The Eastern Health Diversity Project: Examining needs and establishing priorities

Webinar for NL SUPPORT Training Program

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We respectfully acknowledge the territory in which we gather as the ancestral homelands of the Beothuk, and the island of Newfoundland as the ancestral homelands of the Mi'kmaq and Beothuk.

We would also like to recognize the Inuit of Nunatsiavut and NunatuKavut and the Innu of Nitassinan, and their ancestors, as the original people of Labrador.

We strive for respectful relationships with all the peoples of this province as we search for collective healing and true reconciliation and honour this beautiful land together.

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The Eastern Health Diversity Project: Examining needs and establishing priorities.

How well is Eastern Health doing with cultural diversity?

What are the challenges, strategies, needs and barriers related to providing effective, culturally safe, culturally competent health care?

This research was funded by NL Strategy for Patient Oriented Research (NL SPOR)

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Focus of today's presentation…

REFLECTIONS ON THE RESEARCH PROCESS

- "Patient oriented research"
  1. describe patient oriented research
  2. present results
  3. emphasise benefits of POR

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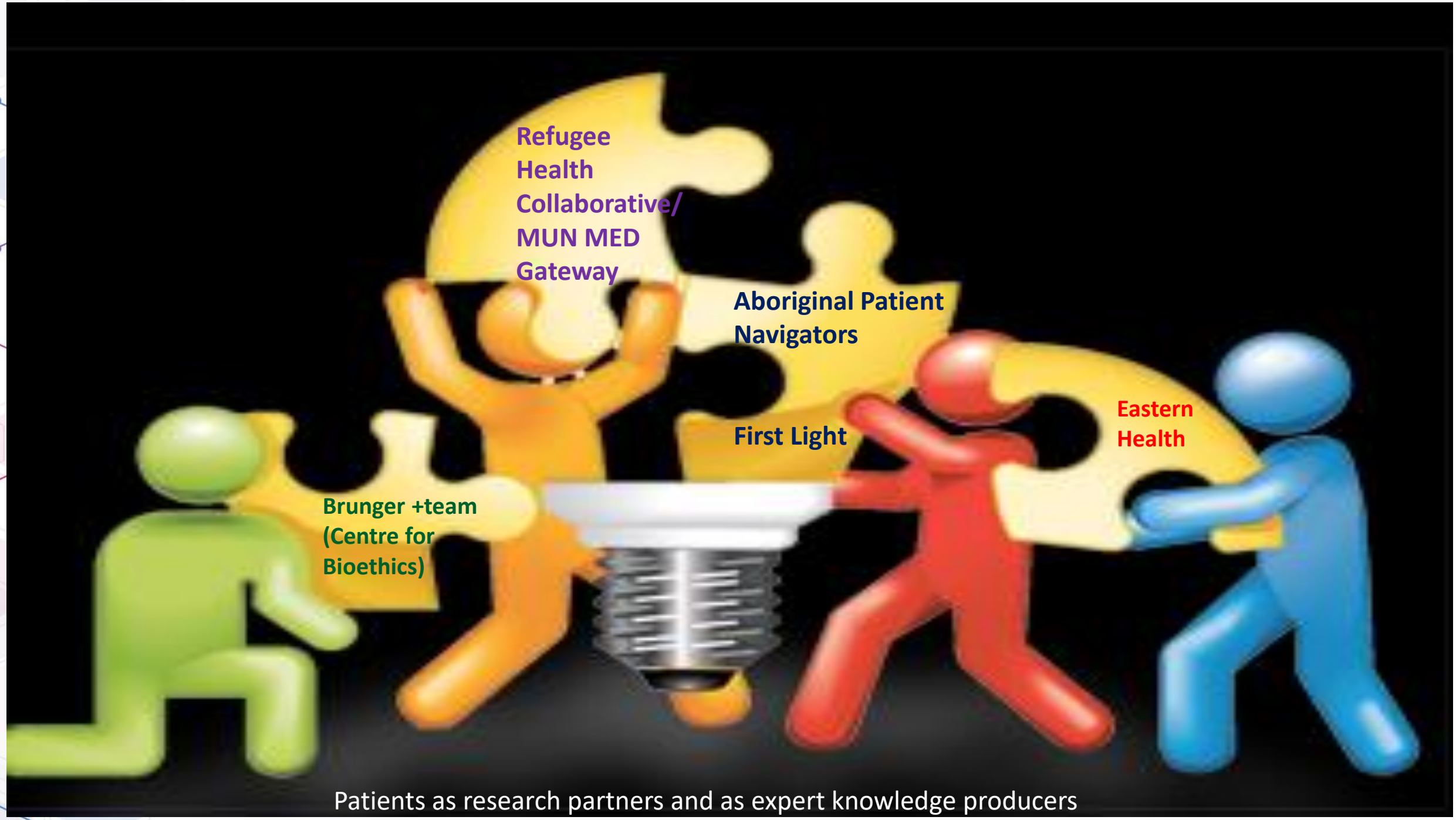

