence of, or to accompany, cultural competency training, information sheets or websites that are

quick and easy to access and readily available are a realistic and efficient way to convey straightforward information. This was the model followed by the Cancer Care program, which created an excellent resource for health care providers to understand the context of health care delivery for Labrador Indigenous patients. A similar resource could be made available for some of the main groups of newcomers to the province.

This need for health care providers to have a basic understanding of culture and religion was particularly expressed by patients and their supporters in the Muslim community:

Maybe something like, *“Those newcomers came from different backgrounds or different cultures”*, so you need to know more, let the nurses or the health care professionals know more about their culture, their place, the background that they came from. And let them know how they usually deal with people or health care professionals in their countries. [Refugee patient 5]

This patient went on to give specific examples of a pamphlet with information that a woman wearing a hijab may prefer a female nurse and doctor. A second Muslim patient/supporter suggested a similar strategy:

I always feel that healthcare providers should get more training about the culture ... Most of the refugees that I go with are Muslim people, so with Muslim people you can't shake hands with other genders ... It's embarrassing for those people here sometimes. [Formal and informal support worker 5]

This model of providing basic information about a particular patient population was supported by family physicians, who had produced a series of pamphlets about some of the main refugee populations being served, as a means of quickly educating physicians about the social and political lives of newcomers and about the kinds of health conditions that may be seen in the particular population.

One of the decision makers we interviewed also advocated for this approach, using the example of a pamphlet that had been created about Syrian newcomers.

When we were seeing a large influx of Syrian refugees one of the things that was done for staff was to try and develop a bit of a profile and a history about, you know, the individuals that were coming, you know the kind of ranges of ages and what their families looked like and decision making within the families, what it was like to live in the country, you know; things around their health care system, how to support them. How do people want to be referred to, that sort of thing. So I think it's just, if there were ways to have some kind of a snapshot of, you know, who this person is and what's their experience. [EH Decision maker 4]

7.2.2 Ensure that information about patient populations is not essentialist in nature

Cultural essentialism is the idea that people within a particular ethnic group have innate characteristics that are inherent to that group, including the belief that all individuals within a group will act similarly in a predictable and culturally defined way when it comes to health beliefs or decision making. This way of thinking is very restrictive and potentially harmful when applied by health care providers who think they are being culturally “sensitive” by believing that all individuals who are members of Group X will act or think in a certain way.

Pamphlets or other training tools should be used as a means of providing some quick background context, not as a “how to” guide for health care decision making. Predicting individual health beliefs or behavior based on ethnic identity is like forecasting rainfall: Knowing what the average rainfall is for St. John’s in July does not tell you what any given day in July will be like. The words of this informal support worker effectively capture this complexity:

I think when we talk about, say, the cultural sensitivity part – I mean, it’s not that you can expect every doctor, every nurse, physiotherapist, and dietician to understand, *“Okay this is how it is in ‘Middle Eastern culture’, when within Middle Eastern culture there are many countries, or ‘Asian culture’ or ‘South American’”* or whatever – I don’t think it’s reasonable. But to draw an awareness to, like, you need to understand this issue of cultural sensitivity, that you are not going to understand everything about these people’s background but you have to have it in your mind that they have likely not experienced the same things that you have. [Informal support worker 1]

7.2.3 Schedule training to mesh with staff schedules and time constraints

Don’t give me a resource to go to that I got to go read it online for 25 minutes to find the answer that was three minutes long for you to tell me – because I don’t have 25 minutes. [Nurse 2]

There was general consensus among health care providers and decision makers that long, didactic training sessions are not practical and will not reach sufficient numbers of staff.

It hurts my soul to say this out loud, but unless someone is working and getting paid they are not overly interested in anything that you have to say for any time of continuing education or anything ... We have one eight hour education day a year. In order to do that I have to give 70 nurses a day off paid. A day off the unit paid. So they have a day in the classroom, but in order to do that I had to pay 70 more to work that shift that they aren’t working. So you either have to bring them in on overtime on their day off or you have to give them their day off on their day and cover them. So it’s very expensive to do an education day, which is why they only get one. [Nurse 2]

This nurse went on to explain that only half of that 8-hour block can be devoted to the special topic, the other four must be saved for mandatory training sessions. She suggests that mini-education sessions over coffee breaks are the most efficient way to provide education. In order to get nurses on both sides of the 12-hour shift, it would require 8 sessions of 20 minutes. Lunch and learns are sometimes also effective, but these only work for those on day shift, and if it is very busy, then often nurses would not even be available to do that.

