

## Review Article

# Mapping the Landscape of Equitable Access to Advanced Neurotechnologies in Canada

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**ABSTRACT:** Geographic, social, political, and economic factors shape access to advanced neurotechnologies, yet little previous research has explored the barriers, enablers, and areas of opportunity for equitable and meaningful access for diverse patient communities across Canada. We applied a mixed-mode approach involving semi-structured interviews and rating scale questions to consult with 24 medical experts who are involved in the care of patients who undergo functional neurosurgery targeting the brain. Seven major themes emerged from the qualitative analysis: *Health care system, Neurotechnology features, Patient demographics, Target condition features, Ethics, Upstream barriers and enablers, and Areas of opportunity*. Descriptive statistics of the Likert-scale responses suggest that interviewees perceive a disparity between the imperative of access to advanced neurotechnologies for people living in rural and remote areas and the likelihood of achieving such access. The results depict a complex picture of access to functional neurosurgery in Canada with pockets of excellence and a motivation to improve the availability of care for vulnerable populations through the expansion of distributed care models, improved health care system efficiencies, increasing funding and support for patient travel, and increasing awareness about and advocacy for advanced neurotechnologies.

**RÉSUMÉ :** Accès équitable à la neurotechnologie de pointe : tableau de la situation au Canada. L'accès à la neurotechnologie de pointe dépend de facteurs géographiques, sociaux, politiques et économiques. Pourtant, il s'est fait peu de recherche sur les obstacles et les facteurs favorables ainsi que sur les champs d'amélioration qui influent sur les possibilités d'un accès équitable et valable à ce type de technologie, dans différentes communautés de patients, partout au Canada. Nous avons donc adopté une approche mixte, consistant en des entrevues semi-structurées et en des questions d'appréciation, et avons consulté 24 spécialistes du domaine actifs dans les soins aux patients soumis à une intervention de neurochirurgie fonctionnelle ciblant le cerveau. Il s'est dégagé de l'analyse qualitative sept grands thèmes : le système de soins de santé, différents aspects liés à la neurotechnologie, les données démographiques des patients, les affections cibles, l'éthique, les obstacles et les facteurs favorables en amont ainsi que les champs d'amélioration. D'après les statistiques descriptives des réponses au questionnaire de type Likert, les participants ont l'impression qu'il existe un écart entre les motifs d'accès à la neurotechnologie de pointe et les probabilités d'un accès réel à ce type d'intervention en milieu rural ou en région éloignée. Les résultats brossent un tableau complexe de l'accès à la neurochirurgie fonctionnelle au Canada, qui fait ressortir à la fois des îlots d'excellence et des sources d'amélioration de l'offre de soins aux populations vulnérables par l'élaboration d'autres modèles de prestation de soins, une amélioration de l'efficacité du système de soins de santé, une augmentation du soutien aux patients et du financement de leur déplacement, la sensibilisation de la communauté à la neurotechnologie de pointe et la promotion de ce type d'intervention.

**Keywords:** Neurotechnology; Neuroethics; Equitable access; Vulnerable populations; Rural access; Neuromodulation; Movement disorder surgery; Epilepsy surgery; Functional neurosurgery; Stereotactic surgery

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## Introduction

*“Access to healthcare—particularly in rural areas—goes far beyond proximity of services. Achieving accessibility also necessitates choice, economic and informational resources, and care that is perceived to be effective and appropriate”*.<sup>1</sup>

Canada is a geographically expansive and multicultural country, where rural areas account for more than 90% of the total

land mass and are home to nearly one-third of the population.<sup>2</sup> Higher proportions of Indigenous peoples live in rural and remote areas and are a majority population in the north.<sup>2</sup> Some advocates have characterized medical care in Canada as a two-tier system, split by rural and urban or by Indigenous and settler populations.<sup>3,4</sup> Others have highlighted opportunities; Bell and Menec described rural areas as “a hub for innovation” to “demonstrate innovative models of delivery that can be translated to urban areas later”.<sup>5</sup>

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**Highlight Box: Opportunities for Action**

