


BMJ Open Canadian healthcare capacity gaps for disease-modifying treatment in Huntington's disease: a survey of current practice and modelling of future needs

Angèle Bénard,¹ Sylvain Chouinard,^{2,3} Blair R Leavitt,^{4,5} Nathalie Budd ,⁶ Jennifer W Wu,⁶ Kerrie Schoffer^{7,8}

To cite: Bénard A, Chouinard S, Leavitt BR, *et al.* Canadian healthcare capacity gaps for disease-modifying treatment in Huntington's disease: a survey of current practice and modelling of future needs. *BMJ Open* 2022;**12**:e062740. doi:10.1136/bmjopen-2022-062740

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-062740>).

Received 09 March 2022
Accepted 16 May 2022



© Author(s) (or their employer(s)) 2022. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

For numbered affiliations see end of article.

Correspondence to

Dr Nathalie Budd;
nathalie.budd@roche.com

ABSTRACT

Objectives Disease-modifying therapies in development for Huntington's disease (HD) may require specialised administration and additional resource capacity. We sought to understand current and future capacity for HD management in Canada considering the possible introduction of an intrathecal (IT) disease-modifying treatment (DMT).

Design, setting and participants Using a case study, mixed methods framework, online surveys followed by semistructured interviews were conducted in late 2020 and early 2021. Neurologists from Canadian HD (n=16) and community (n=11) centres and social workers (n=16) were invited to complete online surveys assessing current HD management and potential capacity to support administration of an IT DMT.

Outcome measures Survey responses, anticipated demand and assumed resource requirements were modelled to reveal capacity to treat (ie, % of eligible patients) by centre. Resource bottlenecks and incremental support required (full-time equivalent, FTE) were also determined.

Results Neurologists from 15/16 HD centres and 5/11 community centres, plus 16/16 social workers participated. HD centres manage 94% of patients with HD currently seeking care in Canada, however, only 20% of IT DMT-eligible patients are currently seen by neurologists. One-third of centres have no access to nursing support. The average national incremental nursing, room, neurologist and social worker support required to provide IT DMT to all eligible patients is 0.73, 0.36, 0.30 and 0.21 FTE per HD centre, respectively. At peak demand, current capacity would support the treatment of 6% of IT DMT-eligible patients. If frequency of administration is halved, capacity for IT-DMT administration only increases to 11%.

Conclusions In Canada, there is little to no capacity to support the administration of an IT DMT for HD. Current inequitable and inadequate resourcing will require solutions that consider regional gaps and patient needs.

INTRODUCTION

Huntington's disease (HD) is a rare, inheritable, autosomal-dominant,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Quantification of resources/capacity required for intrathecal (IT) disease-modifying treatment (DMT) in Huntington's disease (HD) centres across Canada.
- ⇒ Estimation of the proportion of manifest HD patients (not) currently linked to neurology care.
- ⇒ Questionnaires may have been prohibitively extensive for centres with few HD patients.
- ⇒ Data collection was based on self-reported survey responses, verified by interviews.
- ⇒ The model focused on IT DMT-related support and did not account for ancillary tasks that may be impacted by increased patient loads.

neurodegenerative disorder that affects an estimated 4700 people living in Canada^{1,2} and its prevalence is increasing.³ HD is caused by an expansion of the CAG (cytosine, adenine, guanine) trinucleotide repeat in the huntingtin (*HTT*) gene, which translates into an aberrant *HTT* protein. Mutant huntingtin (mHTT) leads to neuronal dysfunction and death, with progressive motor, cognitive and psychiatric impairments.^{1,4} The disease typically presents during the prime of adulthood, with a median survival of 18 years from motor symptom onset or 'manifest' disease.^{1,4} Despite over 100 years of research, HD remains incurable and multidisciplinary symptom management is the mainstay of treatment.^{1,4,5}

Knowing the genetic cause of HD, however, has been advantageous to the development of targeted therapeutics, with recent research focused on *HTT*/mHTT-lowering strategies.^{4,6–9} One class of agents, antisense oligonucleotides (ASOs), showed promise as a disease-modifying treatment (DMT) in early studies.^{7,10} Although some ASOs have since failed in later stage trials, new treatments

continue to be studied.¹¹ Many emerging therapies will also require specialised modes of administration.^{9 11 12} Health Canada has acknowledged the need for a national drug strategy that enables fair, consistent and evidence-based access to specialised drugs for rare diseases such as HD.¹³

Considering the late stage exploration of intrathecal (IT) agents for movement disorders^{14 15} and anticipated healthcare capacity limitations,^{16–18} challenges were expected in the geographically vast, regionally diverse and publicly-funded Canadian healthcare system.¹⁹ In alignment with implementation science and practice improvement,²⁰ we sought to understand current and future capacity for HD management in Canada and to qualify potential gaps arising from the theoretical introduction of an IT DMT.

METHODS

Study design

Using a case study, mixed methods framework,²¹ cross-sectional online surveys and follow-up phone interviews were modelled on a global study,¹⁶ modified by the Canadian study team, and validated by both Canadian neurologists with experience administering an IT DMT^{15 16} and a Canadian HD patient organisation representative. Clinical trial experience indicated that an HD IT DMT could be administered by a trained neurologist in a hospital or community setting, given adequate supports and capacity. The study recruited neurologists from Canadian movement disorder clinics²² or social workers meeting the following criteria (see online supplemental appendix table S1 for full criteria):

1. A movement disorder neurologist managing >20 patients with HD and a dedicated HD neurologist ('HD centres'),
2. A movement disorder neurologist managing <20 HD patients ('Community centres'),
3. Social workers (also referred to in Canada as 'Resource Center Directors') focused on HD client support ('Resource centres').

HD centres were identified by the steering committee or referral by survey participants. Identification of Community centres was based on environmental scans conducted on the Canadian Movement Disorder Group website, with the guidance of the steering committee, and by referral within the survey. Resource centre directors were identified directly by the Huntington Society of Canada and Société Huntington du Québec. Surveys were emailed to each centre (see online supplemental appendix table S2 for invited centres and online supplemental appendix file 2–4 for copies of the survey) in November 2020 requesting that one be completed by the person most familiar with HD healthcare capacity for that centre. Survey questions varied by centre type and were designed to collect dependent variables required for capacity modelling and qualitative data reporting. Guided phone interviews were conducted by a single interviewer to support common

question interpretation among participants and validate survey data (see online supplemental appendix file 5 for a copy of the interview guide).

The primary participants in this study were physicians and other healthcare professionals (HCP) (eg, social workers). Informed consent was requested prior to study participation. No patient identifiers, like name, age, gender, address, phone number or health insurance information were collected. Thereby, according to the Tri-Council Policy, site-specific ethics approval and patient consent are not required for use of deidentified secondary data (the Tri-Council Policy Statement, 2019).

Study objectives and data analysis

The first objective of the study was to characterise HD patient care across Canada, with a focus on capacity for IT DMT provision. This included understanding the proportion, age and stage of patients with HD currently linked to care as well as the healthcare capacity dedicated to their management.

The second objective was to model the needed capacity of HD centres to deliver an IT DMT in Canada and to highlight key bottlenecks to achieving full provision. Linear quantitative capacity modelling was used to estimate the current and needed capacity (ie, resources and infrastructure). To achieve this, two sets of assumptions, based on a phase III IT DMT trial¹⁵ and expert Canadian steering committee feedback, were necessary. First, the steps and resources (ie, time and infrastructure) required to administer an IT DMT were assumed (see online supplemental appendix table S3). Second, the anticipated IT DMT demand was calculated as the number of Canadians (national population 38 005 238²³) with a diagnosis of manifest HD (prevalence of 13.7 per 100 000²), meeting IT DMT criteria (67.2% with stage 1 or 2 HD and 25–65 years of age²⁴) and expected to seek treatment (70%). Eligible patients were assigned provincially based on population distributions²³ and then by centre based on the relative proportion of patients with HD currently seen in each centre (per survey response). Percentage of patients linked to care (ie, neurologist-seen) was calculated as the number of eligible patients currently in care (per survey response) divided by the anticipated IT DMT demand (per calculation above) multiplied by 100. Required social worker full-time equivalent (FTE) was based on an assumption of one social worker per HD centre.

The capacity gap was then determined, by centre, as the difference between current capacity (dependent variables) and required future capacity (independent variables). Capacity was modelled for two demand scenarios: (1) capacity to treat patients 'linked to care'; the percentage of patients with HD currently linked to care and theoretically eligible for an IT DMT that could be treated considering the resources available and (2) capacity to treat 'all eligible' patients, that is, the percentage of patients with HD theoretically eligible for an IT DMT that could be treated considering the resources available. The model

used the scarcest resource as the upper limit of a centre's capacity.

Data reporting

Survey methods are reported according to the CHER-RIES methodology²⁵ (see online supplemental appendix table S4). Results are reported using descriptive statistics by centre (anonymous), region (Western Canada, Ontario, Quebec and Atlantic Canada; online supplemental appendix table S2) or nationally. In cases where national extrapolations were made, data points for non-responding centres were assumed to be equal to the national average of the responding centres (ie, archetyped). For continuous variables, measures of central tendency (medians and means) and dispersion (SD, range) are reported. Any binary or categorical variables are described with frequencies and percentages. Time is reported in units of FTE with one FTE=40 hours/week and 48 weeks/year. Microsoft Excel was used for data analysis and visualisation.

Post hoc analysis

To test the impact of an extended dosing interval (ie, every 16 weeks vs every 8 weeks) on capacity for treatment, changes to the model's assumptions were applied (ie, half of the required resource time). The same methods outlined above were then used to assess the key outcomes of interest; number of centres with capacity, % of IT DMT-eligible patients treated, and incremental FTE required to treat all eligible patients.

Patient and public involvement

Importantly, the design, analysis and reporting of this study involved a representative (author and registered social worker, Angèle Bénard) from Huntington Society of Canada, a non-profit organisation that supports Canadians impacted by HD.

RESULTS

HD centres and HD patient distribution

A total of 16 HD centre neurologists, 11 community neurologists and 16 social workers met eligibility for inclusion in the surveys. Responses were received by a total of 15/16 (93.8%) HD centre neurologists, 5/11 (45.5%) community neurologists and 16/16 (100%) social workers responded to the survey. Follow-up with non-responding community centres indicated that low survey participation was due to a lack of HD case load in those clinics and, thus, a perceived lack of value in participating in the study.

Most HD centres (69.2%, n=9/13) have more than a quarter of patients living >2 hours' drive away, with Western and Atlantic Canada reporting the highest remote patient populations (three centres had up to 75% of patients living >2 hours' drive away). Ten centres (66.7%) support remote patients by telephone, telemedicine and/or satellite clinics (see online supplemental

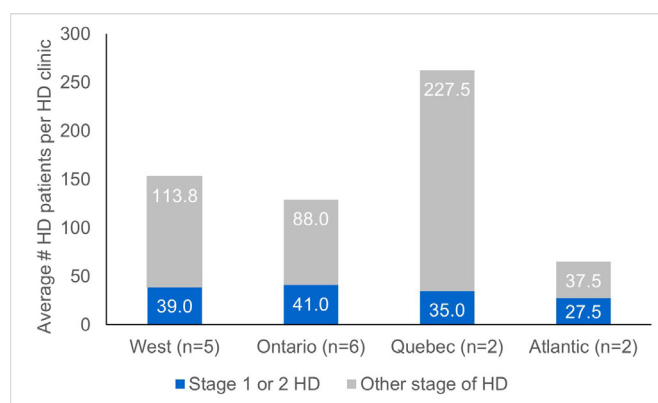


Figure 1 Regional distribution of Huntington's disease (HD) patients (stage 1 or 2 vs other) currently seen within Canadian HD centres (n=15). HD, Huntington's disease.

appendix table S5). Average wait time for a first visit at an HD centre is 7.1 (SD: 7.7) months.