7.2.4 Emphasise cultural safety and humility

I honestly think that some staff do not think that some comments are racist or culturally insensitive. There are sayings in Newfoundland that are very insensitive to minorities that are commonly said by people in the province, and I don’t think that people stop to think ABOUT what they are saying and how it is being perceived. [Anonymous respondent to Staff survey]

It is well established in the literature that training in cultural competency alone is insufficient, and that establishing a culture of safety should be the goal. Establishing a culture of safety requires training in cultural humility. Cultural humility requires turning the gaze inward (for individual health care providers

and decision makers, and for the institution as a whole), rather than focusing on the cultures of patients (with the dangers of essentialism that such an approach entails). For example, in this report we pursued in depth some of the reasons for missed appointments from the patient perspective. An important theme was that missed appointments are seen by physicians as a problem with refugee patients; for patients, missed appointments are seen as a problem with the Canadian health care system. We have a culturally shaped health care system that is odd in the context of the world's health systems – we are odd, not our patients.

An approach that turns the gaze inward and focuses on cultural humility is more time consuming and more difficult to deliver than training that focuses on the cultures of patients. Health care workers emphasised that any training needs to be obviously and immediately applicable to their work. This social worker explains:

They do want some stuff around cultural sensitivity to some degree, in a way that's palatable and usable for them. I mean, see, people are a little bit afraid to, you know, let's bring somebody in that's going to lecture us about our neocolonial ways ... You know, you got good people here trying to figure it out ... *Really* what we can do – *practically*. What works, what kinds of programs have been developed and what's worked in other places, what kind of approaches are usable and supportable? [Social worker 1]

There is a tension in the two goals of training, on one hand having it be accessible and immediately applicable and focused on cultural beliefs and the lived experiences of particular patient populations; and on the other hand, having it be about cultural humility, institutionalized racism, the culture of the Canadian health care system, and colonialism. Currently across Canada, in the wake of social movements such as Idle No More and Black Lives Matter, all public institutions are being called on to turn the gaze inward, to learn, and to change. This is the priority.

7.2.5 Plan training in partnership with community-embedded experts

Training must be done in partnership with community, in particular the ANC and First Light; and community groups should not bear the burden of cost.

7.3 CAREFULLY CONSIDER THE VISION FOR REFUGEE PATIENT NAVIGATION

Cultural safety includes ensuring patients can successfully manage health care visits. Hospitals are notoriously confusing for patients, even for those who speak English and are experienced with the health care system generally. The APN program is a success story, because it serves the purpose for which that particular program was designed. The question of whether there should be a patient navigator program for refugees was one that we considered and invited commentary on.

As described earlier in this report, there are three competing models of navigation that have been proposed by refugee health advocates (health care providers, formal and informal support workers, and patients) that we spoke with. One model (which we refer to as the “support to learn the system” model) emphasises independence. This model advocates teaching patients how to become fully functioning members of society, by training patients how to navigate the system themselves. The competing model (which we refer to as the “navigate individual patients” model) emphasises full patient support with navigation and interpretation. A third model is to have on-site navigators for assistance with finding

appointments for all patients, regardless of whether they are non-English speaking or newcomers to the province.

Many participants who advocated for a refugee patient navigator referred to the successes of the APN program and Cancer Care's patient navigation program. However, there are good reasons to argue that these models are inappropriate for support to refugee newcomers. First and perhaps most obviously, such direct assistance contradicts ANC's model of support, which is one of ensuring that newcomers are able to be independent as soon as possible in the resettlement process.

