Huntington Society of Canada
HUNTINGTON
Société Huntington du Canada

“WE’RE FALLING THROUGH THE CRACKS”

A Multi-Stakeholder Qualitative Report of Resource Gaps in Huntington Disease Care

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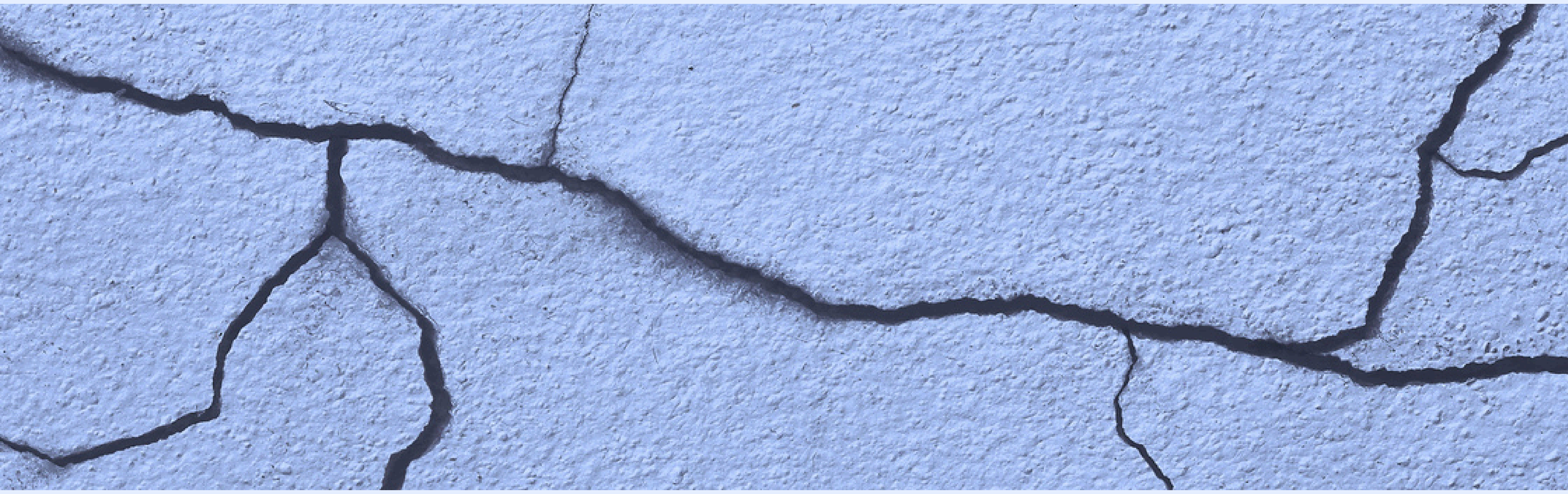


DEFINITION PAGE

RCD: Resource Centre Directors (RCDs) are registered social workers/ psychotherapists employed by HSC. RCDs offer critical counselling and advocacy support for HD families.

HSC: Huntington Society of Canada

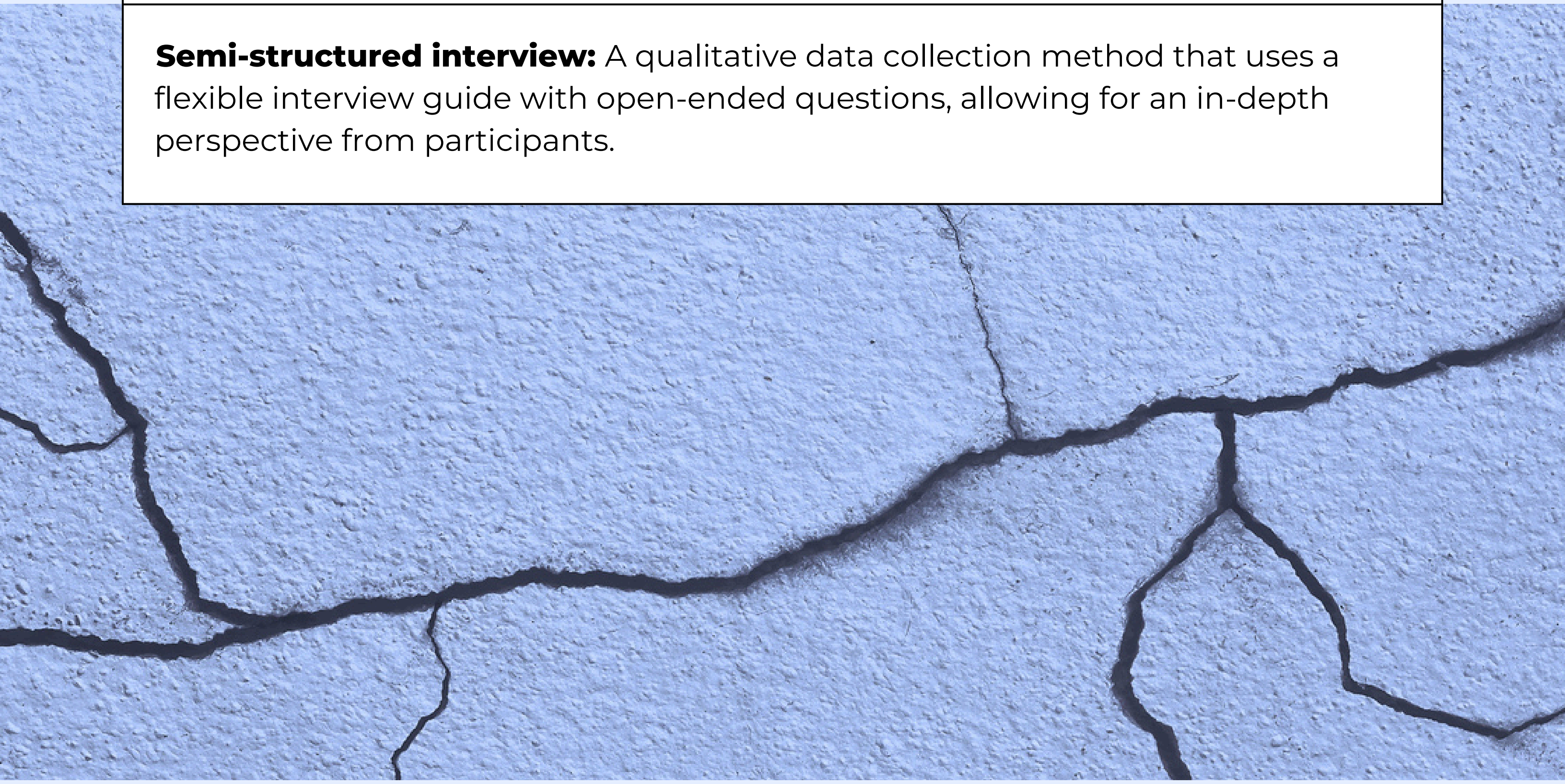
HD: Huntington disease

YPAHD: Young People Affected by Huntington Disease

GP: A GP, or general practitioner, is a medical doctor who provides primary care

LTC: Long-term care

Semi-structured interview: A qualitative data collection method that uses a flexible interview guide with open-ended questions, allowing for an in-depth perspective from participants.