Patients as research partners and as expert knowledge producers

Collaborators

- **Eastern Health**: Josee Dumas (Chair, Diversity Steering Committee), Mollie Butler (Regional Director, Professional Practice), Debbie Molloy ([former] VP, Eastern Health)

- **First Light** (formerly St. John's Native Friendship Centre): Chris Sheppard ([former] Exec. Dir.), Solomon Semigak and Katie Dicker (Aboriginal Patient Navigators), along with Emma Reelis (Elder)

- **MUN MED Gateway/Refugee Health Collaborative**: Jill Allison (Global Health Coordinator, Gateway advisor), Christine Bassler and Francoise Guigné (MUN Family Medicine Clinic/MUN MED Gateway/Refugee Health Collaborative)

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Core research team

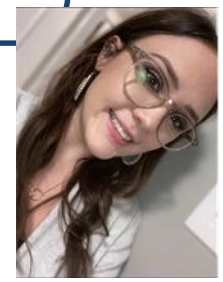
The Eastern Health Diversity Project

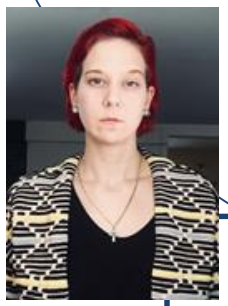
Fern

Mohammed Syaket **Shakil**, MPH – Senior RA, data collection

Rouba Isshak, MD – Syrian physician, community-embedded RA for refugee component

Adriana Pack, RN – Miawpukek First Nation, nurse, community-embedded RA for Indigenous component





Valerie Webber,

PhD candidate – community and scholarly dissemination

Rachel Hewitt,

MHE student -- community dissemination

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“Patient oriented research”