Patients with HD represent a fraction of the entire movement disorder patient population (mean 17.2%; n=2193/12740) currently seeking care within HD centres. However, survey responses and extrapolation suggest that HD centres (n=15 responding +n=1 archetyped) manage 94% of patients with HD currently seeking care in Canada, with community centres (n=5 responding +n=6 archetyped) supporting 6%. The average number of patients with HD per HD centre varies by region (figure 1), with the national average being 146 (SD: 121), of which 38 (SD: 32) are in stage 1/2. HD centre neurologists spent 2.5 (SD 2.0) hours/week and 36 (SD: 12) min/visit on care of patients with HD.

Access to multidisciplinary care

The challenge of administering IT therapy rests not just on the procedure itself, but also providing patients in this vulnerable population a support network through a multidisciplinary team (MDT). Of the 10 HCP-types asked about in the survey, HD centres had variable onsite access to each (range: 3–11 HCP types) (figure 2). Notably, 66.7% of centres (10/15) reported having onsite nursing staff, each of whom dedicate an average of 0.6 (SD 0.8) hours/week to HD patient care. Five centres had no access to nursing support. Social workers, additional neurologists, psychiatrists and nurses were the most likely members to be working onsite as part of an MDT (figure 2), with nurses typically being seen at the same visit as the neurologist, but other HCPs requiring separate visits (online supplemental appendix figure S1). Social workers support an average of 263 clients each (160 patients, 64 caregivers and 39 others) from the HD community and spend approximately 28.0 (SD: 11.6) hours/week supporting HD clients (see online supplemental appendix figure S2 for proportion of time per task).

Anticipated demand for an IT DMT in manifest HD

An estimated 18.4% of IT DMT eligible patients are currently linked to care within HD centres (n=15 + n=1

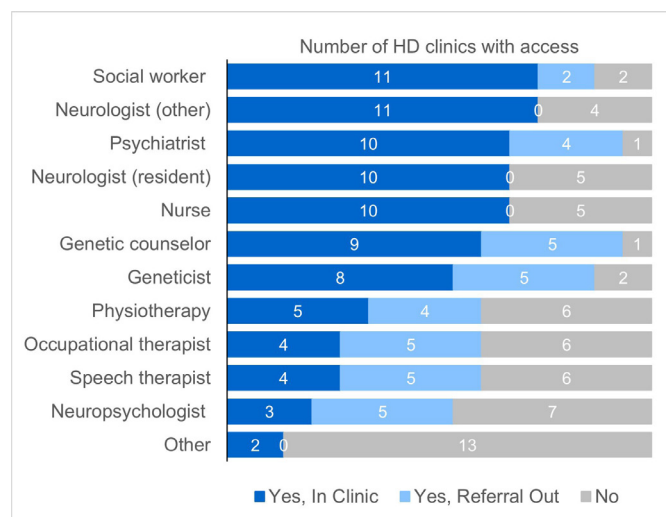


Figure 2 Access to MDT members (allied HCPs) by type for HD centres (n=15). HCP, healthcare professional; HD, Huntington's disease; MDT, multidisciplinary team.

archetyped), and 1.0% (n=5 + n=6 archetyped) are linked to care in community centres; 80.6% are likely not currently under the care of a neurologist. Regionally, Quebec had the highest proportion of eligible patients not linked to care (87.3%), and the Atlantic had the highest proportion linked to HD or community centres (24.8% and 2.9%, respectively) (figure 3).

Modelled capacity for an IT DMT, HD centres only

When only considering patients linked to care in HD centres, five centres (33.3%) are estimated to have capacity to treat nearly all their IT DMT-eligible patients with HD. Another two centres (13.3%) would be able to provide support to the majority (>50%), but eight centres (53.3%) would have no capacity to support IT DMT administration (figure 4A). The number of centres with available capacity decreases once all IT DMT-eligible patients are accounted for. Just one HD centre (6.7%) is expected to be able to treat all eligible patients at peak

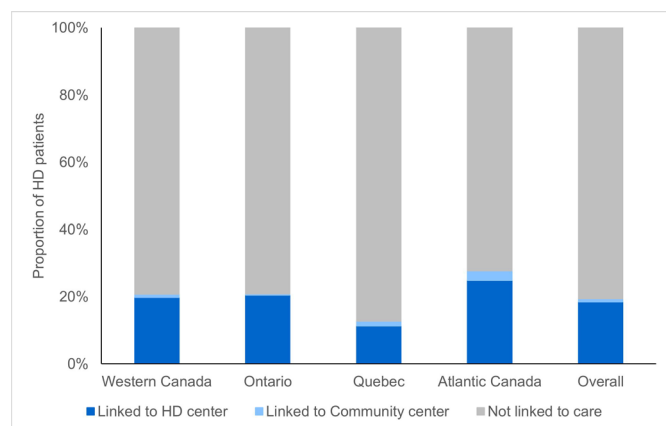


Figure 3 Proportion of IT DMT eligible HD patients (25–65 years old and stage 1/2) and how they are currently linked to care. HD, Huntington's disease; DMT, disease-modifying treatment; IT, intrathecal.

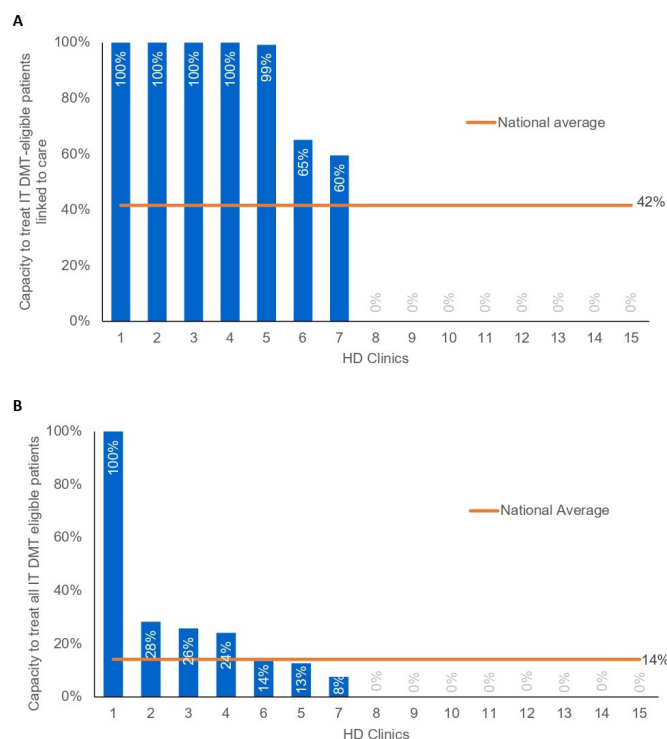


Figure 4 Capacity of HD centres (n=15) to treat: (A) IT DMT-eligible HD patients linked to care and (B) all eligible HD patients with IT DMT. DMT, disease-modifying treatment; HD, Huntington's disease; IT, intrathecal.

demand, six (40.0%) would have some capacity and eight (53.3%) would have none (figure 4B). Considering HD centre capacity alone, there is an 85.9% gap in the capacity to treat all IT DMT-eligible patients with HD.

The average national incremental nursing, room and neurologist/proceduralist time required to support all IT DMT eligible patients is 0.73, 0.36 and 0.30 FTE per HD centre, respectively (see online supplemental appendix table S6). The most common bottleneck for HD centres was nursing staff (n=9/15), while neurologist time and room/bed availability were limiting for a few (n=4/15 and 2/15, respectively). Interestingly, while 11 HD centre neurologists (73.3%) agreed or completely agreed to be willing to perform IT DMT, four completely disagreed. In interviews, barriers to willingness to administer an IT DMT included lack of time and lack of funding.

Modelled capacity for an IT DMT, including community centres and resource centres

Expanding the modelling to include the resources available in community centres and the support required from social workers results in a 93.7% gap in the capacity to treat (nationally) following the introduction of an IT DMT (figure 5). This is driven by limited social worker time. An incremental 0.21 FTE of social worker support per centre would be required to provide IT DMT to all eligible patients with HD (see online supplemental appendix table S6).

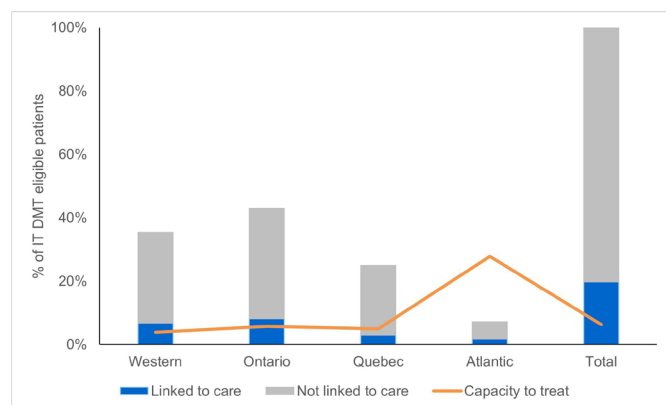


Figure 5 Capacity of all centres, by region, to treat all IT DMT-eligible HD patients (n=15 responding +1 archetyped HD centres and n=5 responding +6 archetyped community centres). DMT, disease-modifying treatment; HD, Huntington's disease; IT, intrathecal.

Post hoc analysis

Applying an IT DMT dosing of every 16 weeks rather than every-8-weeks had no impact on the number of HD clinics in Canada that have capacity to treat at peak demand (see online supplemental appendix figures S3 and S4); eight centres have zero capacity to treat in either scenario (patients currently linked to care or all eligible). Total gap in the capacity to treat, including support from community centres and social workers, would be 88.9% (a 4.8% absolute improvement) with a halving of administration. Using the every 16-week dosing interval, an additional 0.34 nurse, 0.16 room, 0.13 neurologist and 0.09 social worker FTE would be needed.

DISCUSSION

In Canada, HD patient care is concentrated in HD centres, where neurologists manage an average of 146 patients with HD per centre; about 10 times the number seen in community centres. This is in line with centres in the USA, where 135 patients with HD/site are seen.²⁶ In approximately two-thirds of Canadian centres, more than a quarter of patients live over a 2 hours' drive away, which creates unique issues for follow-up and management of patients receiving therapies between visits. Sixty per cent of HD centres in our survey offered telemedicine services. This is higher than an international survey of HD centres in which less than a quarter did²⁷ and suggests that access to HD treatments requiring specialist administration will pose a unique challenge for remote Canadian patients.

Unfortunately, access to multidisciplinary care is inconsistent across the country, with nursing support inaccessible to 5/15 responding centres. Onsite nursing support, nursing time and social worker capacity are prominent areas of need if IT medications are introduced in Canada for HD. The current literature strongly promotes a multidisciplinary approach to HD patient care,^{28–31} and research has shown the benefit of MDTs for similar chronic and degenerative conditions, such as cystic

fibrosis and Parkinson's disease.^{32–35} It can be expected that separate visits with social workers and other HCPs place added burden on patients and their families, particularly those living a distance from care.³¹

In a survey of US Huntington Study Group sites, it was estimated that 70% of patients with HD evade care.²⁶ Our data similarly show that less than 20% of IT DMT-eligible patients with HD are currently managed in Canadian community or HD centres. As such, introduction of and demand for a DMT would strain the system. We confirmed that Canadian HD centres have limited current capacity to administer IT DMTs due to nursing, neurologist or room time. Overall, the incremental FTEs required in Canadian centres appear similar to those predicted internationally.¹⁶ Neurologist capacity and willingness to administer IT DMTs are also serious areas of concern, with shortages and waning interest in the specialty already a threat to the system.^{36 37} Furthermore, when limitations in social worker capacity were accounted for, national capacity to treat decreased to only 6% of IT DMT-eligible patients with HD. Not surprising, given the full absence of resources in some centres, extension of IT DMT dosing to every 16 weeks rather than every 8 weeks had minimal impact on the available capacity to treat all IT DMT-eligible patients.