BACKGROUND

Huntington disease (HD) is a progressive, hereditary, and ultimately fatal neurodegenerative disorder caused by the expansion of a CAG trinucleotide repeat in the Huntington gene located on the fourth chromosome (Nance et al., 2013). This genetic mutation leads to the production of an abnormally long polyglutamine, which is toxic to neurons (Nance et al., 2013). HD follows an autosomal dominant pattern of inheritance, meaning each child of an affected parent has a 50% chance of inheriting this disease (Nance et al., 2013). Given this inheritance pattern, it is estimated that one in every 7,000 Canadians has HD, and one in 5,500 are at risk for developing the disease (Brain Canada Foundation, 2025).

HD is characterized by a triad of motor, cognitive, and psychiatric symptoms that become quite debilitating as the disease progresses (Nance et al., 2013). Individuals with HD may gradually lose awareness of their circumstances, creating challenges for health professionals and family members (Røthing et al., 2015; Novak & Tabrizi, 2010). Given the complex and multifaceted nature of HD, resources are required from multiple fronts, emphasizing the need for coordinated, multidisciplinary care (Mühlbäck et al., 2023). However, access to appropriate care and support services remains inconsistent, with studies revealing families affected by HD have many unmet needs (Røthing et al., 2015; van Walsem et al., 2015). A study by Skirton et al. (2010) revealed that family caregivers are frequently concerned about accessing appropriate healthcare services for the affected individual, particularly those residing in rural areas. Additionally, frustration over a lack of HD-related knowledge among general practitioners remains a concern (Etchegary, 2011).

Despite growing awareness of the challenges faced by those affected by HD, there is notably a lack of qualitative research that investigates gaps in care from a comprehensive, multi-stakeholder perspective. This report aims to address this gap by gathering insights from a diverse range of stakeholders, from families affected by HD to professionals involved in HD care and support across Canada.

METHODS

Study Design:

This report employed a qualitative descriptive approach with semi-structured interviews to explore perceived gaps in care for individuals affected by HD. Thirty-five semi-structured interviews were conducted remotely with a diverse range of stakeholders across Canada. Participants were grouped into one of three categories: Huntington Society of Canada (HSC) staff, healthcare professionals (e.g., neurologists specializing in HD, genetic counsellors), and community members, including caregivers and symptomatic, gene-positive, asymptomatic, at-risk, and gene-negative individuals. This sample was selected to capture a broad range of perspectives and experiences.

A survey was also distributed to HSC staff and community members to gather additional insights.

Participant Recruitment:

Participants were recruited using a combination of snowball sampling and targeted outreach. Snowball sampling, a technique where participants help identify and recruit participants, was conducted with initial interviews, especially among HSC staff. Additionally, HSC staff assisted in targeted outreach by identifying and connecting the researcher with relevant stakeholders across clinical and community contexts.

Data Collection:

The semi-structured interviews were conducted either on Microsoft Teams, or over the phone and ranged from approximately 20-30 minutes in length. With participant consent, interviews were audio-recorded and transcribed verbatim. All audio recordings were destroyed at the end stage of the project. A semi-structured interview guide was used to ensure consistency, while allowing for flexibility in conversations.

Using a semi-structured interview approach, the researcher invited participants to discuss primary systemic gaps in care and resources, as well as common challenges that the stakeholders (HSC staff, healthcare professionals, and community members) faced or witnessed.

A total of 35 semi-structured interviews were conducted across the three participant groups. Recruitment and participation details are as follows:

HSC staff: 9 individuals were contacted, and all agreed to participate (100% participation rate).

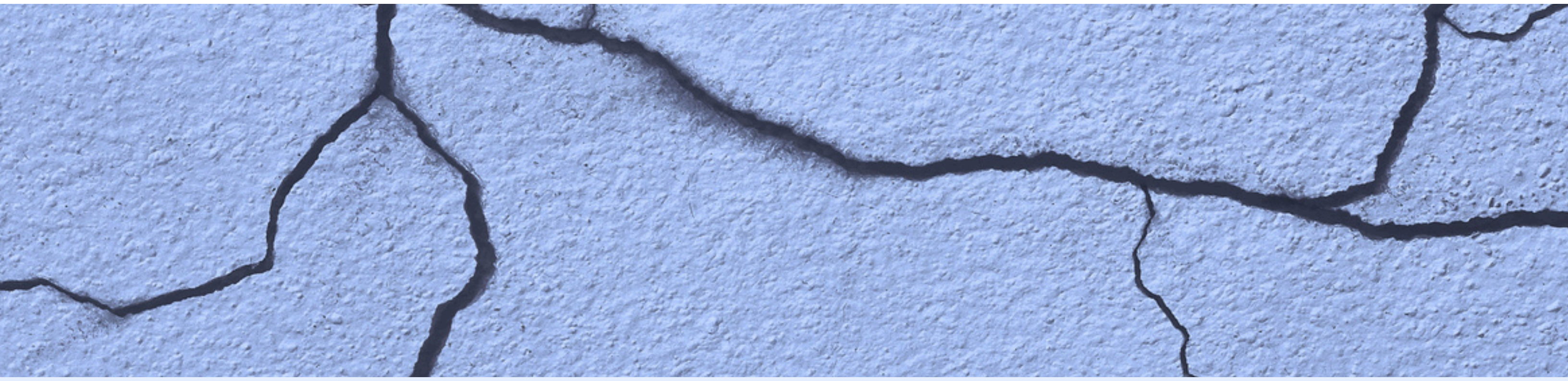
Healthcare professionals (genetic counsellors and neurologists): 15 individuals were contacted (9 genetic counsellors, 6 neurologists), with 11 completing interviews (5 genetic counsellors, 6 neurologists), for an overall participation rate of 73%.

Community members: 29 individuals were contacted, with 15 completing interviews (52% participation rate).

In addition to the interviews, 41 individuals completed the survey. Survey respondents consisted of caregivers, family members, healthcare providers, HSC staff members, symptomatic, gene-positive, at-risk, and gene-negative individuals (refer to figure 3 for the survey questions).

Data Analysis:

This report followed a qualitative descriptive approach with the researcher reviewing all transcripts and dividing them into one of three groups (HSC staff, healthcare professionals, or community members) based on the participants interviewed. Additionally, relevant quotes were retrieved from the original transcripts for integration into the report. Notes and summaries were constructed following review of each interview transcript. Key themes were formed from the researcher reviewing all transcript notes and organizing expressed gaps into different categories. The categories that were noted the most formed the key themes. Additional categories mentioned are summarized in figure 2. Commonly perceived gaps were identified with the goal of preserving participants' own views and experiences. The survey was analyzed to support the trends identified in the interviews.



RESULTS

Analysis of the data revealed three main themes reflecting participants' perceived gaps in: (1) Knowledge and Awareness (2) Staffing Shortages, and (3) Long-Term Care.

KNOWLEDGE AND AWARENESS

A common theme identified in all of the stakeholder groups were gaps in HD knowledge and awareness. While the need for better education was explored throughout the groups, the specific challenges and implications varied by the stakeholder group.