The ANC feel, and rightly so, that the people who come here have to learn to live here and so they want them to learn the bus system, they want them to learn how to navigate all of the ways that they have to get to appointments the things that they need to do for themselves because they're capable of doing that, it's just giving the tools. [Formal support worker 3 (not affiliated with ANC)]

Second, the assistance model would require an enormous pool of volunteers. Several participants addressed this. Comparisons were made with the Cancer Clinic patient navigators. In that model, volunteers – many of whom are retired health professionals – drive patients from home to appointments. Very often the same navigator is matched to a patient, so that a relationship is formed over time, which is conducive to trust. That model has been applied to refugee patients by some informal (nonprofessional) supporters, and has been critiqued for not attending sufficiently to matters of effective communication (language) and modesty.

It should be noted, too, that the idea of a patient navigator providing both navigation and interpretation is logistically problematic. Most obviously, it would require having a pool of navigators representing the range of languages of newcomers, which would be unsustainable.

A third model of navigation responds solely to the need for on-site assistance on Eastern Health premises. Several participants suggested moving away from the idea of navigators in the sense of the Aboriginal patient navigators and Cancer care navigators, and instead having volunteers placed in strategic areas throughout hospitals, armed with phones for basic interpretation in multiple languages, to help to direct all individuals – regardless of origin – to where they need to be within hospital sites, a solution that only solves the challenge of navigation within EH premises. One formal support worker noted that these general health navigators would be very useful because often patients are reluctant to ask strangers for help, even with the clinic name clearly written on a paper that can be shown; and in those circumstances a clearly identified navigator would be easier to approach (Formal support worker 2).

No matter what the plan for navigation might be (if, indeed, one is deemed to be required beyond the navigation currently provided by ANC), the role would have to be conceived with ANC, to support the navigation that is already built into this official resettlement process. As this formal support worker put it,

If we were to embark on a plan for funding for a navigator, again, I think I would like it to be very clear what's the value added and what is the role ... because the ANC ultimately – this is their role to deal with people, with newcomers, so they – this has to work with what they want. [Formal support worker 3]

7.4 PROVIDE SUFFICIENT PROFESSIONAL INTERPRETATION THROUGHOUT THE EASTERN HEALTH REGION

Interpretation remains one of the key challenges for both Indigenous and refugee patients. A number of recommendations for successful interpretation emerged from this research. Each are discussed in turn.

7.4.1 Educate staff about the use of the telephone interpretation system

Interpretation for times when professional interpreters are not available requires a functioning telephone interpretation service that is widely known by, understood by, and accessible to, all providers within Eastern Health. Currently, telephone interpretation is not being effectively used by staff – even since the switch to a service that is more user-friendly – and this is a source of concern. Staff need to be made aware that the service exists; they need to be instructed in how to access and use the service; and they need to be informed that standards of practice require them to use it when appropriate to do so.

7.4.2 Make the telephone interpretation service more widely available

Currently, the telephone interpretation service is limited in its availability. In particular, there is an urgent need to make the service available to community clinics and to pharmacists. Re-aligning resources to make this happen should be a priority.

7.4.3 Train providers in how to work with interpreters

There are well established best practices for health care providers to work with interpreters. It was clear from our interviews with interpreters that many physicians are unaware of how to work with interpreters. Training on this should be mandatory.

7.4.4 Ensure in-person interpreters are professional (trained and paid)

For refugee patients, there is a process in place to have interpreters accompany patients to clinic visits when required, with professional interpreters arranged through the ANC. For refugee patients who are not under the jurisdiction of the ANC, private sponsors are to arrange for professional (paid and trained) interpreters. For Indigenous patients, the APN program provides or arranges for interpretation when required. However, there are still massive gaps in the system, as described in this report. Physicians and other health care providers need to be educated on best practices when a professional in-person interpreter is not available and when the telephone interpretation system is not available.

Most obviously, children should never be used for interpretation of personal health information in emergency or any other circumstances. It is advisable to avoid using family members. Calling in a taxi driver or cleaning staff to interpret (both are practices we have heard about) is unacceptable – this practice results in substandard interpretation, is potentially embarrassing to both interpreter and patient in small ethnic communities, takes the interpreter away from their paid employment and duties that need to get done, and is stressful on the interpreter. Paid and trained interpreters are the standard.

7.4.5 Expand availability of interpreters for Innu patients and Arabic speaking patients

Gaps exist for interpretation for Innu patients and Arabic speaking patients.