While our study is unique in its characterisation of existing systems of care for Canadian patients with HD, challenges related to the servicing of remote communities, centralised specialist care, long wait times and inequitable access to MDTs align with known systemic complexities plaguing the Canadian healthcare system as a whole.¹⁹ These challenges, together with the burden of illness,^{38 39} put tremendous strain on patients with HD and their caregivers. Furthermore, constrained capacity to treat patients with HD with novel DMTs is a barrier to achieving the benefits that those therapies may offer.

Future directions

Our study explores the practical facets of IT-DMT implementation on healthcare capacity; however, the introduction of a DMT would raise several potential additional avenues of research. First, prevalence estimates could be impacted by a DMT that could prolong disease duration. Second, overall healthcare utilisation throughout the course of the disease, including both early and late phases, would likely be impacted by the introduction of a DMT. Third, economical burden associated with changes in healthcare utilisation should also be considered. Combined, following the release of data on the clinical benefit of the DMT in question, future studies should integrate measures of disease burden, estimates of health resource utilisation and assessment of overall economic value.

Our study highlights the current variability of care delivery across Canada for HD. Given the diversity of challenges among the provincial health systems, solutions for increasing capacity, should a DMT become available, need to be customised by region. Further research

should be conducted to correlate care delivery characteristics with quality of care and patient outcomes to help identify the most impactful interventions for capacity building.^{40 41} Our study can serve as a model for assessing capacity needs for future DMTs or alternative administration schedules. Importantly, policymakers, administrators and healthcare providers need to consider the time required to implement change and the benefits of doing so; improving the existing system and building a foundation to support future treatments.

Limitations of the study

To mitigate the risk of implicit bias in questionnaire design, diverse steering committee input was incorporated, and a third party was used to administer questionnaires and interviews. Some model assumptions were based on the best available data or steering committee opinion; although these may differ in actuality, they can be adjusted and the model rerun accordingly. Finally, survey responses were subjective and the perspective of one respondent at each centre; however, respondents were those most involved in HD patient care.

One of the limitations of our study was the low response rate from community centres. Although, there was a high response rate from HD centres, which service the majority of patients. Indeed, some non-responding centres indicated lack of patients with HD as the reason for not participating. Therefore, responding community centres may not be accurate representations of all community centres and the proportion of patients seen in the community may be lower than our numbers suggest.

It should also be noted that the model used considers only the resources required for IT DMT administration and not ancillary tasks that may be associated with the influx of new patients or increased complexity of existing cases (eg, administrative impact of patients new to clinic or other social worker tasks that may expand).

CONCLUSION

Current systems of HD care in Canada have little to no capacity to support a new IT DMT. Capacity constraints are driven by the high proportion of patients with HD not currently seeking care and are compounded by limitations in neurologist, nurse and social worker time or access. Considerable planning and collaboration would be required to ensure unburdened access for eligible patients.

Author affiliations

¹Huntington Society of Canada, Waterloo, Ontario, Canada

²Department of Medicine, Université de Montréal, Montreal, Quebec, Canada

³Unité des troubles du mouvement André Barbeau, Centre Hospitalier de l'Université de Montréal, Montreal, Quebec, Canada

⁴Department of Medical Genetics and Department of Medicine, Division of Neurology, University of British Columbia, Vancouver, British Columbia, Canada

⁵Centre for Molecular Medicine and Therapeutics, Vancouver, British Columbia, Canada

⁶Hoffmann-La Roche Limited, Mississauga, Ontario, Canada

⁷Division of Neurology, Dalhousie University Faculty of Medicine, Halifax, Nova Scotia, Canada

⁸Movement Disorder Clinic, QEII Health Sciences Centre Foundation, Halifax, Nova Scotia, Canada

Acknowledgements The authors thank Dr. Mark Guttman (Centre for Movement Disorders, Toronto, Canada), Daniel Correia and Laura Pepler (F. Hoffmann-La Roche Ltd), and the team at LSC Life Sciences Consultants (Milan, Italy) for their contributions to the study design, execution and data analysis. We also appreciate the support provided by Stevie Kenyon of Placencia Holdings Ltd (Hamilton, Canada) for data analysis and medical writing, which were funded by F. Hoffmann-La Roche Ltd (Mississauga, Canada).

Contributors AB, SC, BRL, NB, KS and JWW contributed substantially to the study concept and design, NB and JWW assisted with the acquisition of data and conducted data analyses and AB, SC, BRL, NB, KS and JWW contributed to the interpretation of findings. AB, SC, BRL, NB, KS and JWW reviewed the manuscript critically and approved the final version. NB is the guarantor.

Funding This study was funded by F. Hoffmann-La Roche Ltd (Mississauga, ON, Canada). Grant number: N/A.

Competing interests AB reports employment by Huntington Society of Canada, which has received unrestricted grants from F. Hoffmann-La Roche, uniQure, Prilenia, PTC Therapeutics, Novartis, Triplet Therapeutics, and Wave Life Sciences; and has participated in research projects with F. Hoffmann-La Roche. SC reports receiving honoraria from F. Hoffmann-La Roche. BRL reports receiving personal compensation in the 3 past years as a paid scientific advisor or consultant to Novartis, Roche Canada, Remix Therapeutics, Sintetica, PTC Therapeutics, sRNAlytics, Teva, Triplet Therapeutics, F. Hoffmann-La Roche, Pfizer, Takeda, Design Tx, and uniQure regarding the development of new therapies for Huntington disease and similar disorders; receiving contract research funding from F. Hoffmann-La Roche, Teva, and uniQure to perform basic research projects in mouse models of Huntington disease; and receiving compensation for administrative expenses as the Co-Editor-in-Chief of the Journal of Huntington's Disease. SC reports receiving honoraria from F. Hoffmann-La Roche. BRL has patents related to and is a co-founder and CEO of Incisive Genetics Inc. NB and JWW are employed by the study sponsor, F. Hoffmann-La Roche Ltd. KS reports receiving research funding from F. Hoffmann-La Roche and Prilenia Therapeutics.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval Research ethics board approval was granted by Advarra.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The dataset from this study is held securely by Hoffmann-La Roche Ltd. Data requests can be sent to Laura Pepler (laura.pepler@roche.com).

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Nathalie Budd <http://orcid.org/0000-0002-9430-4712>

REFERENCES

- 1 Bachoud-Lévi A-C, Ferreira J, Massart R, *et al.* International guidelines for the treatment of Huntington's disease. *Front Neurol* 2019;10:710.
- 2 Fisher ER, Hayden MR. Multisource ascertainment of Huntington disease in Canada: prevalence and population at risk. *Mov Disord* 2014;29:105–14.
- 3 Baig SS, Strong M, Quarrell OW. The global prevalence of Huntington's disease: a systematic review and discussion. *Neurodegener Dis Manag* 2016;6:331–43.
- 4 Bates GP, Dorsey R, Gusella JF, *et al.* Huntington disease. *Nat Rev Dis Primers* 2015;1:1–21.
- 5 Keogh R, Frost C, Owen G, *et al.* Medication use in Early-HD participants in Track-HD: an investigation of its effects on clinical performance. *PLoS Curr* 2016;8. doi:10.1371/currents.hd.8060298f ac1801b01ccea6acc00f97cb. [Epub ahead of print: 11 Jan 2016].
- 6 Lane RM, Smith A, Baumann T. Translating Antisense Technology into a Treatment for Huntington's Disease. *Methods Mol Biol Clifton NJ* 1780;2018:497–523.
- 7 Tabrizi SJ, Ghosh R, Leavitt BR. Huntingtin Lowering Strategies for Disease Modification in Huntington's Disease. *Neuron* 2019;101:801–19.
- 8 Wild EJ, Tabrizi SJ. Therapies targeting DNA and RNA in Huntington's disease. *Lancet Neurol* 2017;16:837–47.
- 9 Juliano RL. The delivery of therapeutic oligonucleotides. *Nucleic Acids Res* 2016;44:6518–48.
- 10 Leavitt BR, Kordasiewicz HB, Schobel SA. Huntingtin-Lowering therapies for Huntington disease: a review of the evidence of potential benefits and risks. *JAMA Neurol* 2020;77:764–72.
- 11 Sheridan C. Questions swirl around failures of disease-modifying Huntington's drugs. *Nat Biotechnol* 2021;39:650–2.
- 12 Calias P, Banks WA, Begley D, *et al.* Intrathecal delivery of protein therapeutics to the brain: a critical reassessment. *Pharmacol Ther* 2014;144:114–22.
- 13 Health Canada. Building a National Strategy for Drugs for Rare Diseases: What We Heard from Canadians [Internet]. Ottawa, ON, Canada: Health Canada. 2021. Available: <https://www.canada.ca/en/health-canada/programs/consultation-national-strategy-high-cost-drugs-rare-diseases-online-engagement/what-we-heard.html> [Accessed 31 Oct 2021].
- 14 Haché M, Swoboda KJ, Sethna N, *et al.* Intrathecal injections in children with spinal muscular atrophy: nusinersen clinical trial experience. *J Child Neurol* 2016;31:899–906.
- 15 Hoffmann-La Roche. A Randomized, Multicenter, Double-Blind, Placebo-Controlled, Phase III Clinical Study to Evaluate the Efficacy and Safety of Intrathecally Administered RO7234292 (RG6042) in Patients With Manifest Huntington's Disease [Internet]. clinicaltrials.gov. Report No: NCT03761849, 2021. Available: <https://clinicaltrials.gov/ct2/show/NCT03761849> [Accessed 15 Jun 2021].
- 16 Guttman M, Pedrazzoli M, Ponomareva M, *et al.* The impact of upcoming treatments in Huntington's disease: resource capacity limitations and access to care implications. *J Huntingtons Dis* 2021;10:303–11.
- 17 Yong J, Moffett M, Lucas S. Implementing a global expanded access program (EAP) for infantile-onset spinal muscular atrophy (type I): understanding the imperative, impact and challenges. *J Neuromuscul Dis* 2019;6:227–31.
- 18 Johannsen J, Weiss D, Schlenker F, *et al.* Intrathecal administration of nusinersen in pediatric SMA patients with and without spine deformities: experiences and challenges over 3 years in a single center. *Neuropediatrics* 2021;52:179–85.
- 19 Martin D, Miller AP, Quesnel-Vallée A, *et al.* Canada's universal health-care system: achieving its potential. *The Lancet* 2018;391:1718–35.
- 20 Leeman J, Rohweder C, Lee M, *et al.* Aligning implementation science with improvement practice: a call to action. *Implement Sci Commun* 2021;2:99.
- 21 Feters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. *Health Serv Res* 2013;48:2134–56.
- 22 The Canadian Movement Disorders Group. Centers by Geography [Internet]. Available: <http://www.cmdg.org/AcrossCanada/acrosscanada.htm#que> [Accessed 30 Nov 2021].
- 23 Government of Canada SC. Population estimate 2021 [Internet], 2021. Available: <https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000501> [Accessed 21 Oct 2021].
- 24 Jacobs M, Hart EP, van Zwet EW, *et al.* Progression of motor subtypes in Huntington's disease: a 6-year follow-up study. *J Neurol* 2016;263:2080–5.
- 25 Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of Internet E-Surveys (cherries). *J Med Internet Res* 2004;6:e34.
- 26 Huntington Study Group. Huntington Study Group Data & Findings, Site Survey: Patients Supported by HD Centers (2019) [Internet]. Rochester, NY, USA: Huntington Study Group, 2019. Available: <https://huntingtonstudygroup.org/hsg-research/> [Accessed 02 Oct 2021].
- 27 Frich JC, Rae D, Roxburgh R, *et al.* Health Care Delivery Practices in Huntington's Disease Specialty Clinics: An International Survey. *J Huntingtons Dis* 2016;5:207–13.
- 28 Bourke D, Finucane G, Dysart J, *et al.* The Appointment of a Huntington's Disease Nurse Specialist has Reduced Admission Rate and Improved Admission Quality. *J Huntingtons Dis* 2012;1:27–30.
- 29 Stoker TB, Mason SL, Greenland JC. Huntington's disease: diagnosis and management. *Pract Neurol* 2021;practneurol-2021-003074.
- 30 Moskowitz CB, Rao AK. Making a measurable difference in advanced Huntington disease care. *Handb Clin Neurol* 2017;144:183–96.
- 31 Bardakjian TM, Klapper J, Carey A, *et al.* Addressing the Value of Multidisciplinary Clinical Care in Huntington's Disease: A Snapshot of a New Huntington's Disease Center. *J Huntingtons Dis* 2019;8:501–7.
- 32 Mogayzel PJ, Dunitz J, Marrow LC, *et al.* Improving chronic care delivery and outcomes: the impact of the cystic fibrosis care center network. *BMJ Qual Saf* 2014;23 Suppl 1:i3–8.
- 33 Marshall BC, Nelson EC. Accelerating implementation of biomedical research advances: critical elements of a successful 10 year cystic fibrosis Foundation healthcare delivery improvement initiative. *BMJ Qual Saf* 2014;23 Suppl 1:i95–103.
- 34 van der Marck MA, Bloem BR, Borm GF, *et al.* Effectiveness of multidisciplinary care for Parkinson's disease: A randomized, controlled trial: Multidisciplinary/Specialist Team Care in PD. *Mov Disord* 2013;28:605–11.
- 35 Willis AW, Schootman M, Tran R, *et al.* Neurologist-associated reduction in PD-related hospitalizations and health care expenditures. *Neurology* 2012;79:1774–80.
- 36 Kirby S, Weston LE, Barton JJS, *et al.* Report of the Canadian neurological Society manpower survey 2012. *Can J Neurol Sci* 2016;43:227–37.
- 37 Meloff K. Impending Shortage of Neurologists In Canada?2021. Available: <https://www.bmj.com/rapid-response/2011/10/28/impending-shortage-neurologists-canada> [Accessed 23 Oct 2021].
- 38 Shaw E, Mayer M, Ekwaru P, *et al.* Disease burden of Huntington's disease (HD) on people living with HD and care partners in Canada. *J Huntingtons Dis* 2022;10.3233/JHD-210505. [Epub ahead of print: 23 Mar 2022].
- 39 Gaskin J, Gomes J, Darshan S, *et al.* Burden of neurological conditions in Canada. *Neurotoxicology* 2017;61:2–10.
- 40 DeCorby-Watson K, Mensah G, Bergeron K, *et al.* Effectiveness of capacity building interventions relevant to public health practice: a systematic review. *BMC Public Health* 2018;18:684.
- 41 Crisp BR, Swerissen H, Duckett SJ. Four approaches to capacity building in health: consequences for measurement and accountability. *Health Promot Int* 2000;15:99–107.