HSC Staff:

Staff at HSC emphasized a lack of HD awareness and training across multiple sectors, including healthcare, law enforcement, and the broader community. Staff noted that general practitioners (GPs) and most specialists (excluding providers specializing in HD) lacked formal training to identify or manage HD symptoms, which may delay diagnosis and/or result in poor quality of care. This sentiment was also reflected in the survey responses, with 51% of respondents rating the knowledge and awareness of HD among healthcare providers (excluding HD specialists) as poor, while 29% rated it as fair.

> "I've had, you know.. an older physician... that made the mistake of saying that it [HD] was menopause to one lady... because of her age at the time."
>
> *- RCD*

> “I think that people know that it's a genetic disorder... but they think it's Parkinson's. It's a little bit worse than Parkinson's, right?”
>
> *- RCD*

This knowledge and awareness gap also extends to the police force. HSC staff and community members expressed concern over individuals with HD being mistaken as intoxicated by law enforcement due to their motor and cognitive symptoms. Miscommunication at this level can potentially lead to unsafe or inappropriate interactions. HSC has made efforts to address this by developing and distributing a range of educational resources for law enforcement, including informational cards, videos, and several in person presentations.

Healthcare Professionals:

Healthcare professionals also expressed concerns regarding lack of HD-specific knowledge and awareness within the healthcare system, particularly among GPs, psychiatrists, and long-term care (LTC) staff. Some GPs may be unaware of HD or dismiss early symptoms, potentially causing missed or delayed referrals. While motor symptoms are often addressed, the broader medical community tends to minimize psychiatric symptoms. Psychiatrists and LTC staff are also rarely offered formal HD education or training despite their critical involvement in HD care. Overall, coordination is necessary to promote effective education initiatives and resource sharing for patients, caregivers, and allied healthcare professionals.

Community Members:

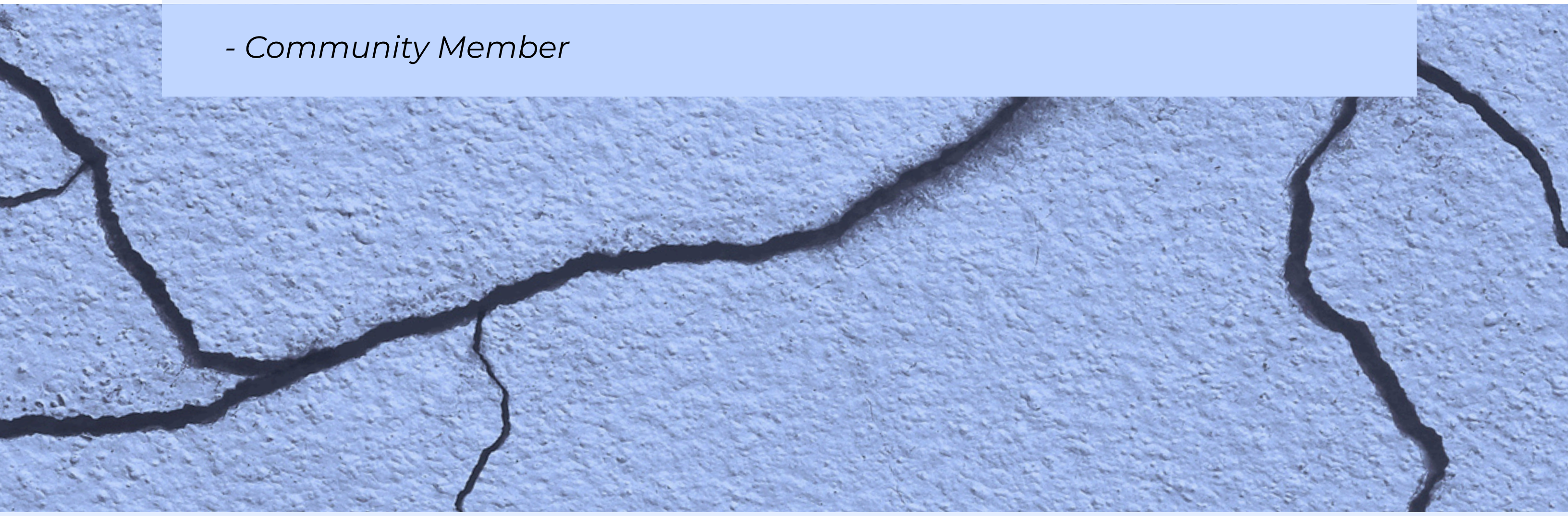
Community members noted a significant emotional and practical burden as a result of a lack of HD awareness among allied healthcare professionals. Many individuals mentioned that their GPs and LTC staff were unfamiliar with the disease or how to interact with HD patients, requiring families to assume the role of educators. This challenge was compounded by high staff turnover in LTC settings, making it difficult to build rapport. Inadequate education can, and has led to poor and unsafe care, particularly in LTC settings.

> “You could get a new PSW seven days a week and three times a day [in LTC]. So you know it's not always the same person. And I think that's hard on the person with Huntington's because you have to explain it all the time...So yeah, it's training and retraining and retraining”
>
> *- Community Member*

> “Once we got her [participant’s family member] into a home, there was a lot of challenges with the staff not understanding HD and not understanding you know the troubles with speaking and swallowing.”
>
> *- Community Member*

Participants also felt a lack of HD awareness from allied healthcare providers.

> “I go to a therapist and I feel like every time I talk about it [HD], it's like an education session. And it's not serving me. So I'm actually not seeing her anymore... Our family doctor doesn't know much either. We gave him the physicians guide.”
>
> *- Community Member*



STAFFING SHORTAGES

Across all stakeholder groups, participants described staffing shortages and unequitable access to HD care. A shortage of neurologists specializing in HD was a major concern. This is exacerbated when experts retire with no clear replacement arranged. Urban centres often benefit from multidisciplinary HD clinics (i.e., in Toronto, Vancouver, Montreal) that offer access to neurologists specializing in HD, genetic counsellors, nurses, and psychiatrists; individuals in rural and remote areas often must travel long distances, sometimes even across provinces or territories, to access these resources. However, HD clinics in both Toronto and Montreal have independently arranged outreach resources. Each year, a multidisciplinary HD team travels from Toronto to Northern Ontario and similarly an HD team travels from Montreal to Northern Quebec, providing in-person care to patients in such remote regions. Unfortunately, this practice has not been adopted nationwide, leaving many individuals facing long wait times, infrequent visits, and significant transportation barriers when accessing healthcare. This concern is supported by survey findings, with 37% of respondents finding access to specialized HD healthcare to be difficult and 27% finding it very difficult.

> “The further you are away from the major hubs, the less you know. Effectively the less support you have.”
>
> - *Community Member*

> "I go see a neurologist that's in North York...So it's a six hour round trip for me to go for a half hour appointment.”
>
> - *Community Member*

Participants also noted shortages of psychiatrists, counselors, and allied healthcare professionals (e.g., nurses, physiotherapists, occupational therapists, dieticians, etc.) with HD-specific training.