- Ease the burden of travel for neuromodulation follow-up by enabling distributed care models, increasing local competencies in device management, offering resources to offset travel costs, and considering other clinically appropriate treatment options with lower long-term maintenance requirements.
- Increase awareness and advocacy for advanced neurotechnologies and treatment refractory functional conditions within the medical community and the general public.
- Improve health systems efficiencies through the sharing of information across health care networks, referral systems, and jurisdictional changes under the auspices of a national strategy for equitable access to functional neurosurgery.
- Develop cultural competencies within the Canadian neurological sciences community about diverse meanings of brain wellness and disease.<sup>13</sup>

For Canadians living with neurologic disorders such as Parkinson's disease, epilepsy, chronic pain and mental illness, access to advanced healthcare is considered essential and is codified in Canada's Health Act.<sup>6</sup> Modern neurotechnologies that intervene on the brain such as deep brain stimulators (DBS) and magnetic resonance imaging-guided focused ultrasound (MRgFUS) can offer hope, dignity, and the remediation of unbearable symptoms. As functional neurosurgery is only offered in major academic medical centres, geographic, social, political, and economic factors shape access. Honey and colleagues, for example, reported significant variability in DBS implantation rates between provinces based on more than 700 implantations that occurred in Canada between 2015 and 2016.<sup>7</sup> They also reported that the median household incomes of communities where people received DBS were significantly higher than the national median household income. They did not identify any access differences between rural and urban communities. There were no implantations in persons from the Territories; however, a finding that they attributed to the short study time frame and a relatively small, young population. Harding and Illes conducted a secondary analysis of the data to compare the expected number of implantations in the urban and rural areas of each province with the national rate and reported a possible access issue in the Atlantic provinces.<sup>8</sup> Crispo and colleagues reported significant regional variation in DBS implantation rates in Ontario.<sup>9</sup>

Recently, two priority areas that have been identified for neuroethical inquiry are "issues of equity, resource allocation, and distributive justice"<sup>10</sup> and the cultural meanings of advanced neurotechnologies.<sup>11</sup> To our knowledge, no Canadian study has looked at whether access may differ across the lines of race, ethnicity or culture, or applied qualitative methods to investigate access disparities. This gap is significant because the varying definitions of rural and remote and the size of populations can impact results and conclusions derived from quantitative models.<sup>9,12</sup>

**Case Study****Methods****Design**

We used a mixed-mode approach to consult with Canadian and international medical experts, identified through their affiliation with two relevant professional organizations, who refer patients to neurosurgery or who use functional neurosurgery to ameliorate the symptoms of neurologic and mental health disorders. We conducted individual semi-structured interviews between January and April 2020 involving a series of open-ended questions focusing on the current level of access to functional neurosurgery as well as barriers, facilitators, and opportunities for access for specific populations including adults and children, people living in rural and remote communities, and people from a range of cultural backgrounds (Box 1). In the preamble to the interviews, we specified that our focus was on access for interventions to

**Box 1: Semi-structured interview questions**

1. How are you involved with functional neurosurgery using advanced neurotechnologies in your clinical or research practice?
2. In your impression, what is the current level of access to functional neurosurgery in < country of residence > for diverse geographic and ethnic communities?
  - 2a. What may be some barriers and facilitators to access?
 

Prompts:

    - i. Travel
    - ii. Developments in telehealth
    - iii. Resource constraints in rural communities
    - iv. Other competing health priorities
    - v. Cultural, historical, or policy considerations
    - vi. Features of the technologies, such as level of invasiveness or risk/benefit trade-off
  - 2b. Are you familiar with policies in your province pertaining to advanced healthcare, surgical or otherwise, which enable or block access for rural and remote populations?
3. What are the opportunities around access, benefits, and applications for functional neurosurgery using advanced neurotechnologies in the healthcare of people living in rural and remote areas?
  - 3a. Do these opportunities differ:
    - i. Across the different medical conditions they aim to remediate: movement disorders, epilepsy, chronic nonmalignant physical pain, and mental illness?
    - ii. By the features of the technologies?
    - iii. According to cultural, historical, or policy considerations?
    - iv. Between pediatric and adult populations?
4. Is there anything else you would like to share with us about functional neurosurgery, advanced neurotechnologies, and rural and remote populations?

**Box 2: Likert Scale questions (abbreviated)**

*Part 1:* Rate the < imperative / likelihood > of access to < neuromodulation / ablation and resection > for rural and remote communities in < their country of practice >, using a scale of 0–4, where 0 is none and 4 is high.