SUPPLEMENTARY INFORMATION

For: Canadian healthcare capacity gaps for disease modifying treatment in Huntington's disease: a survey of current practice and modelling of future needs.

APPENDIX 1

Table S1. Inclusion and exclusion criteria and clinic eligibility as validated by the steering committee

Inclusion criteria
<ul style="list-style-type: none">• HD clinics were defined as clinics having >20 HD patients in care, a dedicated (not necessarily full-time) HD neurologist onsite, and supporting HCPs (e.g., nurses) located in either private practice, community hospitals, or academic institutions; n=16 HD neurologists• Community clinics included clinics with a neurologist that manages <20 HD patients and a willingness to manage HD in the future; n=11 HD neurologists• Resource centres (RCs) included all centers with social workers employed by either the Huntington's Society Canada or by the Société Huntington's du Quebec at the time of the study; n=16 resource center directors (RCDs) (i.e., social workers)• <i>Survey participants were also invited to provide additional neurology clinics that may not have been captured in the target list.</i>
Exclusion criteria
<ul style="list-style-type: none">• <i>not managing or not willing to manage HD patients</i>• <i>not working in Canada</i>

Table S2. Centers invited to participate in the Canadian HD IT DMT capacity survey.

HD CLINICS (n=16)	Province	Region
University of British Columbia Hospital Division of Neurology, HD Centre	BC	West
University of Alberta Movement Disorder Clinic	AB	West
University of Calgary Movement Disorder Clinic	AB	West
Saskatoon HD Clinic, Royal University Hospital	SK	West
Deer Lodge Movement Disorders Clinic	MB	West
London Movement Disorder Centre	ON	Ontario
HD Clinic at Hamilton General Hospital	ON	Ontario
Centre for Movement Disorders in North York	ON	Ontario
North York General Hospital	ON	Ontario
Kingston Hotel Dieu Hospital HD Clinic	ON	Ontario
Ottawa Hospital HD Clinic	ON	Ontario
CHUM	QC	Québec
McGill Université - Institut Neurologiques de Montréal	QC	Québec
Université de Laval	QC	Québec
Halifax Infirmary HD Clinic	NS	Atlantic
Newfoundland Balance & Dizziness (Movement Disorder Private Clinic)	NL	Atlantic
COMMUNITY CLINICS (n=11)		
Private Clinic (Abbotsford)	BC	West
Fraser Health Movement Disorder Clinic	BC	West
St. Boniface Clinic	MB	West
Kitchener, Private Clinic	ON	Ontario
Parkinson and Movement Disorder Clinic of East Toronto	ON	Ontario
Centre Hospitalier Universitaire de Sherbrooke	QC	Québec
Lévis - Chaudière Appalaches (Université de Laval)	QC	Québec
Hôpital Maisonneuve-Rosemont	QC	Québec
Neuro Rive-Sud	QC	Québec
Saint John Regional Hospital (New Brunswick HD Clinic)	NB	Atlantic
Newfoundland HD Clinic Leonard Miller Centre	NL	Atlantic
RESOURCE CENTERS (n=16)		
British Columbia	BC	West
Northern Alberta	AB	West
Southern Alberta	AB	West
Saskatchewan	SK	West
Manitoba	MB	West
Northern ON	ON	Ontario
Southwest ON	ON	Ontario
Toronto/York regions	ON	Ontario
Central ON	ON	Ontario
Eastern ON	ON	Ontario
Société Huntington du Québec -Montréal 1	QC	Québec
Société Huntington du Québec-Montréal 2	QC	Québec
Société Huntington du Québec -Québec	QC	Québec
Moncton	NB	Atlantic
Halifax	NS	Atlantic
St. John's	NL	Atlantic

Table S3. Assumptions of standard operating procedures and resource utilization (independent variables) for the administration of an IT DMT in HD in Canada. (Model assumes 6 infusions per patient per year).

	Assumptions per infusion per patient	Assumptions for 6 infusions per patient per year
Proceduralist / Neurologist (n)	1	
Patient preparation / clinic visit	15 min	90 min
CSF collection / IT bolus injection	60 min	360 min
Total	75 min	450 min / 7.5h
Nurse (n)	1	
Patient check-in education	15 min	90 min
Facility preparation	10 min	60 min
Patient preparation	15 min	90 min
CSF collection / IT bolus injection	1x60 min	360 min
Patient mobilization & monitoring	45 min	270 min
Follow-up visit	15 min	90 min
Total	160 min	960 min/ 16 h
Social worker (n)	1	
Clinic visit	50 min	300 min / 5h
Total	50 min	300 min/ 5 h
Facilities (n)	1	
Exam room	15 min	90 min
Facility / patient preparation	25 min	150 min
CSF collection / IT bolus injection	60 min	360 min
Total	100 min	600 min / 10 h

Table S4. Checklist for Reporting Results of Internet E-Surveys (CHERRIES).

Item Category	Checklist Item	Explanation
Design	Describe survey design	Target population: Neurologists treating HD patients in HD centers or community centers, and social workers supporting HD patients and their care partners. Sample: the target sample was purposive in that target centers were identified by the study group who has expertise in the field. Respondents were asked to fill out a screener survey in order to direct them to the appropriate survey based on exclusion and inclusion criteria. The survey asked respondents to complete one survey per clinic by the person most familiar with the health care capacity for HD patients. Language: Surveys were offered in English or French.
IRB (Institutional Review Board) approval and informed consent process	IRB approval	The primary participants in this study are physicians and other healthcare professionals (e.g., social workers). No patient identifiers, like name, age, gender, address, phone number, or health insurance information were collected. Thereby, according to the Tri-Council Policy, site specific ethics approval and patient consent are not required for use of de-identified secondary data (the Tri-Council Policy Statement, 2019). REB approval was granted by Advarra (tracking number Pro00047023).
	Informed consent	Consent was requested at the beginning of the survey and included a description of the research, the length of time expected to complete the survey, compensation provided for completion, privacy and data storage plans, and a contact for questions about the research.
	Data protection	Roche will keep the study dataset in a secure and confidential location at least 15 years, and then destroy it according to Roche policy. The study dataset will be analyzed by Roche and Life Sciences Consulting for the purpose of this research. Data collected from participants was de-identified and held in a database for further sharing and use by Roche, Roche affiliates, and Roche's collaborators and licensees (people and companies who partner with Roche). The "Confirmit" survey platform is a General Data Protection Regulation (GDPR) and Personal Information and Electronic Documents Act (PIPEDA) compliant platform. It complies with the Health Insurance Portability and Accountability Act (HIPAA) to ensure secure data storage.
Development and pre-testing	Development and testing	The survey was designed by the research team, in consultation with experts at Life Sciences Consulting and administered using the Confirmit platform. Usability and technical functionality were tested before official dissemination.

Item Category	Checklist Item	Explanation
Recruitment process and description of the sample having access to the questionnaire	Open survey versus closed survey	Ours was a closed survey, by invitation (unique link) only.
	Contact mode	Email invitation.
	Advertising the survey	The surveys were not advertised.
Survey administration	Web/E-mail	The survey was web-based, with data captured by the Conformat platform. Online surveys were distributed either by the steering committee to their professional medical network or by Huntington Society of Canada (HSC) or Société Huntington du Québec (SHQ), depending on pre-existing connections with the target stakeholder group
	Context	Surveys were accessed by invitation only, and responses were uploaded and completed using the “Conformat” survey platform. “Conformat” survey platform is a General Data Protection Regulation (GDPR) and Personal Information and Electronic Documents Act (PIPEDA) compliant platform that can be used to build and manage online surveys and databases, particularly for research studies.
	Mandatory/voluntary	Voluntary.
	Incentives	Compensation for the time spent taking the survey was provided by Roche at fair market value rates aligned with the profession of the responder. No additional compensation or incentive was provided. Participants were offered a summary report of survey results following analysis.
	Time/Date	The survey was open (11/11/2020-1/18/2021).
	Randomization of items or questionnaires	No randomization or alternation was applied.
	Adaptive questioning	Yes, adaptive questioning was used where applicable.
	Number of Items	Each question had its own dedicated screen / page.
	Number of screens (pages)	Each question had its own dedicated screen / page.
	Completeness check	Validation was turned on for all model-critical quantitative questions: Respondents were prompted to answer missing questions before moving on to the next.

Item Category	Checklist Item	Explanation
		All validated questions offered a non-response option ("not applicable" or "none") where logical.
	Review step	Although there was no review offered at the end of the survey, there was the option to go back and modify responses.
Response rates	Unique site visitor	Not applicable.
	View rate (Ratio of unique survey visitors/unique site visitors)	Not applicable.
	Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors)	The number of people agreed to participate (consented), divided by visitors who visit the first page of the survey. For our survey this was 100%.
	Completion rate (Ratio of users who finished the survey/users who agreed to participate)	The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). For our survey this was 100%.
Preventing multiple entries from the same individual	Cookies used	Cookies were not used.
	IP check	IP addresses were not collected or used.
	Log file analysis	Log file analysis was not used.
	Registration	Unique survey links for each user gated entry into the survey.
Analysis	Handling of incomplete questionnaires	Incomplete questionnaires were included in the analysis, with N numbers in the results indicating completeness of response.
	Questionnaires submitted with an atypical timestamp	No responses were excluded based on atypical timestamp.
	Statistical correction	No weighting of items or propensity scores were used to adjust for the non-representative sample. For data analysis, archotyping based on respondent averages was applied to missing centers where national estimates were required.