> “I am only familiar with the Huntington's clinic in St. Johns and I'm pretty sure it's only once a year and there is no psychiatrist available. So there's a lot of medications with people with Huntington's disease that would require at least someone with experience in psychiatry.”
>
> - *RCD*

> “Under the Ontario Health at home, which is a provincial system, there's no consistency as to what each community provides and what they have access to. Some don't have occupational therapists and some do, some have dieticians, and some don't.”
>
> - *RCD*

Mental health supports are often also limited, with few HD-informed counselors or psychologists available, and limited public coverage for private psychological or therapy services. Registered social workers/psychotherapists, known as Resource Centre Directors (RCDs), employed by HSC, offer critical counselling and advocacy support for HD families. Across Canada, there are 11 part-time and 5 full-time RCDs, with the majority serving in part-time roles and responsible for covering large geographic regions. High caseloads and broad coverage areas result in delayed contact, limited follow-up and reduced access to individualized counselling, particularly for those not in immediate crisis. Some families also voiced apprehension seeking support, feeling others were more deserving of the limited resources.

> "They [RCDs] are so busy that if I needed to talk to somebody, well, I'm not high on their priority list because somebody [else] needs them...So you kinda fall through the cracks...Or you talk to them and then it's two months before you talk to them again. So it's not very consistent...It's no fault to the RCD, like they can only do what they can do, and they get stretched so thin."
>
> - *Community Member*

RCDs provide essential support groups centred around education and counselling, while also dedicating much of their time to helping families navigate the various challenges experienced throughout an individual's life course. However, it is not within their job description to provide individual therapy. As such, community members expressed a gap in individualized mental health resources. Participants also noted a lack of respite resources for caregivers, making it even more challenging for caregivers to access mental health support when needed.

> “As a caregiver, I'm a part-time doctor, psychologist, social worker, financial planner, computer repair person, lawyer, just to name a few. I do all the grocery and house shopping, cook, clean clothing, shopping, car repairs... house repairs and maintenance... I'm a chauffeur, [I] take him to his multiple regular medical appointments all while trying to care for myself, giving myself some personal time. But there's no time to rest. We need to be here for our husband, our loved one as much as we can. But caregiving is a volunteer full-time job on top of my former full-time. Not too much time or energy left for me.”
>
> - *Community Member*

Participants voiced a desire to expand the number of RCDs and multidisciplinary clinics, with one neurologist even saying,

> “My recommendation is that [RCDs] should be supported by the government... social work services are medical services and they should be supported by the government. Other people that are involved in HD care, including nurses, are not covered as well. So, a proper multidisciplinary model should have a social worker, a nurse, as well as physicians, and there's many other allied health professionals that should be brought in.”
>
> - *Neurologist*

LONG-TERM CARE

Participants across all stakeholder groups noted significant systemic challenges in accessing appropriate long-term care (LTC). LTC facilities are typically designed for older adults, making them poorly suited for younger symptomatic individuals. Additionally, participants reported that some homes in the past have refused admission to younger people with HD due to age restrictions, or denied entry regardless of age, citing safety concerns. Rejection on the basis of “safety concerns” reflects an underlying stigma about HD’s behavioural symptoms and displays an unpreparedness or unwillingness to accommodate HD’s complex needs. In certain cases, HSC staff and healthcare professionals noted instances where individuals had to remain in the hospital until a LTC placement became available. This situation can create a cycle in which individuals are denied LTC due to medical/psychiatric instability, admitted to a hospital, and then discharged from the hospital for lack of acute illness, ultimately increasing the risk of homelessness, neglect, and institutionalization.

> “We had a patient here at our hospital, who was homeless and had nowhere to live and was in a really bad state... So that patient was admitted to [the hospital] and had real behavioural problems like aggression and irritability. And she was here at the hospital for two years because no long-term care homes would take her... because of her behavioural problems. So it's, you know, it's challenging and being here at the hospital is not ideal, you know either.”
>
> *- Genetic Counsellor*

HSC staff also highlighted rigid LTC eligibility criteria, including flawed capacity assessments that overlook the cognitive decline associated with HD, delaying access to appropriate care. Community members also expressed frustration with the long waitlists and wait times for LTC placements. Once granted admission into LTC, barriers persist. Frequent staff turnover, understaffing, and poor facility conditions can compromise quality of care, leaving families to constantly monitor basic needs (i.e., eating, drinking, hygiene). These conditions place a high burden on caregivers to provide persistent advocacy to ensure basic care needs are met, making the transition emotionally difficult.

> “At a certain point, my mom couldn't speak anymore. So they [LTC staff] weren't feeding her or doing anything in a timely manner because she couldn't say anything, right?... At one point they [LTC facility] argued for almost three years to give her water between lunch and dinner. Like that was a fight... It was like literally going to the upper echelons of the organization to say it's inhumane to not give someone who cannot move water from six hours ago, how many times are you drinking water?”
>
> *- Community Member*

CONCLUSION AND RECOMMENDATIONS

In conclusion, significant systemic gaps in resources persist in the delivery of care and support for individuals affected by HD. Across all stakeholder groups, there was a clear consensus on the need for increased education, awareness, and training related to HD. As such, greater efforts should be made to raise public awareness. Additionally, targeted education and training should be provided to GPs, LTC staff, and law enforcement to better equip them to meet the needs of individuals with HD. One cost-efficient strategy to enhance HD awareness is to arrange for guest speakers to present a lecture on HD at medical schools across Canada.

A second key theme identified in interviews was a shortage of professionals specializing in HD. To help address this gap, more funding should be allocated to expand clinical fellowship opportunities and broaden funding access for a wider range of care professionals (i.e. neuropsychiatrists, psychiatrists, GPs, nurse practitioners). Additionally, resources should be allocated to promote awareness of this initiative to improve recruitment. Furthermore, HD-specific training should be incorporated into seminars for both neurologists and psychiatrists as part of ongoing continuing education efforts. This would have the benefit of enhancing clinical competencies while fostering greater interest and engagement in HD care. To ensure equitable access to specialized care, particularly in rural and remote regions, efforts should also be made to improve the geographic distribution of HD resources. Availability of RCDs and limited availability of mental health support were a concern. To address this, formally integrating individual therapy and psychological support in multidisciplinary HD clinics is suggested. Extending RCD service hours is also recommended to improve the community's access to brief mental health interventions and advocacy support.

The final theme raised by stakeholders centred around insufficiencies in LTC. Participants described numerous barriers to accessing LTC placements, along with challenges in ensuring that staff were equipped to meet the unique needs of individuals with HD. Given the complex medical and behavioural needs associated with HD, it is recommended to adopt proactive planning models that prepare both the individual and the LTC home for this transition. This approach could include early application to LTC, advance care planning, and regular educational sessions with LTC staff. In addition to improving the quality of the transition, proactive planning may also reduce LTC wait times by allowing for earlier coordination and more efficient placement.