*Part 2:* Rate the < imperative / likelihood > of access to < neuromodulation / ablation and resection > for < movement disorders / epilepsy / chronic nonmalignant physical pain / mental illness > for rural and remote communities in < their country of practice >, using a scale of 0–4, where 0 is none and 4 is high.

the brain. All interviews were audio recorded, transcribed professionally, and made software-ready for analysis using NVivo 12 software (QSR International).

Participants also responded to 20 Likert-scale questions evaluating the likelihood and imperative (0: none; 4: high) of access to neuromodulation or ablation and resection for individuals living in rural and remote communities in their country of residence for movement disorders, epilepsy, chronic nonmalignant physical pain, and mental illness, and in general (Box 2). Deep brain stimulation (DBS), motor cortex stimulation and responsive

neurostimulation, and the technologies used for ablative and resective brain surgeries were in scope for the interview. Noninvasive technologies such as transcranial direct current stimulation (tDCS), transcranial magnetic stimulation and electroconvulsive therapy, spinal and peripheral nerve interventions including vagal nerve stimulation and spinal cord stimulation, infusions, cell and gene therapies, and neurowearables were out of scope.

The research was approved by the University of British Columbia Research Ethics Board (#H19-03196), and consent was obtained from study participants prior to all consultations.

### Data Analytic Approach

We applied qualitative content analysis and thematic analysis methods to derive themes from the interviews,<sup>14,15</sup> guided by a pragmatic neuroethics interpretive framework.<sup>16</sup> Our goal for the analysis was to provide an overall description of this under-researched area.<sup>14</sup> The process involved bracketing our own presupposed notions on the topic from influencing our analysis,<sup>17</sup> and then engaging in multiple rounds of iterative category formation using a constant comparison method and a rich coding strategy so that more than one theme could be applied to a single statement.<sup>14,18</sup> We refined the final set of themes based on prevalence within the dataset, the quality of the supporting data, and each theme's importance for answering the research question.<sup>14</sup> Prevalence was calculated as the number of interviewees who articulated each theme. Major thematic categories were defined as the broad organizing themes; minor themes constitute the major themes identified, and subthemes in turn constitute the minor themes.

LH was the primary coder, and a trained research assistant (JM) co-coded 15% of the transcripts to test for interrater reliability.<sup>19</sup> Discrepancies were discussed until there was consensus.

We also used Wilcoxon signed-rank tests to test the *a priori* hypothesis that the median rating of the likelihood of access to neuromodulation in general for people living in rural and remote areas is lower than for ablation and resection. This hypothesis was based on our prediction that the burden of maintaining the functionality of a reversible neuromodulatory intervention (e.g., programing, battery replacement) that requires travel is greater than the burden of undergoing a more invasive, one-time irreversible ablative or resective procedure.

## Results

### Demographics

We interviewed 22 experts practicing medicine in Canada and two practicing abroad ( $n = 24$ ). Twenty-one are subspecialized physicians; three are nurses specializing in neuromodulation (Table 1). All are involved in some stage of care for patients who undergo functional neurosurgery, involving the assessment and referral to surgery through continuing care and follow-up. Seventeen interviewees work only with adults; seven with both adults and children. One interviewee works exclusively with spinal cord stimulation and ablation for pain. Most are involved in research. Only six interviewees had experience in rural areas, of which four had worked rurally. Mean length of the interviews was 27 minutes.

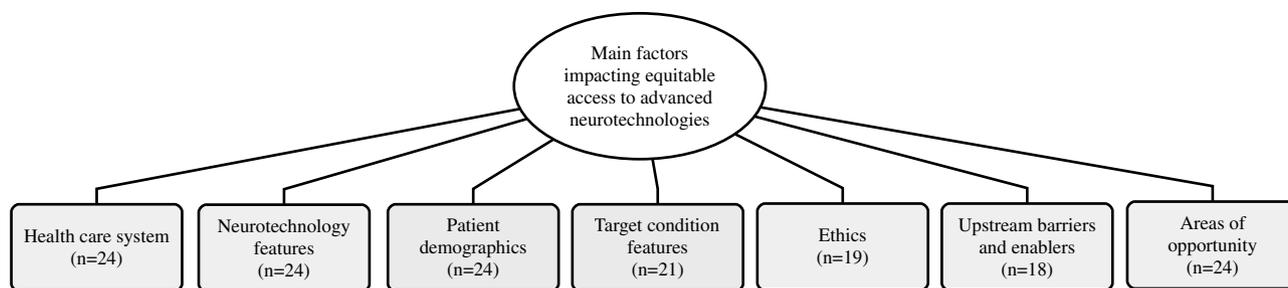
### Qualitative Results

A Cohen kappa of 0.9 was achieved in the analysis of transcript coding indicating high intercoder reliability. The content from the