APPENDIX 2

Table S5. Methods used by Canadian HD centers (prior to the COVID-19 pandemic) to support remote patient populations (n=15)

Method	# of Centers Using (n)	% of Centers Using (%)
Telephone consult	4	26.7%
Telemedicine	7	46.7%
Telephone or telemedicine	9	60.0%
Virtual	1	6.7%
Asynchronous	1	6.7%
Satellite	5	33.3%
Virtual HCP-HCP consult	2	13.3%
Total using any method(s)	10	66.7%

Figure S1. Same visit access to allied HCP by type for HD clinics (n=15).

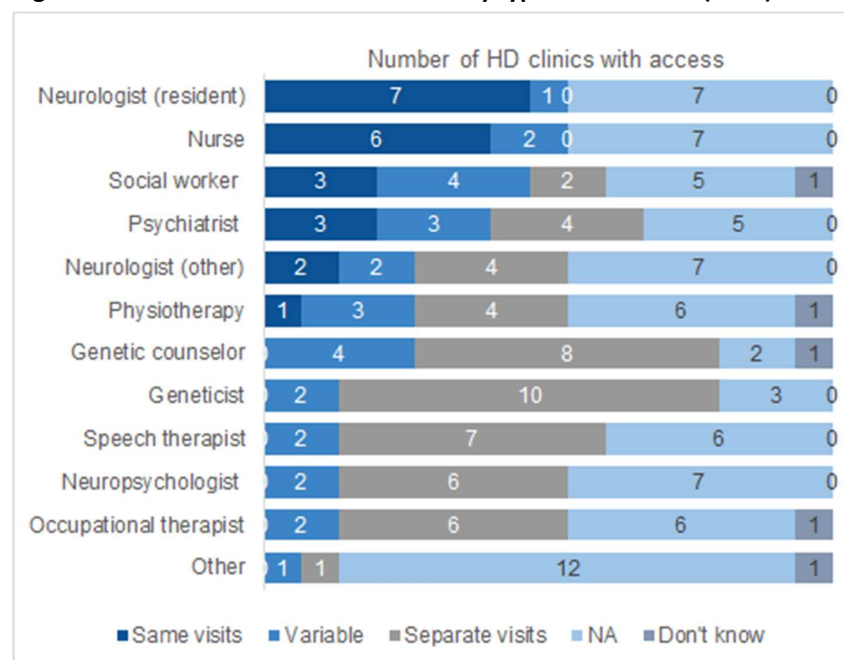


Figure S2. Social worker's proportion of time per task per week in support of HD clients (n=16).

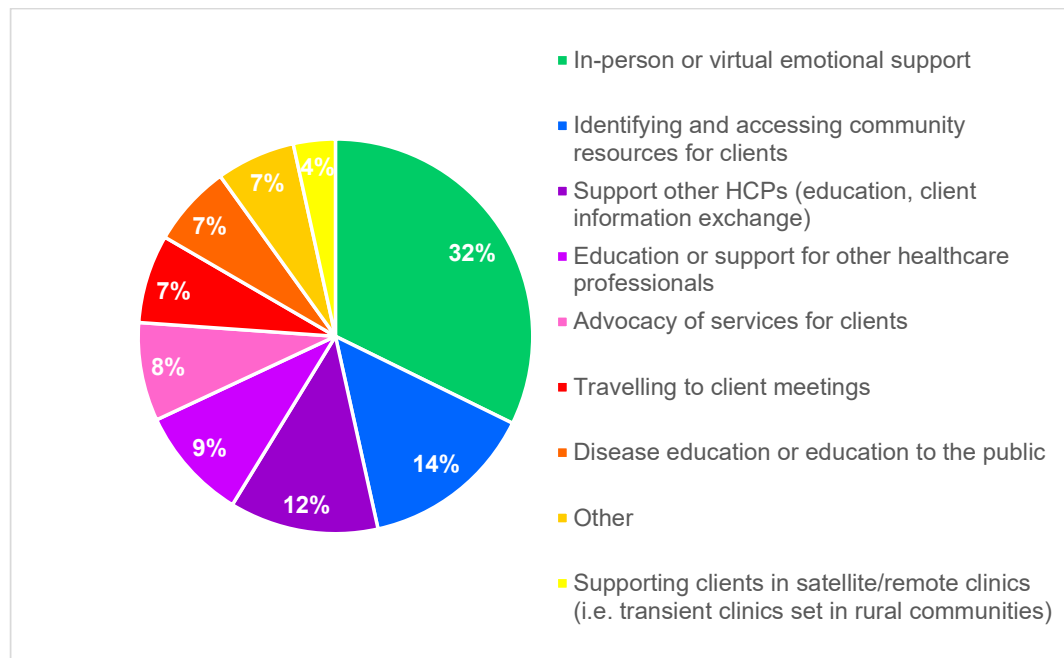


Figure S3. Capacity of HD centers (n=15) to treat IT DMT-eligible HD patients linked to care: analysis assuming less frequent IT-DMT dosing (i.e., q16 weeks versus q8 weeks).

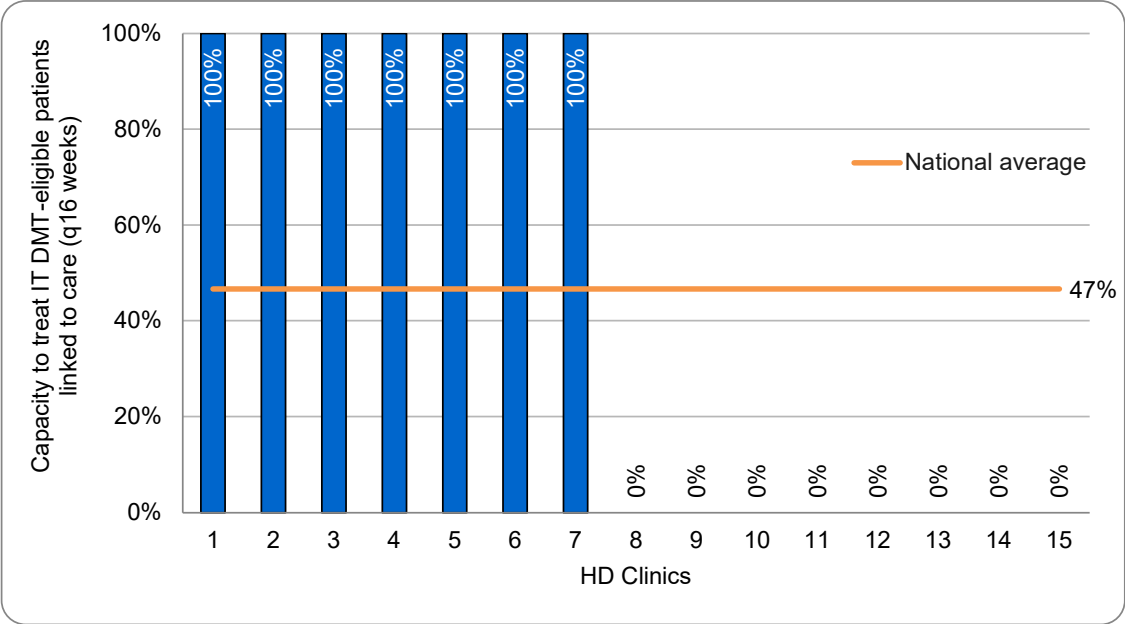


Figure S4. Capacity of HD centers (n=15) to treat all eligible HD patients with IT DMT: post-hoc analysis assuming less frequent IT-DMT dosing (i.e., q16 weeks versus q 8 weeks).

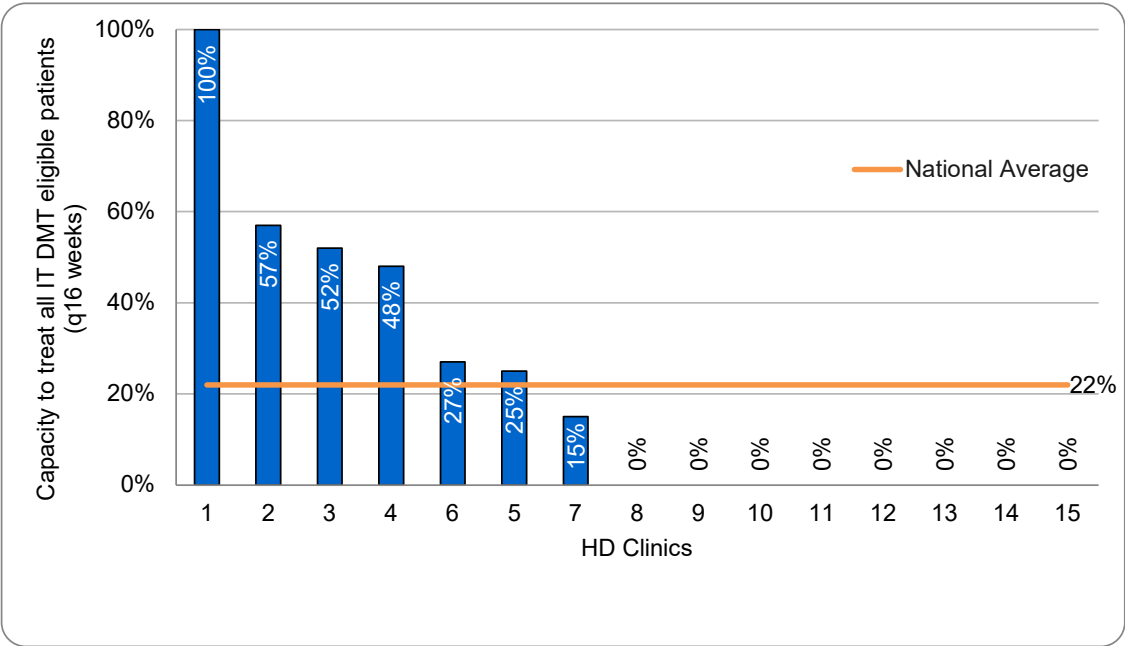


Table S6. Average national incremental nursing, room, neurologists/proceduralists, and social worker FTE required to support all IT DMT eligible patients in HD clinics (n=15 respondents + n=1 archetyped) for main analysis (i.e., q8 weeks administration)

	Nurse	Room	Neurologist	Social worker
Current FTE available	0.04	0.10	0.07	0.03
Incremental FTE required	0.73	0.36	0.30	0.21

Table S7. Average national incremental nursing, room, neurologists/proceduralists, and social worker FTE required to support all IT DMT eligible patients in HD clinics (n=15 respondents + n=1 archetyped): Post-hoc analysis with less frequent administration (i.e., q16 weeks versus q8 weeks)

	Nurse	Room	Neurologist	Social worker
Current FTE available	0.04	0.10	0.07	0.03
Incremental FTE required	0.34	0.16	0.13	0.09

Based on research plan template Version 3.0 released on 01 Jan 2020

APPENDIX 3 – HD CAPACITY ONLINE SURVEY QUESTIONS

HD Centre (30 min)

Thank you again for your participation in this assessment on the impact of the first Disease Modifying Treatment (DMT) for Huntington's disease (HD). The primary objective of this study is to assess and model the current and potential future health care capacity for the management of Huntington's patients across Canada.

The outputs generated could be used to influence policy, interagency collaboration, or research and development priorities at a local/provincial level potentially bettering the clinical care for HD patients.