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APPENDIX

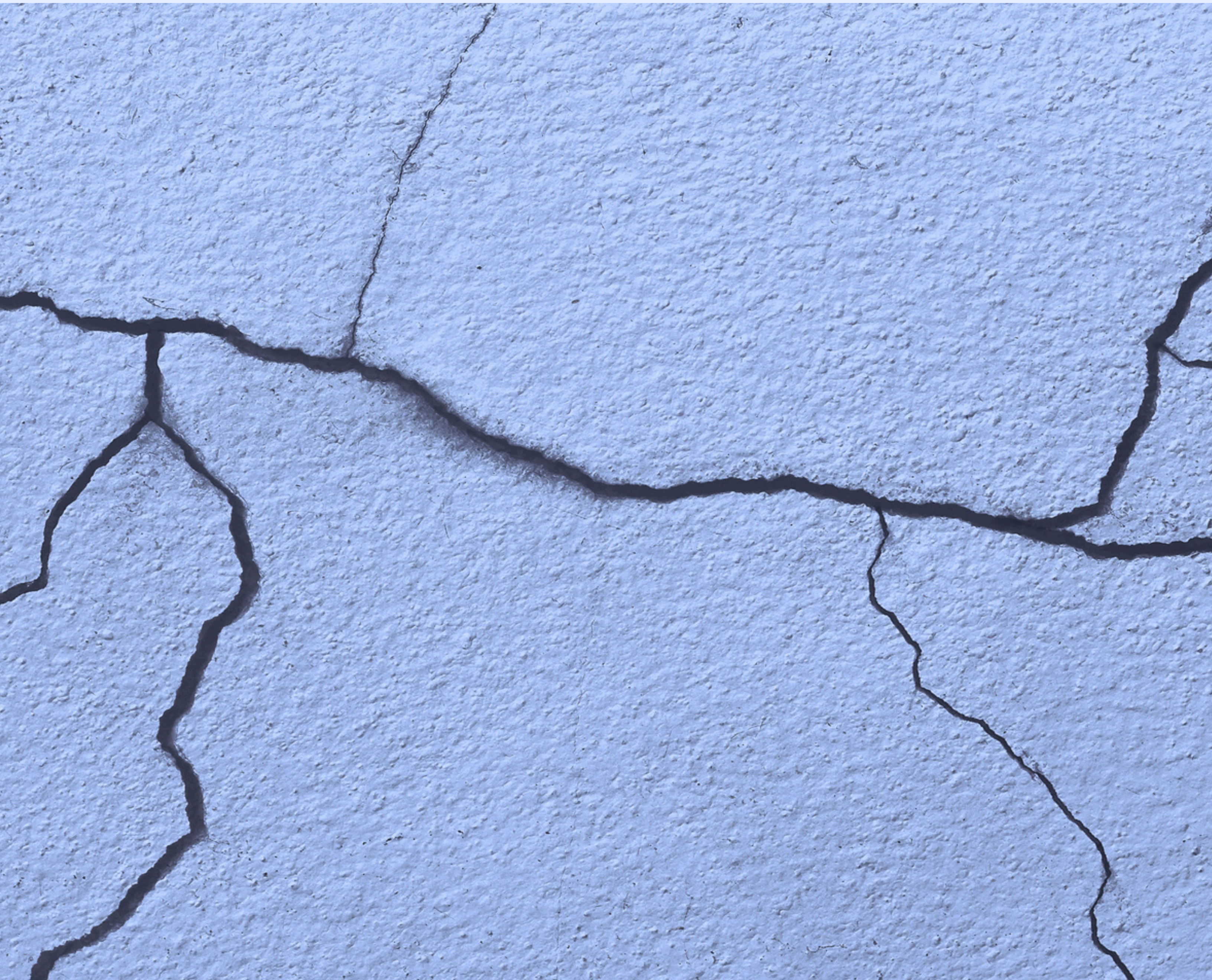


Figure 1: Summary of main themes identified in stakeholder interviews

Theme	**Description**
Knowledge and Awareness	• Widespread lack of HD awareness across healthcare, law enforcement, and the general public. • GPs, psychiatrists, and LTC staff often lack HD-specific training, leading to delayed diagnoses and poor care. • Families frequently have to educate healthcare providers due to knowledge gaps.
Staffing Shortages	• Shortages of HD-specialized neurologists, psychiatrists, counselors, and allied health professionals. Limited number of specialized HD clinics. • Rural and remote areas face long travel times and limited access to specialized HD clinics. • Limited availability of HD-informed mental health supports (e.g., therapy).
Long-Term Care	• Admissions are sometimes denied due to age or behavioural “safety concerns,” reflecting stigma and lack of preparedness. • Rigid eligibility criteria and flawed capacity assessments delay access to appropriate care. • Once admitted, poor conditions, understaffing, and high caregiver burden persist within LTC settings.

Figure 2: Additional insights addressed in stakeholder conversations

Theme	**Description**
Inadequate Caregiver Resources	Caregivers often lack adequate psychological, practical, and in-home supports.
Financial Support	Costs related to IVF, PGD, in-home care, and medical devices. Caregivers often reduce or leave paid work to provide care, resulting in significant household income loss.
Health Insurance Gaps	Limited government-funded hours for at-home care, slow/inadequate access to mobility aids with high out-of-pocket costs. Disparities to access for these resources based on location.
Outreach Gaps	Limited proactive and personal engagement, few clinics and RCDs travel to remote regions, and lack of outreach infrastructure.
Programming Gaps	Lack of age-appropriate programming and insufficient day/evening programming available for symptomatic individuals. Limited options for those who have aged out of YPAHD. Insufficient programming for individuals in the mid-to-late-stages of HD.
Clinical Trial and Research Barriers	Clinical trials face informed consent challenges, geographic barriers, limited outreach, and small eligible populations. There is also an ongoing need for effective treatments and equitable healthcare system readiness when treatment becomes available.

Figure 3: Survey questions

Question 1: What is your connection to HD?

a) I am gene-positive for HD
b) I am symptomatic with HD
c) I am gene-negative for HD
d) I am at risk for HD but have not undergone genetic testing
e) I am a caregiver/family member of someone affected with HD
f) I am a healthcare provider or work in an HD-related field
g) I am a staff member at HSC
h) I am part of the board of directors at HSC
i) I prefer not to say

Question 2: What Province/Territory do you live in?

a) Alberta
b) British Columbia
c) Manitoba
d) New Brunswick
e) Newfoundland and Labrador
f) Nova Scotia
g) Ontario
h) Prince Edward Island
i) Quebec
j) Saskatchewan
k) Northwest Territories
l) Nunavut
m) Yukon

Question 3: What is your age group?

a) Under 18
b) 18-24
c) 25-34
d) 35-44
e) 45-54
f) 55-64
g) 65+

Question 4: On a scale of 1 to 5, how easy is it to access specialized HD healthcare in your area? (1 = Very difficult, 5 = Very easy)

Question 5: How would you rate the level of knowledge and awareness of HD among general practitioners, nurses, and other healthcare providers (excluding HD specialists)? (1 = Poor, 5 = Excellent)

Question 6: What policy issues in relation to HD do you feel need the most attention? (Select up to 3)