Placing interpretation at the level of the clinic (Eastern Health) rather than community is counter-productive to an authentic community-EH partnership. As one informal community-embedded support worker explained, it is important to not have interpreters linked to clinical care or to a government organization, but rather embedded in cultural organizations affiliated with individual communities, with an Eastern Health-embedded navigator or coordinator who reaches out to community, such that communities become an integral part of the navigation process (Formal support worker 6).

There should be a roster of in-person interpreters who are trained and paid, and drawn from community. We are advocating that Eastern Health create an arrangement with community groups who would control interpretation, in a model similar to how Eastern Health subcontracts to First Light.

7.5 PROMOTE AN ORGANIZATIONAL CULTURE OF CULTURAL SAFETY BY EMPHASISING CULTURAL HUMILITY AND RELATIONS OF POWER

We believe that the health-care system should be a welcoming and safe place for all individuals and groups regardless of race, ancestry, place of origin, colour, ethnic origin, citizenship, class, creed, sex, gender, size, gender identity, sexual orientation, age, education, marital status, source of income, same-sex partnership status, family status or disability. [EH Foundational statement, Diversity and Inclusion⁵⁰]

When I was filling out forms at the ER and they asked me ... what religion I would like to put down, the only options given to me were various forms of Christianity. While I'm blond haired, green eyed and white I am culturally Jewish, but the assumption was made that I was Christian. This may seem minor but it was hurtful. There's no basis to assume that I am Christian and it put a bad taste in my mouth. I think having staff be aware of the importance of open ended questions, not just options, is important. First impressions when you're in pain are long lasting. I also think allowing people to put down whoever they want for pastoral care would make the process more inclusive. [Anonymous respondent to Refugee and Minority survey]

I have observed EH staff make derogatory and negative, stereotypical comments about people from Indigenous cultures. I feel overall there is a lack of cultural sensitivity & awareness within the EH organization of different cultures and even of regional differences within the province. [Anonymous respondent to Staff survey]

Training in cultural safety needs to be supported by an organizational culture that promotes cultural safety – for patients as well as providers. It was clear to us in our discussion with Eastern Health leaders and decision makers that this important aspect of creating a context of cultural safety is already well recognized. In response to the question, “What does diversity in Eastern Health look like to you?”, one decision maker summarized what a culturally safe health care system means:

For me that would mean when we produce things in promotion or in advertisement, that we show diversity in a way that's open. It would mean that we're designing – when we're building new structures and capital projects – that we're considering it from a diverse lens and what the needs are of different communities ... I think we have to spend more time talking to people about what cultural safety is ... I think we have to find ways to incorporate how their culture is different than mine might be, and I think we forget that sometimes. So how do we do that? I think it's heightening awareness. I think there is education that we can do. Again, I think it's showing people from those cultural backgrounds in some of our promotional materials. [EH Decision maker 2]

The hierarchy of power needs to be considered and also dismantled in several key ways that require advocacy in a sustained way for long-term change to the culture of the health care system itself. Self-

⁵⁰<http://www.easternhealth.ca/AboutEH.aspx?d=1&id=709&p=73>

reflection and evaluation needs to be done by Eastern Health leadership to fully explore this. Here, we present some observations on some of the ways this can be done, focusing on the most obvious “low hanging fruit”. We assume that a clear leadership structure that focuses on connecting the various parts of the system (as described in the first set of recommendations) will facilitate this advocacy process.

These recommendations focus not on the cultures of patients, but on the culture of Eastern Health.

7.5.1 Reflect on Eastern Health’s place in the context of ongoing colonial oppression

While establishing a culture that supports diversity in general is important, the immediate priority is to establish a sense of cultural safety for Indigenous patients.

It is a sad irony that newcomers to Canada report feeling welcomed and supported by staff who are going out of their way to try to accommodate the needs of newcomers, while Inuit, Innu and other Indigenous patients are consistently experiencing racism and marginalization in our health care system.

Several *Calls to Action* in the final report of the Truth and Reconciliation Commission pertain to health. Of these, two calls are directly related to creating a culture of safety:

TRC Recommendation 18 – We call upon the federal, provincial, territorial and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties.

TRC Recommendation 23 – We call upon all levels of government to: Increase the number of Aboriginal professionals working in the health care field. Ensure the retention of Aboriginal health-care providers in Aboriginal communities. Provide cultural competency training for all health-care professionals.