For HD centres, there are two parts of the study: an online survey and phone interview. The survey a total of **eight sections**:

- A. General questions
- B. HD patient population
- C. Current capacity within HD centre
- D. Future capacity within HD centre
- E. Future willingness and barriers
- F. Future capacity outside HD centre
- G. Survey close
- H. Honorarium

Abbreviation Legend:

Disease Modifying Treatment (DMT)
Huntington's disease (HD)
Healthcare professionals (HCP)
Intrathecal (IT)

A. General questions

1. Name of centre & affiliated hospital (if different/applicable): [free text]
2. Address: [free text]
3. Name: [free text]

B. HD patient population

In this section of the survey we will be asking you questions regarding your current HD patient population.

1. How many HD patients have you managed in the last 12 months? Please list the number of clients by Shoulson-Fahn stage below.

Prodromal: Prior to stage 1. Patient has inherited the gene expansion but does not meet criteria for motor onset of HD. Subtle changes in motor, cognitive and often emotional function, with consequent subtle changes in functional abilities.

Based on research plan template Version 3.0 released on 01 Jan 2020

Stage 1: Marginal engagement in occupation, having part-time voluntary or salaried employment potential AND maintains typical pre-disease levels of independence in all other basic functions, such as financial management, domestic responsibilities, and activities of daily living (eating, dressing, bathing, etc.); OR performs satisfactorily in typical salaried employment (perhaps at a lower level) and requires slight assistance in only one basic function: finances, domestic chores, or activities of daily living.

Stage 2: Typically unable to work, requiring only slight assistance in all basic functions: finances, domestic, daily activities; OR unable to work and requiring different levels of assistance with basic functions (some are still handled independently).

Stage 3: Unable to engage in employment AND requires major assistance in most basic functions: financial affairs, domestic responsibilities, and activities of daily living. Care may be provided at home but needs may be better provided at an extended care facility.

Stage 4: Requires major assistance in financial affairs, domestic responsibilities, and most activities of daily living. For example, comprehension of the nature and purpose of procedures may be intact, but major assistance is required to act on them.

Stage 5: Requires major assistance in financial affairs, domestic responsibilities, and all activities of daily living. Full-time skilled nursing care is required.

- a. **Prodromal:** Number of patients: _____
- b. **Stage 1-2:** Number of patients: _____
- c. **Stage 3:** Number of patients: _____
- d. **Stage 4-5:** Number of patients: _____
- e. Total number of **HD patients:** Number of patients: _____
- f. Total number of **all patients** in the centre. Number of patients: _____

2. What percentage of your HD patients live within 2 hours of your HD centre?

- a. 0-25%
- b. 25-50%
- c. 51-75%
- d. 76-100%
- e. I do not know

3. What percentage of your Stage 1 or Stage 2 patients are between ≥ 25 and ≤ 65 years of age (except DMT eligibility criteria)?

- a. 0-20%
- b. 20-40%
- c. 40-60%
- d. 60-80%
- e. $>80\%$
- f. I do not have an estimate of the patient number

Based on research plan template Version 3.0 released on 01 Jan 2020

C. Current capacity within HD centre: resources, infrastructure and networks

The objective of this section is to assess the current capacity within your centre. This is divided into three parts: resources (personnel), infrastructure, and networks.

Definitions:

HD clinical care: activities related to medical care of HD patients (in clinic visits, RCD visits etc) excluding IT treatment.

a. Part 1: Resource (Personnel)

1. How often do you run your HD clinic?
 - a. Time (min) per HD patient visit: _____
 - b. Number of HD patient visits seen per clinic: _____
 - c. Number of HD clinics per year: _____
2. What is the average wait list for your HD patients?
 - a. Average time for **first** visit (months): _____
 - b. Average time for **follow-up** visits (months): _____
3. **In your centre, other than yourself** are any of the following healthcare professionals (HCPs) currently involved in the HD clinical care for HD patients?
 - a. Nurse
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
 - b. Neurologists (other than yourself)
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per patient visit: _____
 - Number of patient visits per year: _____
 - c. Neurologist-Resident
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
- d. Psychiatrist
 - i. No

Based on research plan template Version 3.0 released on 01 Jan 2020

- ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
- e. Social worker (Resource centre director)
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
- f. Physiotherapy
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
- g. Occupational therapist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
- h. Speech therapist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient visit: _____
 - Number of patient visits per year: _____
- i. Neuropsychologist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:

Based on research plan template Version 3.0 released on 01 Jan 2020

- Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care perpatient visit: _____
 - Number of patient visits per year: _____
 - j. Geneticist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care perpatient visit: _____
 - Number of patient visits per year: _____
 - k. Genetic counselor
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care perpatient visit: _____
 - Number of patient visits per year: _____
 - l. Other
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care perpatient visit: _____
 - Number of patient visits per year: _____
4. When patients visit these HCPs, do they see them on the same day or in separate centre visits?
- a. Separate visits
 - b. Same visits
 - c. Variable

b. Part 2: Infrastructure

1. **Prior to the COVID-19 pandemic**, did your centre regularly support any remote patient populations (i.e. live >2 hours from centre)?
 - a. Yes; If so, % of HD patients: _____
 - b. No
2. [Sub-question] If yes, how do you support these HD patients?
 - a. Telephone consultation

Based on research plan template Version 3.0 released on 01 Jan 2020

- i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
 - b. Telemedicine/telehealth consultation (i.e. use of specialized equipment at hospital/clinic)
 - i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
 - c. Virtual consultation (e.g. Zoom, Medeo, virtual care, etc.)
 - i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
 - d. Asynchronous communications (e.g. email)
 - i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
 - e. Satellite clinics (i.e. clinics associated with an HD centre but conducted in a different geographic location to service remote patient populations)
 - i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
 - f. Supporting local HCPs via virtual consults (HCP-HCP consultation)
 - i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
 - g. Other
 - i. Scheduled time (min) per visit: _____
 - ii. Visits per year: _____
- 3. [Sub-question] If no, are there any barriers preventing you from offering telemedicine/telehealth with your HD patients? Select all that apply:
 - a. Patient familiarity/lack of experience with the technology.
 - b. Physical issues (e.g. speech too unclear)
 - c. Lack of approved telemedicine systems in region
 - d. Patient reluctance to participate if expected to perform telemedicine from home
 - e. Physician compensation should replace financing/billing

c. Part 3: Network

- 1. Currently, when an HD patient requires care from another healthcare professional (HCP) how often are they able to access the care they require?
 - a. Psychiatrist
 - i. Always
 - ii. Sometime
 - iii. Never
 - b. Social worker (Resource centre directors)
 - i. Always
 - ii. Sometime
 - iii. Never
 - c. Physiotherapy
 - i. Always

Based on research plan template Version 3.0 released on 01 Jan 2020

- ii. Sometime
 - iii. Never
 - d. Occupational therapy
 - i. Always
 - ii. Sometime
 - iii. Never
 - e. Speech therapy
 - i. Always
 - ii. Sometime
 - iii. Never
 - f. Other
 - i. Always
 - ii. Sometime
 - iii. Never
- 2. What are the biggest barriers when referring HD patients to other allied healthcare professionals? Select all that apply.
 - a. Capacity of the healthcare professional (e.g. waitlist)
 - b. Willingness of the healthcare professional to manage HD patients
 - c. Identifying a health care professional in close proximity to HD patient
 - d. Lack of private coverage and/or cost
 - e. Lack of healthcare professional education and experience
 - f. Lack of transportation or logistical challenges to get to the healthcare professional
 - g. High turnover of health care professional
 - h. Other
 - i. Unknown

D. Future capacity within your Centre: resources and infrastructure

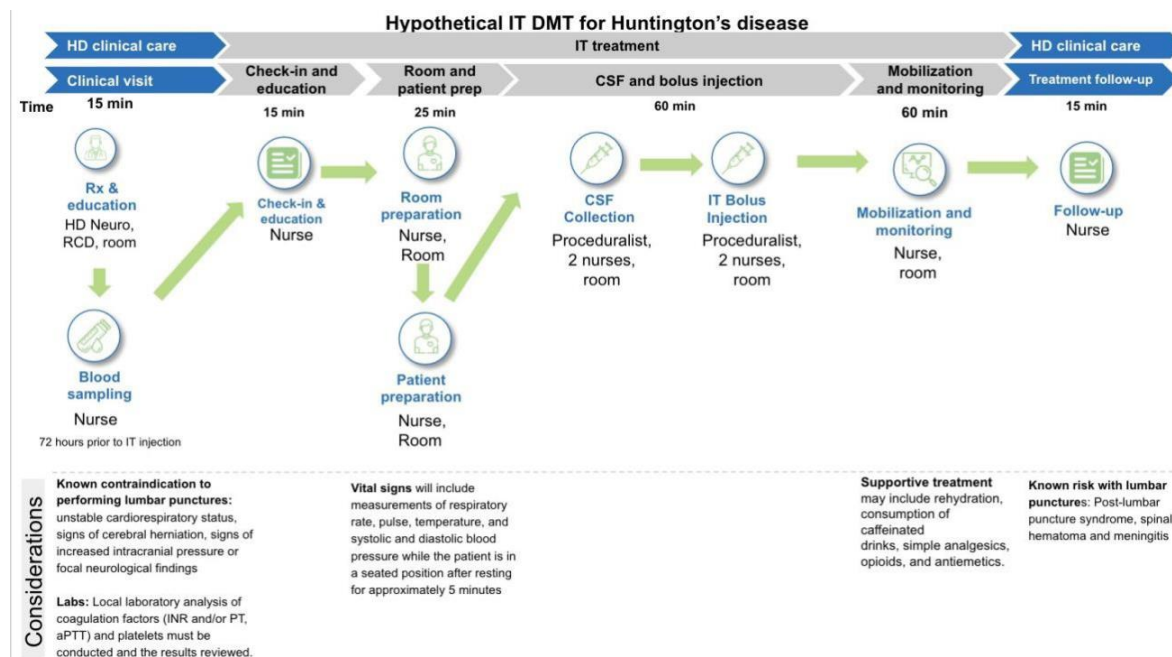
The objective of this session is to understand the **anticipated capacity within your centre** required to manage HD patients **should a DMT become available in the future**. Capacity will be assessed in two parts: resources (personnel) and infrastructure.

In answering the questions below, please make the following assumptions:

- Injection interval: Two-loading doses (28 days apart), then Q8W treatment thereafter
- Sufficient expertise: Training on how to carry out an IT injection has been carried out if necessary
- Financial protection: No financial losses compared to the current status

Based on research plan template Version 3.0 released on 01 Jan 2020

Below is a diagram of the hypothetical treatment flow of intrathecal disease-modifying treatment for Huntington's disease developed by the steering committee of this study (Leavitt et al., 2019 HSG). Please take this into account when answering the following questions.



Capacity reported should represent resources and infrastructure that is either immediately available for use or could be potentially accessible should a treatment become available (e.g. personnel tasks could be rearranged to free up time / space for additional activities). For the purpose of this survey, we will refer to this as **accessible capacity**. Please **do not** consider capacity (infrastructure/resources/personnel) that:

- is exclusively for research purposes and cannot be reassigned to clinical practice
- requires a different source of funding for clinical use that is currently not available

d. Part 1: Resource (Personnel)

1. Do you expect the proceduralist of the first IT infusion will differ from the IT proceduralist for subsequent administrations? *Reminder: Assumption is two-loading doses on Day 1 and Day 29, then Q8W dosing thereafter*
 - a. No, first IT infusion and subsequent IT infusion would be done by the same person
 - b. Yes, the first IT infusion and the subsequent IT infusion will be performed by different proceduralists
 - c. Unsure
2. Within your centre, **at a minimum**, which of the following health care professionals would you require in order to provide a DMT? Please consider personnel required for both IT infusion and ancillary DMT activities.