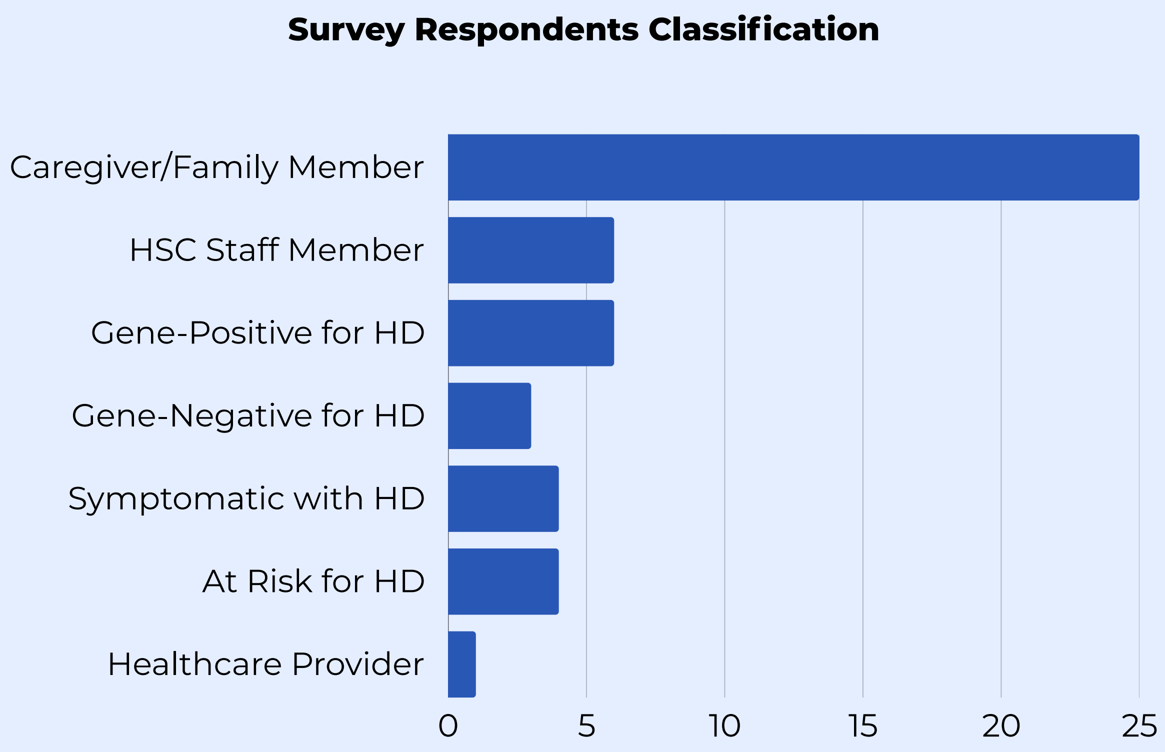
☐ Access to specialized HD clinics
☐ Disability and financial support
☐ Long-term care access
☐ Health insurance gaps (e.g., medication or equipment)
☐ Research funding
☐ Employment protections for gene-positive individuals
☐ Other

Question 7: Based on your personal experience or what you've heard from others in the HD community, what do you see as the biggest gaps/challenges in accessing care or support for HD?

Question 8: What changes do you think would make the biggest difference in the lives of people affected by HD?

Question 9: Is there anything else you'd like to share with us?

Figure 4: Survey respondents’ answer to the question: “What is your connection to HD?”



Note: Respondents were able to select multiple categories.

Figure 5: Survey respondents' answer to the question: "What Province/Territory do you live in?"

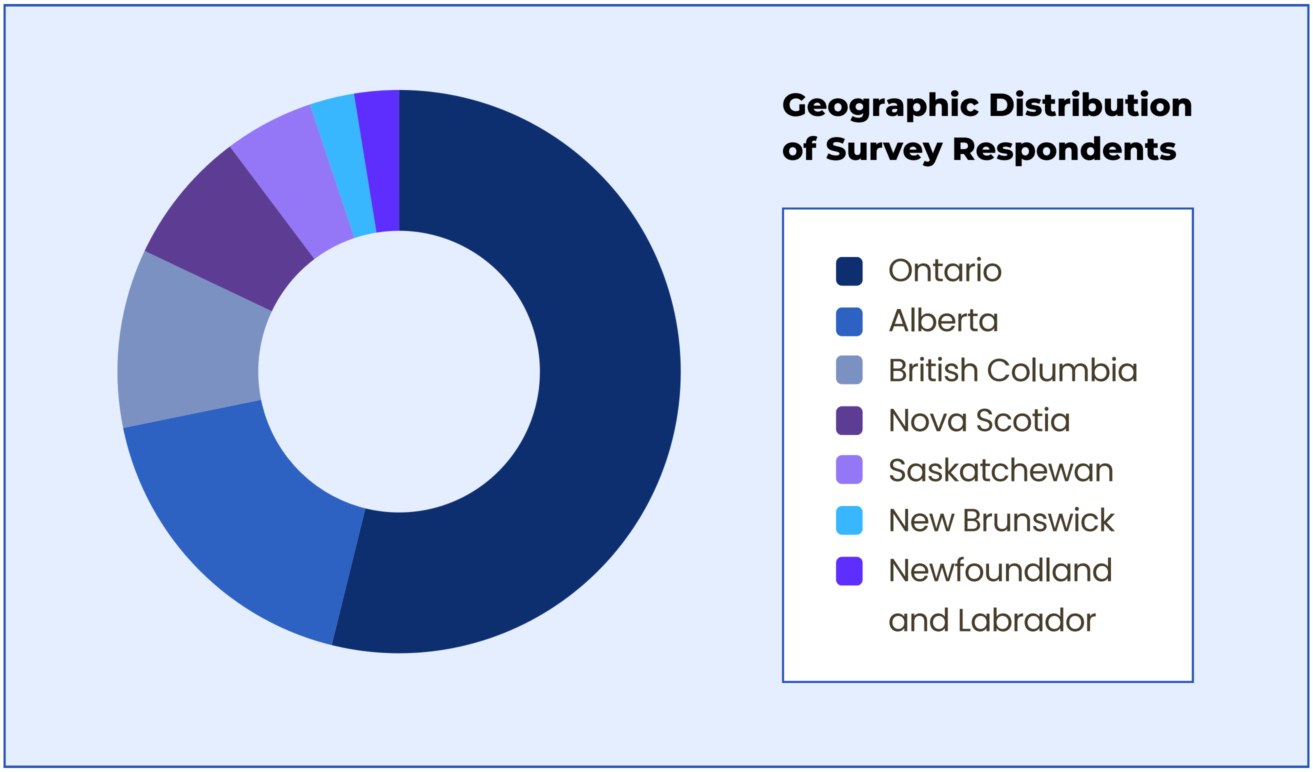


Figure 6: Survey respondents' answer to the question: "What is your age group?"