Design

Recruitment & data collection

Advisory meetings co-creating analysis and recommendations

Draft report

Advisor feedback

Report to EH & community stakeholders

Scholarly publications

Knowledge holders as experts

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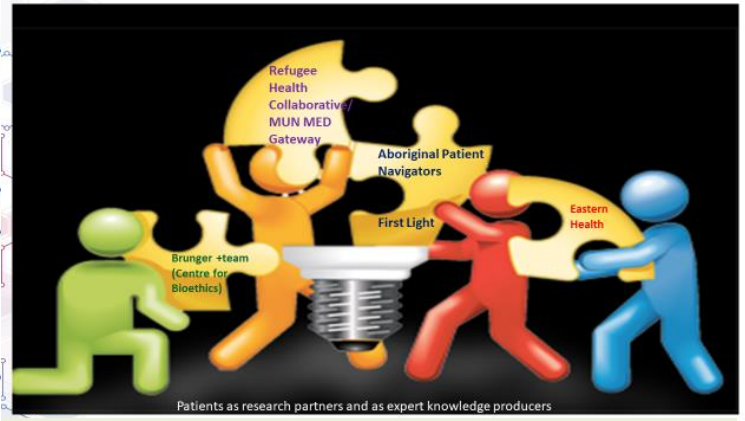
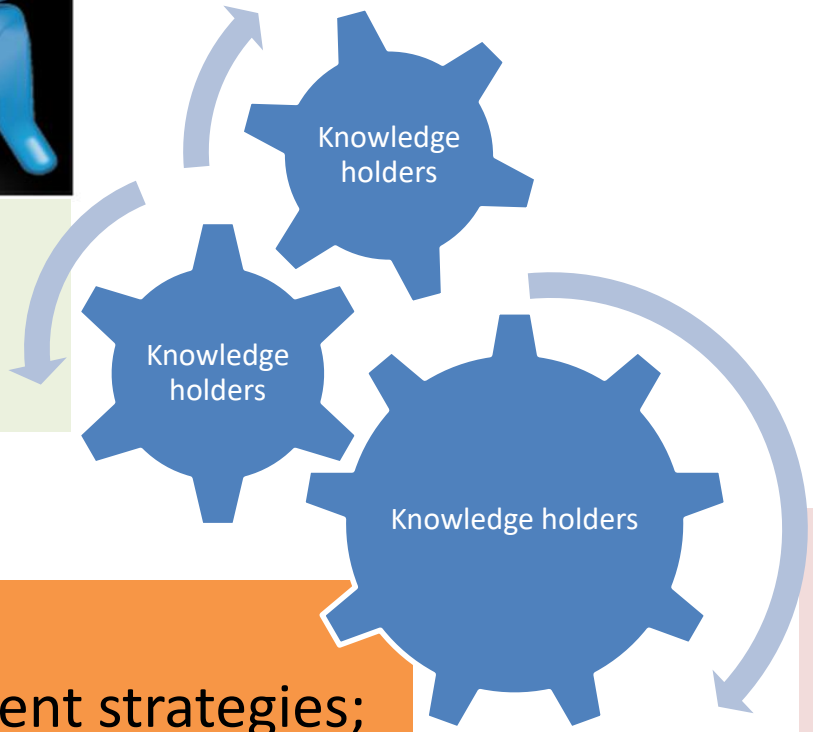
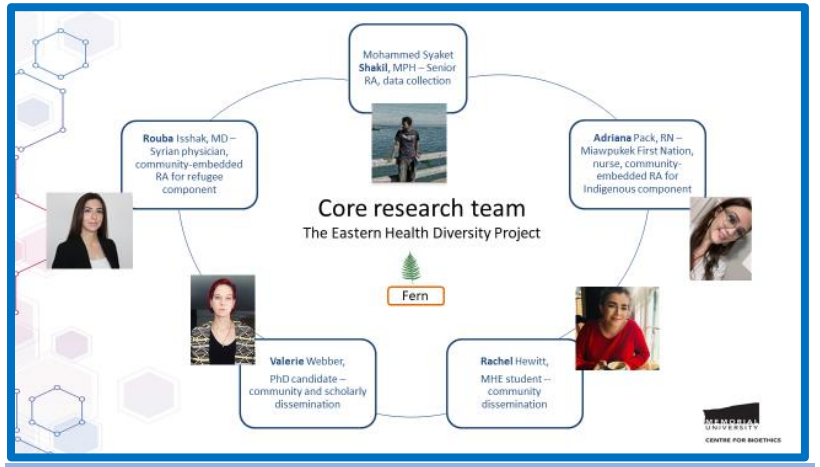


Community-embedded research collaborators

Centralizing knowledge holders





Community-embedded research assistants

Community advisors (revised design/recruitment strategies; analysis meetings; feedback on report)

- Interpreters (ANC, independent)
- Professional patient supporters (APNs, ANC)
- Informal patient supporters, Inuit, Arabic speaking
- Elder with First Light

Research participants

-New immigrants and refugees (Syria, Eritrea, Sudan the Democratic Republic of the Congo) – English, Arabic, French speakers

- Northern Inuit (Nunatsiavut), Southern Inuit (NunatuKavut), Innu (Sheshatshiu & Natuashish), Qalipu and Miawpukek First Nations of Newfoundland

Method

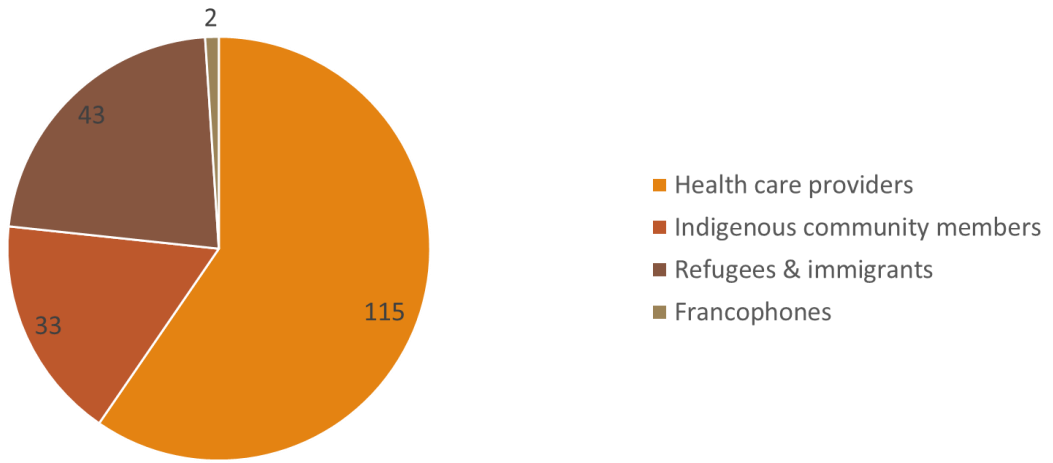
Interviews

Knowledge holders (21)
Refugee/visible minority newcomers (12)
Indigenous patients (9)