Based on research plan template Version 3.0 released on 01 Jan 2020

- a. Nurse
 - a. Psychiatrist
 - b. Social worker
 - c. Neurologists
 - d. Intrathecal proceduralists
 - e. Neurologist-fellow/senior residents
 - f. Other, please specify: _____
3. Within your centre, please indicate the **accessible capacity** of the following HCPs would either perform or support with the care HD patients should a disease modifying therapy become available? Please consider personnel required for both IT infusion and ancillary DMTactivities.
- a. Nurse
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - b. Psychiatrist
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - c. Social worker
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - d. Neurologists (yourself)
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - e. Neurologists (other)
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - f. Neurologist-fellow
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - g.
 - Other, please specify: _____
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

e. Part 2: Infrastructure

1. If a DMT was available, which of the following **rooms** have **accessible capacity** to support HD care in your centre?
 - a. Examination room
 - i. Number of rooms: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year per room: _____
 - b. Dedicated room for intrathecal administration
 - i. Number of rooms: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year per room: _____
 - c. Other
 - i. Number of rooms: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year per room: _____
2. If a DMT was available, in your centre which of the following **equipment** would have **accessible capacity** to support HD care?
 - a. Ultrasound equipment for intrathecal treatment guidance
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - b. Hospital stretcher with ability to achieve Trendelenburg position
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - c. Local lab able to perform cerebral spinal fluid safety studies, prothrombin time, international normalized ratio and platelet count
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - d. Blood pressure equipment
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - e. Epidural positioning chair
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - f. Other
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)

Based on research plan template Version 3.0 released on 01 Jan 2020

E. Future willingness and barriers

The objective of this session is to understand the **willingness and barriers you would experience within your centre** should a DMT for HD patients become available in the future.

1. If a DMT requiring intrathecal infusion would become available, please list for **yourself** how much agree with the following statements regarding your **comfort** and **willingness** to support HD clinical care and IT infusion (see definition above)
 - a. **I would be willing to perform IT infusions**
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - b. **I would be willing to provide HD clinical care**
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
2. If a DMT requiring intrathecal infusion would become available, please list for **yourself** how much agree with the following statements regarding **training**.
 - a. **I would require additional medical training to perform IT infusions**
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - b. **I would require additional medical training to support the clinical care of HDpatients**
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
3. When considering for **other neurologists in your centre**, how much agree with the following statements
 - a. **Other neurologists** would be willing to provide HD clinical care

Based on research plan template Version 3.0 released on 01 Jan 2020

- 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
- b. **Other neurologists** would be willing to perform IT infusion
- 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
- c. **Other neurologists** would require additional medical training should a DMT become available
- 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
4. When considering for **nurses in your centre**, how much agree with the following statements
- a. **Nurses** would be willing to support HD clinical care of HD patients:
- 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
- b. **Nurses** would be willing to support IT infusions
- 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree

Based on research plan template Version 3.0 released on 01 Jan 2020

- 5 - not applicable
- c. **Nurses** would require additional training should a DMT become available
- 0 - completely disagree
- 1 - disagree
- 2 - neutral
- 3- agree
- 4 - completely agree
- 5 - not applicable
5. For capacity **within your centre**, which of the following do you think would need to be addressed in order to deliver the best care for HD patients: (priority 1-6, 1 being the highest priority)
- Increase personnel resources (number or time): _____
 - Expand infrastructures: _____
 - Acquire medical equipment: _____
 - Increase proficiency and training for personnel: _____
 - Increase administrative assistance: _____
 - Increase other HCP support: _____
 - Other: _____

F. Future Capacity **Outside your HD Centre**

The objective of this section is to understand the **capacity outside of your HD centre** (affiliated hospital, other neurology clinics etc) to manage HD patients should a DMT become available in the future.

Capacity reported should represent resources and infrastructure that is either immediately available for use or could be potentially accessible should a treatment become available (e.g. personnel tasks could be rearranged to free up time / space for additional activities). Please **do not** consider capacity (infrastructure/resources/personnel) that :

- is exclusively for research purposes and cannot be reassigned to clinical practice
- requires a different source of funding for clinical use that is currently not available

HD clinical care: activities related to medical care of HD patients (in clinic visits, RCD visits etc) excluding IT treatment.

- Outside of your centre**, are there any other centres or HCPs that would have **accessible capacity** to support HD care?
 - Yes
 - No
 - Unsure
- [Sub-question] If yes, where would you anticipate this capacity to come from?
 - Neurology department in affiliated hospital
 - Other departments in affiliated hospital
 - Outpatient/day hospitals affiliated / networked within the hospital

Based on research plan template Version 3.0 released on 01 Jan 2020

- d. External outpatient/day hospitals without current relation with the hospital
- e. Other non affiliated hospitals
- f. Other
- g. Unsure

3. If a DMT was available, **outside of your** HD centre are you aware of any other HCPs that have **accessible capacity** to support HD care? Please consider personnel required for both intrathecal infusion and ancillary DMT activities.

- a. Nurse in Neurology department
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- b. Nurses in IV / IT units
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- c. Nurse in day hospital (same hospital)
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- d. Interventional Radiologists
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- e. Anesthesiologists
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- f. IV unit doctors (same hospital)
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- g. Day hospital physicians (same hospital)
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- h. Other neurologist for HD clinical care
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- i. Psychiatrist for HD clinical care
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
- j. Unsure _____

4. If a DMT was available, **outside of your** HD centre are you aware of any **rooms** would have **accessible capacity** to support HD care?

Based on research plan template Version 3.0 released on 01 Jan 2020

- a. Examination room in the broader Neurology department
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year: _____
 - b. Examination room in other department
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year: _____
 - c. Dedicated room for intrathecal infusion
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year: _____
 - d. IV infusion suite (with suitable bed for intrathecal infusion)
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year: _____
 - e. Waiting room (for patient resting / walking after the procedure)
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year: _____
 - f. Other
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per year: _____
 - g. Unsure
5. If a DMT became available, would you consider referring your HD patient to other centres?
- a. Yes, only centre with high expertise in treating HD patients
 - b. Yes, any movement disorder centre
 - c. Yes, any neurologists
 - d. Yes, but only for the IT procedure / to administer the DMT
 - e. No, I would not refer patients out of my centre

G. Survey Close

The purpose of the study is to identify health care capacity to better plan for the future of care of Huntington's patients. In order to achieve this goal, we are aiming to capture the capacity within the Canadian health care system.

1. Can we contact you for a follow-up phone interview on additional questions on capacity and solutions mapping?
 - a. Yes
 - b. No

Based on research plan template Version 3.0 released on 01 Jan 2020

2. **Are you aware of any other Other Hospital treating ≥ 20 HD patients? If yes, could you please provide the contact of a reference person?**
3. Are you aware of any Day Hospital (i.e. located in the same hospital or affiliated to the same institution as an HD centre, and may have facilities equipped for IT treatment) in your surrounding area which could provide capacity for this IT DMT administration? If yes, could you please provide the contact of a reference person?

H . Honorarium

Please review your Agreement in its entirety, and note the following information pertaining to Roche's tax reporting obligations:

As this project is being in part supported by Roche, they are be required by law to report payments made to you to the Canada Revenue Agency ("CRA"), and to issue tax statements to you, including, where applicable, a T4A Statement of Pension, Retirement, Annuity, and Other Income. This reporting will be done annually, and any tax slips will be mailed to you in February following the relevant tax year.

In scope for disclosure to the CRA are:

- Any fees for services paid to individuals (but not corporations)
- Any reimbursements paid to individuals (but not corporations) for out-of-pocket expenses (eg. reimbursed meals, mileage, taxi, parking, etc.)
- Grants and other financial support paid to individuals (but not to corporations)

Out of scope for disclosure to the CRA are:

- In-kind items and services (eg. flights, hotels, meals, etc. directly paid by Roche)
- Payments made to corporations instead of individuals
- GST/HST (or equivalent) paid (if any)

For more information on the requirements of CRA reporting, please contact Dina Shi by email at dina.shi@roche.com or by phone at 416-618-2947

1. Who should honorarium be made payable?
 - a. Yourself
 - b. Professional corporation
 - c. Decline honorarium [*Exit survey*]

[If "a", then] Please complete the following information below to receive the honorarium for this activity.

1. Title:
2. First Name
3. Last Name
4. Email Address

Based on research plan template Version 3.0 released on 01 Jan 2020

5. Admin/cc email address
6. Mailing address
 - a. Address
 - b. City
 - c. Province
 - d. Postal code
 - e. Institution/Hospital affiliation
 - f. Telephone
7. Tax number:
 - a. Are taxes applicable?
 - i. Yes
 - ii. No
 - b. Please fill out if applicable:

Tax	Check if payable	Applicable rate*:	Tax ID
HST			HST #:
GST			GST #:
PST/QST			QST #:

* Tax rates subject to change in accordance with applicable tax regulations.

c.

[If “b”, then] Please complete the following information below to receive the honorarium for this activity.

8. Title:
9. First Name
10. Last Name
11. Email Address
12. Admin/cc email address
13. Legal name of the professional corporation
14. Mailing address of the corporation
 - a. Address
 - b. Province
 - c. Postal Code
 - a. Telephone
2. Tax number:
 - a. Are taxes applicable?
 - i. Yes
 - ii. No
 - b. Please fill out if applicable:

Based on research plan template Version 3.0 released on 01 Jan 2020

Tax	Check if payable	Applicable rate*:	Tax ID
HST			HST #:
GST			GST #:
PST/QST			QST #:

* Tax rates subject to change in accordance with applicable tax regulations.
d.

Based on research plan template Version 3.0 released on 01 Jan 2020

APPENDIX 4 **Network centre: Other/General Neurology (30 min)**

Thank you again for your participation in this assessment on the impact of the first Disease Modifying Treatment (DMT) for Huntington's disease (HD). The primary objective of this study is to assess and model the current and potential future health care capacity for the management of Huntington's patients across Canada.

The outputs generated could be used to influence policy, interagency collaboration, or research and development priorities at a local/provincial level potentially bettering the clinical care for HD patients.

The survey a total of eight **sections:**

- A. General questions
- B. HD patient population
- C. Current capacity within your unit
- D. Future capacity within your unit
- E. Future willingness and barriers
- F. Future capacity outside your unit
- G. Survey close
- H. Honorarium

Abbreviation Legend:

Disease Modifying Treatment (DMT)

Huntington's disease (HD)

Healthcare professionals (HCP)

Intrathecal (IT)

A. General questions

- 1. Name of centre & affiliated hospital (if different/applicable): [free text]
- 2. Address: [free text]
- 3. Name: [free text]

B. HD patient population

In this section of the survey we will be asking you questions regarding your current HD patient population.

- 1. How many HD patients have you treated over the past 12 months? Please list the number of patients by Shoulson-Fahn stage below.

Prodromal: Prior to stage 1. Patient has inherited the gene expansion but does not meet criteria for motor onset of HD. Subtle changes in motor, cognitive and often emotional function, with consequent subtle changes in functional abilities.

Stage 1: Marginal engagement in occupation, having part-time voluntary or salaried employment potential AND maintains typical pre-disease levels of independence in all other basic functions, such

Based on research plan template Version 3.0 released on 01 Jan 2020

as financial management, domestic responsibilities, and activities of daily living (eating, dressing, bathing, etc.); OR performs satisfactorily in typical salaried employment (perhaps at a lower level) and requires slight assistance in only one basic function: finances, domestic chores, or activities of daily living.

Stage 2: Typically unable to work, requiring only slight assistance in all basic functions: finances, domestic, daily activities; OR unable to work and requiring different levels of assistance with basic functions (some are still handled independently).

Stage 3: Unable to engage in employment AND requires major assistance in most basic functions: financial affairs, domestic responsibilities, and activities of daily living. Care may be provided at home but needs may be better provided at an extended care facility.

Stage 4: Requires major assistance in financial affairs, domestic responsibilities, and most activities of daily living. For example, comprehension of the nature and purpose of procedures may be intact, but major assistance is required to act on them.

Stage 5: Requires major assistance in financial affairs, domestic responsibilities, and all activities of daily living. Full-time skilled nursing care is required.