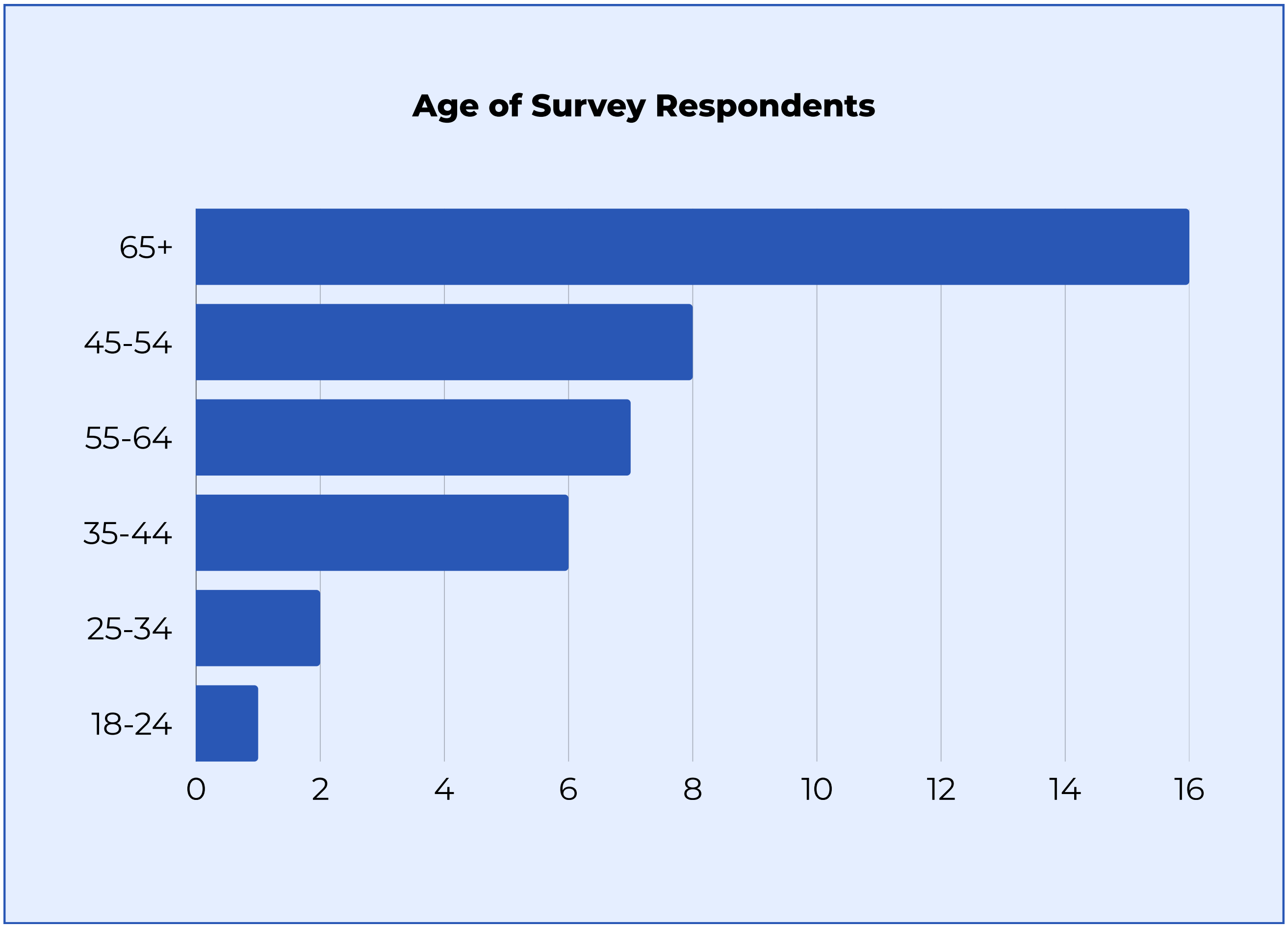


Figure 7: Survey respondents' answer to the question: "How easy is it to access specialized HD healthcare in your area?"

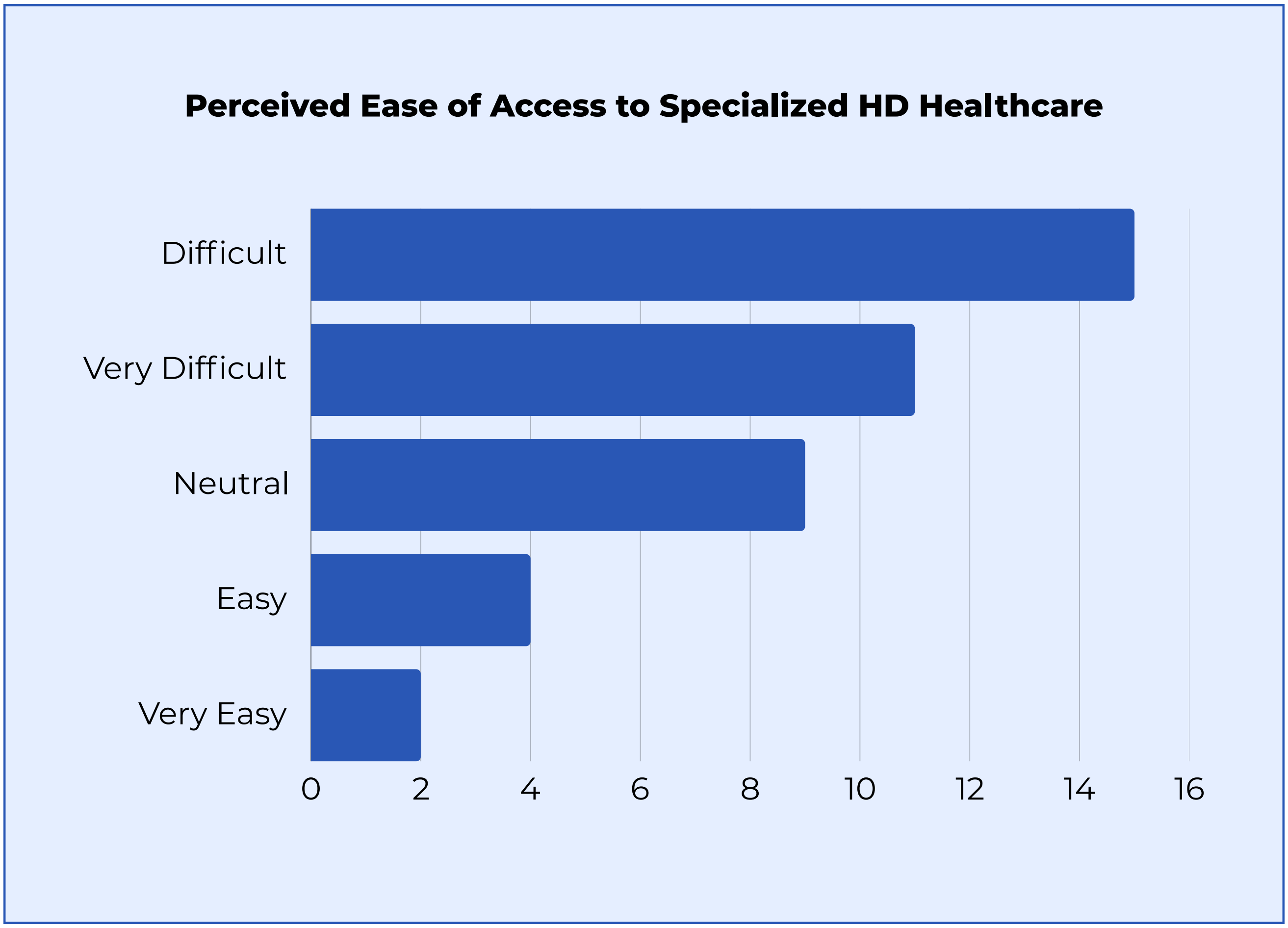


Figure 8: Survey respondents' answer to the question: "How would you rate the level of knowledge and awareness of HD among general practitioners, nurses, and other healthcare providers (excluding HD specialists)?"