**Table 1:** Demographics of interviewees ( $n = 24$ )

<b>Professional specialty</b>	
Functional neurosurgery	8
Neurosurgery resident	4
Neurology	4
Registered nurse	3
Anesthesiology	2
Neuropsychiatry	2
Biochemical genetics	1
<b>Conditions treated</b>	
Movement disorders	21
Chronic nonmalignant physical pain	15
Mental illness	15
Epilepsy	11
<b>Patients' age group</b>	
Adults only	17
Both adults and pediatric	7
<b>Years in practice</b>	
Median	11.5
Range	40
<b>Involvement in research</b>	
Conducts or collaborates in research	21
No research involvement	3
<b>Gender</b>	
Male	19
Female	3
Self-identifying as both male and female	1
Prefer not to indicate	1
<b>Location of practice</b>	
British Columbia, Canada	10
Ontario, Canada	7
Alberta, Canada	2
Nova Scotia, Canada	2
New Brunswick, Canada	1
International (outside Canada)	2
<b>Experience in rural settings</b>	
None	18
Lived experience with minimal or no work experience	2
Both lived and work experience	2
Work experience only	2

interviews fit into seven major thematic categories (Figure 1): 1. *Health care system*; 2. *Neurotechnology features*; 3. *Patient demographics*; 4. *Target condition features*; 5. *Ethics*; 6. *Upstream barriers and enablers*; 7. *Areas of opportunity*. A pedigree depicting the first six major themes and the minor and subthemes that constitute them are provided in Table 2. The seventh major theme is shown in Table 3.



**Figure 1:** Concept map of the major thematic categories of the qualitative analysis. N represents the number of interviewees who discussed the theme.

### 1. Health care system

In the major thematic category *Health care system* ( $n = 24$ ), *Resource allocation* ( $n = 23$ ) was the largest minor theme and encompassed comments about how the processes that underlie the allocation of scarce health resources can prevent or enable equitable access ( $n = 23$ ). The two subthemes were *Economics* ( $n = 17$ ) and *Politics and policies* ( $n = 12$ ):

“And any time a new government comes in or a new budget comes in, I think these things change.” (Interviewee #11)

The second minor theme was *Physically centralized medical system* ( $n = 21$ ), and the third was *Collaboration and information sharing among healthcare professionals* ( $n = 6$ ):

### 2. Neurotechnology features

The theme *Neurotechnology features* describe how the features of advanced neurotechnologies can impact access. It consisted of nine minor themes and two subthemes (Table 2). *Follow-up care requirements* were the most prevalent minor theme ( $n = 23$ ) and focuses on the requirement of *Programming neuromodulation devices* ( $n = 18$ ). Most interviewees also spoke about a state of *Limited awareness and diverse perceptions* among the medical community and public about advanced neurotechnologies ( $n = 22$ ), which included both a shortage of general knowledge about the interventions and the misconceptions and differing opinions that can exist about them:

“[...] that’s sort of like a natural taboo that someone’s going to stick something into my brain, am I going to be a different person when I wake up? There’s a different fear associated with brain surgery as opposed to peripheral general surgery.” (Interviewee #19)

Many interviewees also described a state of *Limited and variable availability* of advanced neurotechnologies across the country ( $n = 21$ ) with extensive *Waitlists* in many areas ( $n = 9$ ):

“[I]n general, Canadians are underserved for this, even in urban populations” (Interviewee #01).