Knowledge users (25)
Formal and informal community support workers (14)
Health care providers (6)
Health system decision makers (5)

Broad scoping survey (193 respondents)

- Range and types of health service needs and expectations of patients who self-define as Indigenous or as ethnic minorities
- Circulated through Indigenous and ethnic community groups



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Interviews (conversational style)

- *How well is Eastern Health doing with providing care?*
- *What are some examples of barriers to access to care?*
- *What is needed and why?*

- "Critical Ethnography"
  - Meaning and power
  - Paying particular attention to how being marginalized affects care

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Results

INDIGENOUS PATIENTS

KUDOS

STELLAR PROGRAMMING AND LEADERSHIP

(ABORIGINAL PATIENT NAVIGATOR PROGRAM)

PATIENTS EXPERIENCE

BEING MARGINALIZED;

DISCRIMINATION, RACISM

CHANGE NEEDED

REFUGEE/VISIBLE MINORITY NEWCOMER PATIENTS

CHANGE NEEDED

LARGELY ABSENT PROGRAMMING AND LEADERSHIP

HEALTH CARE PROVIDERS 'TRYING REALLY HARD'

KUDOS

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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]

ACCESSING HEALTH - INDIGENOUS PATIENTS

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CONTEXT OF HEALTH CARE: Northern Inuit, Southern Inuit, Innu of Labrador; Qalipu and Miawpukek First Nations of Newfoundland

Indigenous community case workers arrange transport to St. John's and liaise with Aboriginal Patient Navigators (APNs) based in St. John's

Eastern Health

Aboriginal Patient Navigator (APN) program

APNs assist patients and their supporters to navigate the health system

First Light (St. John's Friendship Centre)

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Barriers to health care

1. logistics of travel from Labrador pose undue hardship on patients and their travel escorts

2. communication

3. cultural differences exacerbate the lack of trust by patients in the health care system

4. racism and marginalization shape the experience of care

5. settler-Indigenous power relations in general shape mistrust in the health care system

1. Logistics: Geography and scheduling appointments

- Staff unaware of geography
  - ***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]

- Staff unaware of burden of travel on patient well-being
  - ***There's this patient, she was really hungry and she wanted to eat …she hadn't eaten for over eight hours … 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]

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2. Communication: Access to interpretation

- Urgent need for increased access to Innu interpreters
  - *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]

2. Communication: Doctors uninformed about literacy challenges

Some of those young people drop out of school when they're like, four and five years old … And the complicated words – like myself, I can't name those pills … 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]*

My dad is a very low speaker 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?" ... 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]

3. Cultural differences: Visitor restriction policies

- Cultural differences + colonialist power relations exacerbate the lack of trust by patients in the health care system
  - *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 …. we need to stick together and support our patient.* [Indigenous patient 1: Innu man – patient, patient supporter, and interpreter]
- Urgent need for Indigenous family/ healing space
  - *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]

3. Cultural differences: traditional healing practices

- *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*. [Indigenous patient 7: Innu man – patient, patient supporter and interpreter]

- *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]

- *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]

4. Racism and marginalization shape the experience of care

- *I've had multiple experiences of being discriminated against …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… 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.* [Indigenous patient 1: Innu man – patient, patient supporter, and interpreter]

4. Racism and marginalization shape the experience of care

- *We could tell right away [Doctor's] attitude was different toward us. He was speaking to us but he wouldn't let us speak… 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… [I] 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]

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5. Settler-Indigenous power relations in general shape mistrust in the health care system

- *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 [Indigenous] police officers, that kind of thing. We have social workers whose hands are tied because they got to go by the system. …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.*
- *Well, we have this paper in the system, there's all kinds of words written…"*If you don't follow, 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].