Actions with respect to these recommendations include acknowledging the presence of underlying ideologies of racism and colonization. The literature on the health of Indigenous peoples in Canada shows that health gaps for Indigenous patients are the result of racialized policy choices, both past and present. The same policy choices that negatively impact health create unequal opportunity for Indigenous people to meet the eligibility criteria to apply to employment within the health professions.

While the focus of this research has been on patient needs (including the needs of providers with respect to addressing patient needs), this research of course also applies to health care providers who are themselves members of ethnically or racially ‘othered’ groups. When patients see diversity amongst health care professionals, this leads to a feeling of belonging and cultural safety. The community of health care providers and decision makers should closely resemble the patient population. In our province, this is particularly a problem with respect to the dearth of Indigenous physicians and health leaders.

7.5.2 Support education about and acceptance of traditional healing modalities

One area of obvious priority in establishing a culture that promotes cultural safety for Indigenous patients as well as refugee patients is to set practice standards for understanding patients’ use of traditional healing modalities. It was clear for both Indigenous and refugee patients that there is a reluctance to divulge the use of traditional medicines to health care providers. It was also clear that

physicians rarely ask. An exception is in Cancer Care, where there appears to be more openness to discussions with patients. There is a vast literature on the importance of frank and open discussion about the use of alternative medicines in terms of patient well-being, both medically and socially. A structured program of education for staff and establishment of best practices is important here.⁵¹

7.5.3 Notice places of marginalization, and create spaces

There is an urgent need for family rooms for large groups of visitors, and in particular for a dedicated space for Indigenous families. In Canada, arising in part from recommendations out of the court-mandated treatment requests for two Ontario Indigenous youths (Makayla Sault and J.J.), it is now widely accepted that Indigenous family spaces are part of the standard of care⁵². As mentioned earlier in this report, this was a recommendation that had been made by First Light long ago to Eastern Health. This should be a priority.

7.5.4 Create alternatives to the fee-for-service pay structure for physicians

The fee-for-service structure for physicians needs to be seriously reconsidered if access to basic health care is to be fully possible for marginalized patients that require extra time.

7.5.5 Acknowledge and provide opportunity for unpaid informal community volunteers

A large part of the work of cultural safety is currently carried out by informal community volunteers who are not known, noticed, or acknowledged for their contributions. These informal unpaid patient supporters have played a major role in patient support. These individuals need to be acknowledged and supported in a way that does not inadvertently interfere with the work of formal organizations mandated to provide support. These are knowledge holders, experts in the needs of patients, and Eastern Health would benefit from having such individuals engaged with the design of policies, programs and best practices. For example, the Aboriginal patient identifier process would benefit from further discussions with Inuit, Southern Inuit, Innu, and Mi'kmaq leaders, elders, and community members.

7.5.6 Reverse the order of who holds the knowledge

It is patients and their supporters who are the knowledge holders and experts. One of the most striking learning moments we had in the context of this research was a teaching from the Indigenous Elder advisor to the project:

*I'm usually just invited in to give an opening prayer.
No one has ever asked me for my opinion until now.*

While we appreciate that training that includes attention to important cultural rituals and customs is an important way to engage staff in diversity awareness, this may have the effect of reducing culture to performances by “others”, rather than focusing on the culture of Eastern Health, which is where the gaps need to be identified and change enacted. The way to cultural safety is through self-reflection and

⁵¹ Note that the Truth and Reconciliation report also calls for support for the use of traditional medicines: *Recommendation 22 – We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients.*

⁵² For example, Indigenous family rooms have recently been established in [Winnipeg](#), [Edmonton](#), and [Ottawa](#). Toronto's new Indigenous health care institution includes [a teepee and sweat lodge](#). Many other models for Indigenous-specific spaces in health care exist across Canada.

cultural humility. Self-reflection is difficult; as “insiders” to a culture it is difficult to see one’s own normative assumptions and practices.

Engaging patients as advisers to offer commentary on programs and practices is an important way to engage in institutional self-reflection and analysis. This research partnership between Eastern Health and patient advisers advances the work of establishing cultural safety within Eastern Health.