The *Highly specialized* nature of functional neurosurgery ( $n = 20$ ), the *Nature of the evidence* about each intervention ( $n = 19$ ), *Effectiveness and benefit* ( $n = 17$ ), the *High costs* associated ( $n = 13$ ), *Invasiveness* ( $n = 13$ ) and variable levels of *Risk* ( $n = 12$ ) were the other minor themes:

“I think only kind of a perception of neurosurgery maybe being a very, very big expensive field where you know, most people wouldn’t think about working closely with their local neurosurgeon” (Interviewee #02)

### 3. Patient demographics

All interviewees spoke about how *Patient demographics* ( $n = 24$ ) can shape an individual’s access, especially in the context of *Community features* ( $n = 24$ ). Interviewees took into consideration not only the rurality, remoteness, or northerness of a patient’s home community, but also the distance to a centre that offers functional neurosurgery:

“[...] it would be interesting to see if the distance from centre, you know, its effect on number of patients per hundred thousand treated or referred or whatever. Because I’m sure it’s quite profound. Because, you know, the people that we treat tend to be relatively close by. Especially with these mental health interventions.” (Interviewee #03)

Twenty interviewees spoke about *Pediatric populations*. The two subthemes were: *More caution with children* ( $n = 7$ ) and *More resources for children* ( $n = 5$ ):

“Because, I mean, governments and societies will sort of bend over backwards to make sure the kids are taken care of,” (Interviewee #10).

Seventeen interviewees spoke about how a patient’s membership in a particular *Cultural, ethnic, racial, or religious group* may impact their access, and fifteen spoke about *Clinical suitability*. The minor theme *Personal resources* ( $n = 14$ ) split into subthemes about the level of *Social and caregiver support* ( $n = 13$ ) and *Financial resources* ( $n = 11$ ) available to each patient:

“And so a huge, you know, financial burden for people to take time off work. Or for family to take time off work, caregivers, whatnot, to come here for the programming, which could be every week for a little while – every other week and then monthly for a short time.” (Interviewee #08)

### 4. Target condition features

The theme *Target condition features* consists of three minor themes that describe how the *Prevalence* ( $n = 17$ ), *Functional nature* ( $n = 10$ ), and *Severe and treatment refractory nature* ( $n = 6$ ) of the conditions that functional neurosurgery targets contribute to the current picture of access. Statements captured in this theme were frequently related to the management of scarce healthcare resources:

“Because it’s quality of life surgery it seems that it’s a greater battle for us to get funding allocated as opposed to more emergency things, right?” (Interviewee #11)

### 5. Ethics

The ethics content from the interviews fit into two minor themes: *Distributive justice and fairness* and *Exclusion and bias*.

**Table 2:** Pedigree of five major themes and the minor themes and subthemes that constitute them. *N* represents the number of interviewees who discussed the theme

Major and Minor Themes	# Interviews (n = 24)
<b>Health care system</b>	<b>24</b>
Resource allocation	23
Economics	17
Politics and policies	12
Physically centralized medical system	12
Collaboration and information sharing among healthcare professionals	6
<b>Neurotechnology features</b>	<b>24</b>
Follow-up care requirements	23
Programming neuromodulation devices	18
Limited awareness and diverse perceptions	22
Limited and variable availability	21
Waitlists	9
Highly specialized	20
Nature of the evidence	19
Effectiveness and benefit	17
High costs	13
Invasiveness	13
Risk	12
<b>Patient demographics</b>	<b>24</b>
Community features	24
Distance from medical centres	24
Rurality	21
Northernness	15
Remoteness	14
Pediatric populations	20
More caution with children	7
More resources for children	5
Cultural, ethnic, racial, or religious groups	17
Clinical suitability	15
Personal resources	14
Social and caregiver support	13
Financial resources	11
<b>Target condition features</b>	<b>21</b>
Prevalence	17
Functional nature	10
Severe and treatment refractory nature	6
<b>Ethics</b>	<b>19</b>
Distributive justice and fairness	13
Exclusion and bias	9
<b>Upstream barriers and enablers</b>	<b>18</b>

**Table 3:** Minor themes describing future areas of opportunity for equitable access to advanced neurotechnologies. *N* represents the number of interviewees who discussed the theme