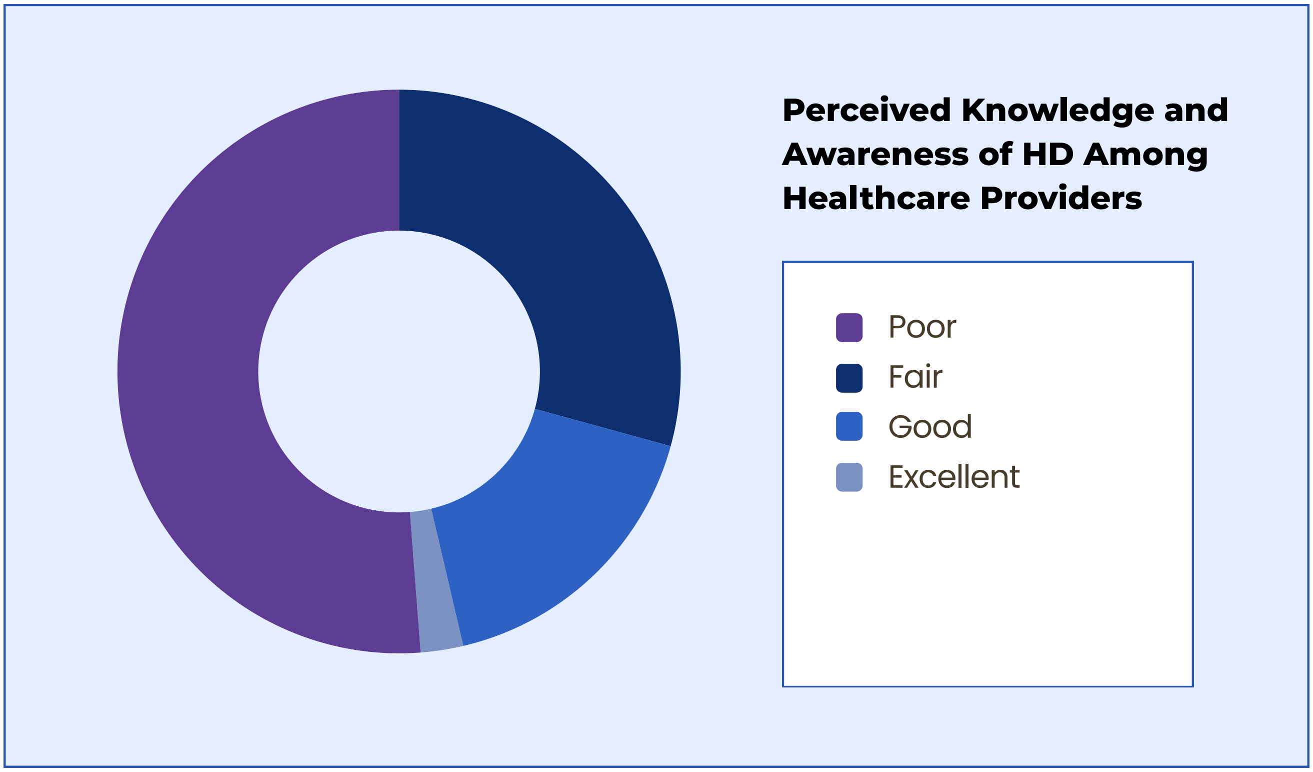
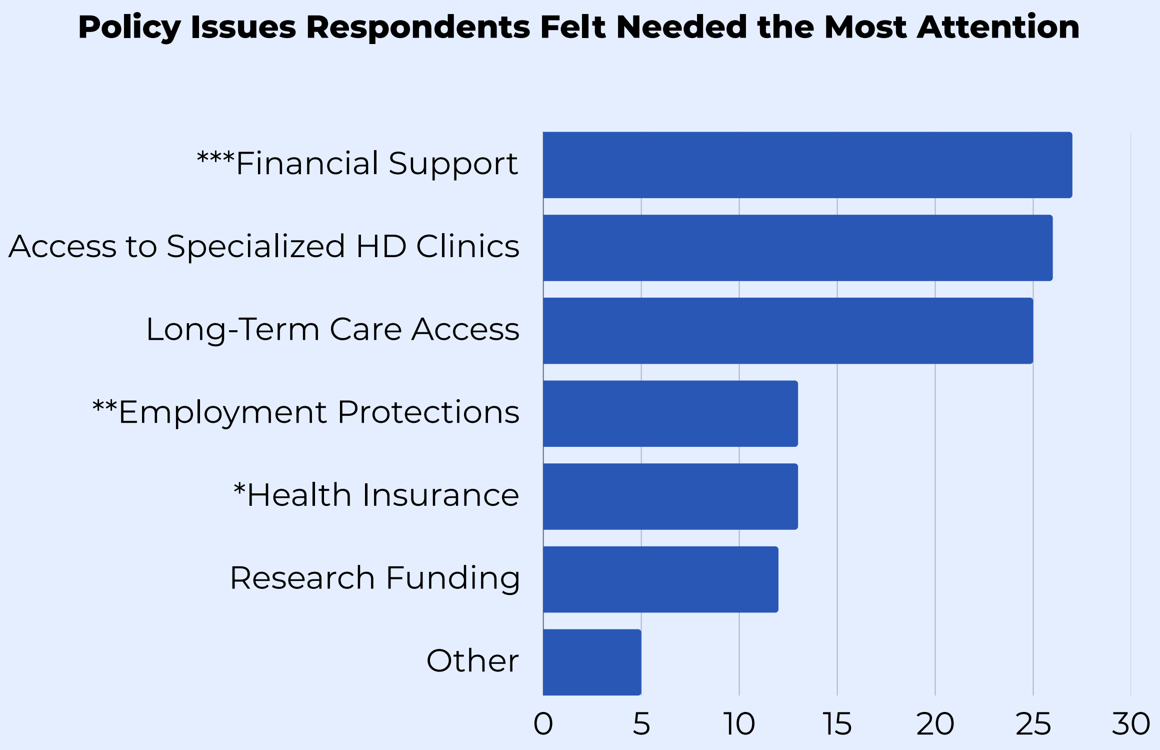


Figure 9: Survey respondents' answer to the question "What policy issues in relation to HD do you feel need the most attention? (Select up to 3)"


Policy Issues Respondents Felt Needed the Most Attention

*** "Financial Support" refers to the amount provided through the Canada Disability Benefit and other related financial assistance programs

** "Employment protections" refers to protections for gene-positive individuals

*"Health insurance" refers to coverage on medication or medical equipment/mobility aids

To learn more about HSC's current efforts to address some of the challenges discussed visit www.huntingtonsociety.ca/advocacy/

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