Then the doctor asked me, like, "Why you didn't bring them [babies] 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…. So I was like, I had a lot of yelling, screaming with the 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" …

[Refugee patient 6: woman, Arabic speaking]

ACCESSING HEALTH - REFUGEE PATIENTS

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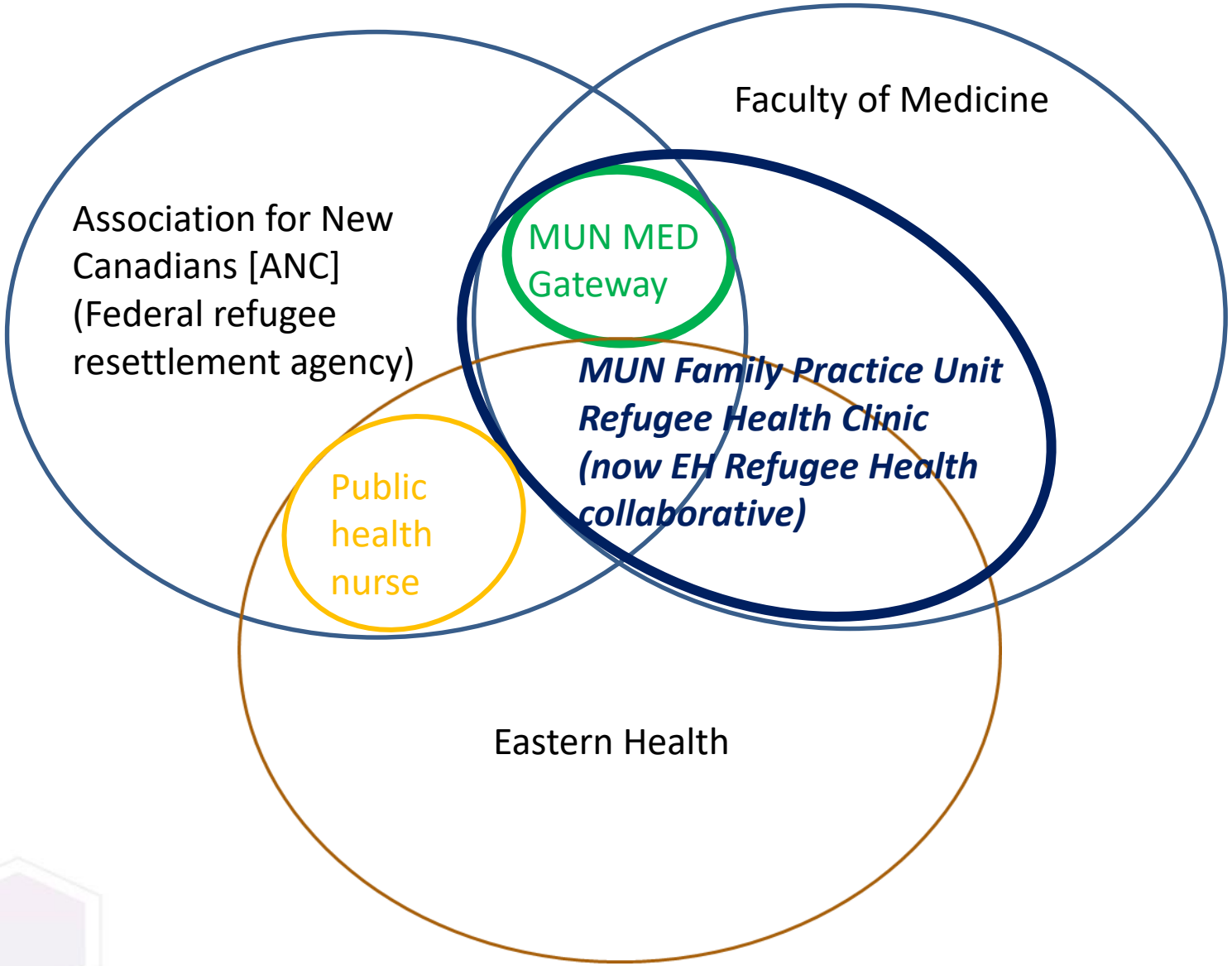

CONTEXT OF HEALTH CARE: refugee newcomers

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Barriers to health care

1. logistical barriers to accessing care
2. language barriers and interpretation challenges
3. challenges posed by cultural differences
4. discrimination
5. mistrust with care; nonadherence to treatment

1. Logistical barriers to accessing care: missed appointments

- Transit system
- Complex systems of registration
- Difficulty finding sites, and finding offices within sites
- Administrative errors and patient doesn't realize
- Patient not properly told who they are being referred to, or why
- Receiving letters at home in English

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 go to the doctor.
[Refugee patient 6: woman, Arabic speaking]

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".
[Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

1. Logistical barriers to accessing care: Access to family physicians

- Physician lack of familiarity with working across languages and cultures
- Physician lack of familiarity with diseases and conditions of newcomers
- Fee for service pay structure –
  - physicians cannot take the time to listen and learn from patients, to work effectively with an interpreter, to practice culturally competent care …