Minor Themes	# Interviews (n = 24)
Expand the use of telehealth	19
Consider lower maintenance interventions for patients to reduce the need for follow-up care	12
Increase education about advanced neurotechnologies and functional conditions	12
Implement outreach and satellite clinics for functional neurosurgery-related care, including assessments and DBS programming	9
Support patient travel with more funding and resources	8
Increase advocacy for patients who could benefit from functional neurosurgery	8
Enable patients to travel outside of home region for surgery	8
Improve system efficiencies in information-sharing across health care networks and referrals, jurisdictional changes, and a national strategy	5
Train more healthcare providers to be comfortable with and to program neuromodulation devices	5

Principles of distributive justice and fairness were expressed by over 50% of the interviewees (n = 13):

*“[ . . . ] there’s no reason why, as we’re one nation from coast to coast to coast, that anybody should have reduced access to appropriate care because of their location. [ . . . ] The fact that you are a resident and a citizen of Canada, as such you should be entitled to access as anybody in Vancouver.”* (Interviewee #19)

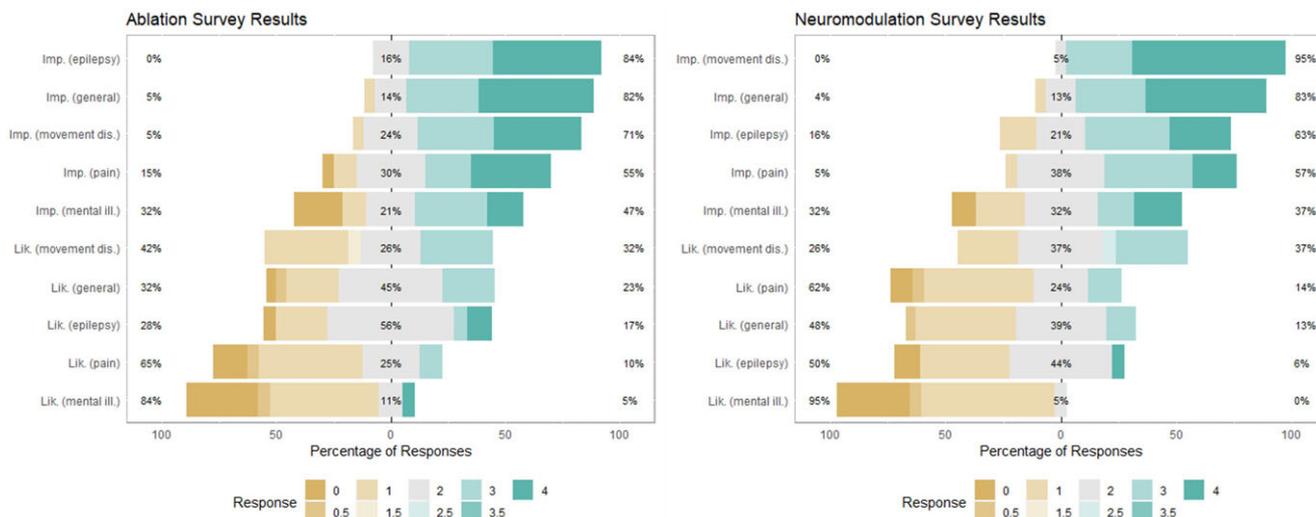
*“I mean if there’s a truly effective modality, we should try to advocate for better awareness of them - you know, who would be candidates for them. We shouldn’t let them linger with a refractory disease without thinking about other options.”* (Interviewee #23)

*“I think it’s important to look at this through many different perspectives and to ensure that you know, Canadians have equal access to health care as one of our core tenants.”* (Interviewee #28)

The minor theme *Exclusion and bias* was discussed in nine interviews, primarily in the context of specific cultural, racial, ethnic, or religious groups, or people who live in communities that are rural, remote, or otherwise far away from major health care centres. Within this minor theme, several interviewees spoke specifically about Indigenous populations:

*“I do certainly have an Indigenous patient here who [ . . . ] always asks me every time he comes why there are no studies looking at Indigenous people with Parkinson’s disease.”* (Interviewee #08)

*“And we have a large Indigenous population [ . . . ] where I work and I see patients from those communities all the time, even in my practice. But I can probably count on one hand the number of*



**Figure 2:** Percentage distribution of rating scale responses (Low: 0; High: 4). Imp.: imperative; lik.: likelihood; movement dis.: movement disorders; mental ill.: mental illness; pain: chronic nonmalignant physical pain; general: in general for any clinical indication.

them that have undergone the neuromodulation treatments that I offer. [...] I also think that it's possible, being self-critical of our own program, it's possible that because one of these things – particularly for implanted devices – we want to make sure is in place is a kind of supportive environment for a patient and a motivated patient that can look after a device and so on. I think it is possible that [...] there's some unconscious bias there and that Indigenous populations are not offered the treatments because there might be the sense that the environment is not suitable for them to be able to look after these devices. [...] I'm not sure that there's anything intentional there specifically, right?" (Interviewee #11)

Another interviewee spoke to the potential impact of living in a remote community:

"[...] just the bias people probably have that if you're living in a remote area, you're probably capable of accepting a decreased accessibility to care. In other words: the bias of practitioners that, well you live so far away you're probably happy with less. [...] why else would we be advocating for people who are from remote areas to get better access? [...] there is the assumption of relative neglect." (Interviewee #15)

## 6. Upstream barriers and enablers

Eighteen interviewees spoke about barriers and enablers encountered in early upstream stages of care that can impact a patient's chances of gaining access to functional neurosurgery downstream. This includes critical bottlenecks and challenges that impact the likelihood of first receiving a timely diagnosis and appropriate treatment, and then being referred to a functional neurosurgeon for assessment as soon as it may be indicated:

"You have to talk to your family doc who has to talk to the neurologist who has to talk to the neurosurgeon, and because there are multiple steps in order to get in contact with - or on the pathway for deep brain stimulation, it is imaginable that there could be disparities." (Interviewee #28)

"Getting referred, getting into the system, I think there's the main barrier." (Interviewee #20)

## 7. Areas of opportunity

Nine minor themes comprise the major theme *Areas of opportunity* (Table 3). Except for two instances, these pertain to health systems and policy changes:

"And whether that's making telemedicine more widely available, training more specialists, easing the ability of patients to make visits etc., it has to be built into the policies that govern the use of this technology." (Interviewee #22)

"[...] it would just be nice [...] if somebody just realized that maybe this should be a national policy rather than 10 different individual provincial policies." (Interviewee #10)

The two exceptions suggest that some patients can gain access to functional neurosurgery by seeking care out of their home province or internationally, or by advocating for themselves:

"It's often patient referral, self-referral, by harassing their doctor to be able to get into some sort of a program like this." (Interviewee #06)

A subtheme of follow-up care requirements for neuromodulation recurred across several areas of opportunity. Ten out of 12 interviewees who spoke about the opportunity of considering lower maintenance interventions referred to how reducing the need for follow-up visits for programming can improve access for some patients. Thirteen out of 19 interviewees who discussed telehealth indicated the need for technology to program neuromodulation devices remotely. The call to train more healthcare providers to be comfortable with neuromodulation devices included doctors and nurses within both major urban centres and more remote areas:

"It's not that every centre has to be able to do DBS, but the knowledge of DBS has to be more widespread and more people should be able to at least access the DBS device, to interrogate it." (Interviewee #25)

## Quantitative Results

The number of responses to each Likert-scale question ranged from 18 to 23, and median ratings ranged from 1 to 4.

Descriptive statistics suggest that respondents perceive a disparity between the likelihood and imperative of access (Figure 2). Without exception, the median ratings for each imperative question were at least one unit higher than for likelihood. Likelihood and imperative scores were also strongly associated: a higher imperative was generally accompanied by a higher likelihood. The medians for likelihood ranged from 1 to 2, and the medians for imperative ranged from 2 to 4.

Access to neuromodulation for movement disorders ranked the highest, and for mental illness the lowest overall. Participants were unified in their low rankings of the likelihood of access to functional neurosurgery for mental illness but were considerably divided on the question of imperative. Questions about the imperative of access for mental illness received more responses at the extreme ends of the rating scale than for any other application.

The Wilcoxon signed rank tests did not reveal a statistically significant difference between the median rating of the likelihood of access to neuromodulation as compared to ablation and resection in general for people living in rural and remote communities ( $p = .34$ ).