1. Logistical barriers – Fee-for-service pay

[mimics doctor speaking] *"*I can't see three of them together*" . So I was like, "*Okay, I know that you can't see them together when there's something that's 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*"* [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

It is fee-for-service, you know, it probably costs 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]

2. Language barriers and interpretation challenges

1. Telephone interpretation
   - Health care providers don't know how to access/use it
   - Not broad enough access to telephone interpretation service
2. Access to in-person interpreter
   - rare language; unexpected need; modesty requirements
3. Variability in training, lack of support for interpreters
4. Clinician incompetence

2. Language and interpretation challenges: interpreters as culture brokers

- Interpreters often do more than interpret
- Supports to patients and families
  - helping to navigate the system
  - helping to "broker" the cultural gap between patients and providers

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]

[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.* [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

3. Challenges posed by cultural differences

- Modesty requirements: beyond appropriate ‘draping’
- Alternative conceptions of autonomy and decision-making
- Power differentials
  - patient to physician
  - female (patient) to male (health care provider)
  - newcomer with no political “clout” to established Newfoundlander

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]

*…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]

3. Challenges posed by cultural differences (cont'd)

- Visitor policies
  - Who counts as "immediate family"?
- Naming systems causing confusion
- Child safety practices
- Alternative healing modalities: patients not telling physicians; physicians not asking

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" …. 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]

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…. 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]

Clinicians fear being culturally incompetent

- *The staff are nervous about the cultural … It's the unknown … Nurses don't like not being comfortable. … 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]

- *People are really worried that they're going to be inappropriate or insensitive … 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…stupid about it". … [Social worker 1]

4. Discrimination – and being unable to be assertive because of the precariousness of residency status

- *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 6a: man, Arabic speaking]

- *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. …* ***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*** **[from the nurse]** *– I don't care about this you know, it doesn't matter. It doesn't bother me at all.*
  [Refugee patient 6b: woman, Arabic speaking]

4. Discrimination: Equating “refugee” with “incapable”

- *[When a refugee patients asks a “silly” question], 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?*” …. [Doctors consider refugee patients to be], like, “*Oh those people do not know anything. Those people are coming from a new country*” … so I have this feeling like I want to tell the doctor, “*Hey, like see we’re not still living in tribes… we have technology, we have everything and we are good people – stop doing that*”, you know …. .* [Formal and informal support worker 5, interpreter, international student, recent immigrant patient]

- *Often times most of the family doctor 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.*”…. 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 and economic immigrant, immigrant patient]

5. Mistrust with care; nonadherence to treatment

Provider assumption – missed appointments

- Patients apparently don't know about, or don't care about, physicians' busy schedules and a congested health care system and their own health care

Patient assumption – missed appointments

- Canadian health care system is odd in the context of the world's medical systems
- Doctors apparently don't know the answers or don't care enough to provide effective and immediate treatment

RECOMMENDATIONS

Recommendations

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.

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Create an obvious governance and leadership structure

1. Have centralized leadership and oversight of the system-wide approach
2. Enable community partners to guide EH decision making
3. Recognize and sanction diversity champions and initiatives
4. Evaluate programs and measure success
5. Communicate and coordinate services
6. Support capacity building

*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]

Promote an organizational culture of cultural safety – emphasise cultural humility and relations of power

1. Reflect on Eastern Health's place in the context of ongoing colonial oppression
2. Support education about and acceptance of traditional healing modalities
3. Notice places of marginalization; create spaces
4. Create alternatives to the fee-for-service pay structure for physicians
5. Acknowledge and provide opportunity for informal community volunteers
6. Reverse the order of who holds the knowledge (patients as advisors)

Emphasise cultural safety and humility

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.

Reverse the order of who has the knowledge

- Engage patients and other knowledge holders in decision making
  - At all levels of decision making

I'm usually just invited in to give an opening prayer.
No one has ever asked me for my opinion until now.
(Project Elder)

Centre for Bioethics: **mun.ca/bioethics**

https://www.mun.ca/bioethics/faculty/fernbrunger/ehdp.php

Learn more about the Eastern Health Diversity Project

- ✓ Results – Refugee component
- ✓ Results – Indigenous component
- ✓ Recommendations
- ✓ Recorded presentation – Refugee session
- ✓ Recorded presentation – Indigenous session
- ✓ PDF of full report

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