### Synthesis of Qualitative and Quantitative Results

Taken together, the results suggest that exceptional barriers exist to accessing neuromodulation for people living in rural and remote areas:

*“So, is living in a rural area of Canada a contraindication to having a gizmo? No. But it certainly makes the logistics a bit more complicated given the complexity of care.”* (Interviewee #01)

Looking at the specific medical conditions, low ratings for access to neurosurgical interventions for pain may relate to a larger issue of how chronic pain is treated:

*“The major barrier is that the treatment of chronic pain is a big black hole in our medical system. It’s not done that well in general.”* (Interviewee #16)

Similarly, the low ratings for the likelihood and imperative of access to neurosurgery for mental illness related to remarks about the continuing impacts of the negative history of psychosurgery:

*“And so I think that it’s important to be mindful of the historical legacy of unbridled enthusiasm on the part of researchers and clinicians for trying certain things without regulations. And we also need to be mindful of making sure that any intervention we try is hypothesis-driven, is done judiciously, and done in a regulated fashion and is done in a way that has a lot of evidence behind it.”* (Interviewee #22)

### Opportunities

#### Discussion

In this case study of expert perceptions of functional neurosurgery for rural, remote, and ethnically diverse communities in Canada, seven major themes emerged: *Health care system, Neurotechnology features, Patient demographics, Target condition features, Ethics, Upstream barriers and enablers, and Areas of opportunity*. Neuromodulation emerged in both parts of this mixed-methods project as carrying unique considerations and potential challenges.

Neurologic disorders such as Parkinson’s disease and epilepsy are perceived to have a higher likelihood of being successfully treated with functional neurosurgery for people living in rural and remote areas than disorders involving physical pain and mental health. While the cohort of medical professionals had little direct experience with rural and remote communities, *per se*, they were able to identify a range of factors that can impact equitable access based on their clinical and research experience.

The interviewees shared a number of ideas about how to improve equitable access for diverse populations. These included possibilities for more distributed care models than are currently available, funding for patient travel, lower maintenance interventions to reduce the burden of travel for follow-up care, increasing awareness and advocacy for advanced neurotechnologies, improving the efficiency of health care systems and, for patients who can afford it, traveling outside of their home region for the surgery. A recurring focus across many areas of opportunity was the need to ease the burden on patients of traveling for frequent neuromodulation device programming appointments.

The findings of this study add to the body of research that has assessed the state of health care access for rural and remote populations in Canada living with movement disorders, epilepsy, chronic pain, and mental illness (e.g., 20–23). Statements about cultural, ethnic, and racial disparities add to what is known about the historical and ongoing injustices that Indigenous peoples face in the Canadian health care system and the need for culturally safe care,<sup>24,25</sup> and relate to evidence from other countries such as the United States from which racial disparities to DBS and epilepsy surgery have been reported.<sup>26–32</sup>

### Limitations

Twenty of the experts had little to no direct experience working in rural and remote communities. Their views are expert but can be taken as hypothetical and anticipatory only. We could not disclose information on the countries of the two international interviewees for reasons of confidentiality. While the sample size provided a sufficient range of interviewee demographics for a rich qualitative analysis,<sup>33</sup> it may not have been sufficiently powered for statistical testing of the Likert-scale questions. Additionally, diversity in the years of experience and countries of practice of the interviewees may have been sources of uncontrolled variability in the data. Finally, the interviews were prior to the COVID-19 pandemic. Recent advancements in remote health care delivery models that were developed in response to the health crisis were not captured (e.g., 34–36).

### Conclusion

Differences in health care access between rural and urban populations or ethnic groups are unacceptable and unethical. This mixed mode study of interviews with medical experts depicts a complex picture of access to functional neurosurgery in Canada with pockets of excellence and a motivation to improve the availability of care for all populations.

A coordinated Canadian strategy is needed to ensure that clinical innovations improve health for all populations, and close rather than widen gaps. Beyond the opportunities identified in the present study, the development of cultural competencies within the Canadian neurological sciences community about diverse meanings of brain wellness and disease can support this movement.<sup>13</sup> Bi-directional approaches that directly engage patient

communities are essential in this process given the evidence showing differences between how clinicians and patients perceive the risks, benefits, and invasiveness of the procedures,<sup>37,38</sup> as well as the enabling effects of patient education highlighted in the present study. Taken together, positive actions drawn from medical, legal, and ethical initiatives can improve care for culturally diverse patients living with severe, treatment refractory conditions, address historic distrust, achieve government support for equalizing access, and realize an ethically grounded future for advanced neuromodulatory and ablative technologies.

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