- a. **Prodromal:** Number of patients: _____
- b. **Stage 1-2:** Number of patients: _____
- c. **Stage 3:** Number of patients: _____
- d. **Stage 4-5:** Number of patients: _____
- e. Total number of **HD patients:** Number of patients: _____
- f. Total number of **all patients** in the centre. Number of patients: _____

C. Current Capacity within your Centre: Resources and infrastructure

[NOTE: This section should not be asked if the responder classified as a “General Neurology” which is currently not involved in the HD patients’ management]

The objective of this section is to assess **the current capacity within your centre.** HD centres: medical clinics with dedicated neurologists along with other allied health care professionals to support the care of HD patients.

HD clinical care: activities related to medical care of HD patients (in clinic visits, RCD visits etc) excluding IT treatment.

1. How much time do you currently dedicate to HD clinical care?
 - a. % time spent on HD clinical care only: _____
 - b. Number of minutes that you spend on HD clinical care per patient visit: _____
 - c. Number of patient visits per year: _____
2. What is the average wait list for your HD patients?
 - a. Average time for **first** visit (months): _____
 - b. Average time for **follow-up** visits (months): _____
3. Do you refer any of your HD patients to HD centres for the management of their disease?
 - a. Yes, if so % patient referred _____

Based on research plan template Version 3.0 released on 01 Jan 2020

- b. No
4. [Sub-questions] If yes, please select all HD centres that apply:
- a. Centre of HD at University of British Columbia
 - b. University of Alberta Hospital Movement Disorder Clinic
 - c. University of Calgary Movement Disorder Clinic
 - d. Saskatoon HD Clinic, Royal University Hospital
 - e. Deer Lodge Movement Disorders Clinic
 - f. The Ottawa Hospital
 - g. London Movement Disorder Centre
 - h. North York General Hospital
 - i. Centre for Movement Disorders-North York
 - j. Hamilton Clinic at Hamilton General Hospital
 - k. Centre Hospitalier de l'Université de Montréal
 - l. Institut Neurologique de Montréal (McGill Université)
 - m. Université de Laval
 - n. QEII Health Sciences Centre Movement Disorders Clinic (Halifax)
 - o. New Brunswick HD Clinic
 - p. Newfoundland Balance & Dizziness (Movement Disorder Private Clinic)
 - q. Kingston Hotel Dieu Hospital HD Clinic
 - r. Other
5. **In your centre, other than yourself** are any of the following healthcare professionals (HCPs) currently involved in the HD clinical care for HD patients?
- a. Nurse
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit: _____
 - Number of HD patient visits per year: _____
 - b. Neurologists (other than yourself)
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

- Number of minutes they spend on HD clinical care per patient visit: _____
- Number of HD patient visits per year: _____
- c. Neurologist-Resident
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit: _____
 - Number of HD patient visits per year: _____
- d. Psychiatrist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit: _____
 - Number of HD patient visits per year: _____
- e. Social worker (Resource centre director)
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit per week: _____
 - Number of HD patient visits per year: _____
- f. Physiotherapy
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit : _____
 - Number of HD patient visits per year: _____
- g. Occupational therapist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit : _____
 - Number of HD patient visits per year: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

- h. Speech therapist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit
: _____
 - Number of HD patient visits per year: _____
 - i. Neuropsychologist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit
: _____
 - Number of HD patient visits per year: _____
 - j. Geneticist
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit
: _____
 - Number of HD patient visits per year: _____
 - k. Genetic counselor
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit
: _____
 - Number of HD patient visits per year: _____
 - l. Other
 - i. No
 - ii. Yes, within my centre
 - iii. Yes, via a referral outside my centre
 - iv. If yes, please indicate the following:
 - Number of this HCP type: _____
 - Number of minutes they spend on HD clinical care per patient per visit
: _____
 - Number of HD patient visits per year: _____
6. When patients visit these HCPs, do they see them on the same day or in separate centre visits?
- a. Separate visits

Based on research plan template Version 3.0 released on 01 Jan 2020

- b. Same visits
- c. Variable

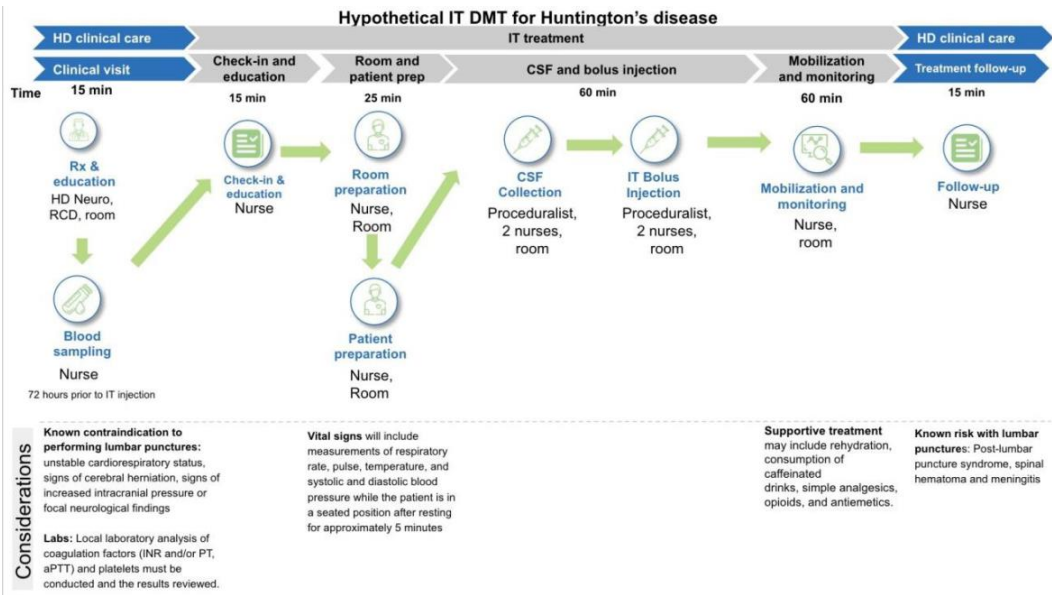
D. Future capacity within Centre: Resources and Infrastructure

The objective of this session is to understand the **anticipated capacity within your centre** required to manage HD patients **should a DMT become available in the future**. Capacity will be assessed in two parts: resources (personnel) and infrastructure.

In answering the questions below, please make the following assumptions:

- Injection interval: Two-loading doses (28 days apart), then Q8W treatment thereafter
- Sufficient expertise: Training on how to carry out an IT injection has been carried out if necessary
- Financial protection: No financial losses compared to the current status

Below is a diagram of the hypothetical treatment flow of intrathecal disease-modifying treatment for Huntington’s disease developed by the steering committee of this study (Leavitt et al.,2019 HSG) . Please take this into account when answering the following questions.



Capacity reported should represent resources and infrastructure that is either immediately available for use or could be potentially accessible should a treatment become available (e.g. personnel tasks could be rearranged to free up time / space for additional activities). Please **do not** consider capacity (infrastructure/resources/personnel) that :

- is exclusively for research purposes and cannot be reassigned to clinical practice
- equires a different source of funding for clinical use that is currently not available

Based on research plan template Version 3.0 released on 01 Jan 2020

a. Part 1: Resource (Personnel)

1. Within your centre, **at a minimum**, which of the following HCPs would you require in order to provide a DMT? Please consider personnel required for both intrathecal infusion and ancillary DMT activities.
 - a. Nurse
 - a. Psychiatrist
 - b. Social worker
 - c. Neurologists
 - d. Intrathecal proceduralists
 - e. Neurologist-fellow/senior residents
 - f. Other, please specify: _____

2. Within your centre, please indicate the accessible capacity of the following HCPs would either perform or support with the care HD patients should a disease modifying therapy become available? Please consider personnel required for both IT infusion and ancillary DMTactivities.
 - a. Nurse
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - b. Psychiatrist
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - c. Social worker
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - d. Neurologists (yourself)
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - e. Neurologists (other)
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - f. Neurologist-fellow
 - i. Number of HCP type: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week: _____
 - iii. Expected number of weeks per year per HCP: _____
 - g.
 - Other, please specify: _____
 - i. Number of HCP type: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

- ii. Expected number of minutes each HCP could dedicate to HD patients per week:
- iii. Expected number of weeks per year per HCP:_____

a. Part 2: Infrastructure

1. If a DMT was available, in your centre which of the following **rooms** have **accessible capacity** to support HD care?
 - a. Examination room
 - i. Number of rooms:_____
 - ii. Expected number of minutes available for HD patients per room per week, in addition to what is already dedicated for current activities (if any):_____
 - iii. Expected number of weeks per year:_____
 - b. Dedicated room for intrathecal administration
 - i. Number of rooms:_____
 - ii. Expected number of minutes available for HD patients per room per week, in addition to what is already dedicated for current activities (if any):_____
 - iii. Expected number of weeks per year:_____
 - c. Other
 - i. Number of rooms:_____
 - ii. Expected number of minutes available for HD patients per room per week, in addition to what is already dedicated for current activities (if any):_____
 - iii. Expected number of weeks per year:_____
2. If a DMT was available, in your centre which of the following **equipment** would have **accessible capacity** to support HD care?
 - g. Ultrasound equipment for intrathecal treatment guidance
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - h. Hospital stretcher with ability to achieve Trendelenburg position
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - i. Local lab able to perform cerebral spinal fluid safety studies, prothrombintime, international normalized ratio and platelet count
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
 - j. Blood pressure equipment
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)

Based on research plan template Version 3.0 released on 01 Jan 2020

- k. Epidural positioning chair
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)
- l. Other
 - i. Yes
 - ii. No
 - iii. Already used by the HD team (even if for non HD patients)

E. Future willingness and barriers

The objective of this session is to understand the **willingness and barriers you would experience within your centre** should a DMT for HD patients become available in the future. There are four questions in this section.

HD clinical care: activities related to medical care of HD patients (in clinic visits, RCD visits etc) excluding IT treatment.

1. If a DMT requiring IT infusion would become available, please list how much agree for **yourself** with the following statements:
 - a. **I would be willing** to perform IT infusion
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - b. **I would be willing** to provide HD clinical care
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
2. If a DMT requiring IT infusion would become available, please list for **yourself** how much agree with the following statements regarding **training**.
 - a. **I would** require additional medical training to perform IT infusions
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree

Based on research plan template Version 3.0 released on 01 Jan 2020

- b. **I would** require additional medical training to support the clinical care of HDpatients
0 - completely disagree
1 - disagree
2 - neutral
3- agree
4 - completely agree
3. When considering for **other neurologists in your centre**, how much agree with the following statements
- a. **Other neurologists would be** willing to provide HD clinical care
0 - completely disagree
1 - disagree
2 - neutral
3- agree
4 - completely agree
5 - not applicable
- b. **Other neurologists** would be willing to perform IT infusion
0 - completely disagree
1 - disagree
2 - neutral
3- agree
4 - completely agree
5 - not applicable
- c. **Other neurologists** would require additional medical training
0 - completely disagree
1 - disagree
2 - neutral
3- agree
4 - completely agree
5 - not applicable
4. When considering for **nurses in your centre**, how much agree with the following statements (able to select n/a)
- a. **Nurses** would be willing to support HD clinical care to HDpatients:
0 - completely disagree
1 - disagree

Based on research plan template Version 3.0 released on 01 Jan 2020

- 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
 - b. **Nurses** would be willing to support IT infusion
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
 - c. **Nurses** would require additional training
 - 0 - completely disagree
 - 1 - disagree
 - 2 - neutral
 - 3- agree
 - 4 - completely agree
 - 5 - not applicable
5. For capacity **within your centre**, which of the following do you think would need to be addressed in order to deliver the best care for HD patients: (priority 0-3, 3 being the highest priority)
- a. Increase personnel resources (number or time): _____
 - b. Expand infrastructures: _____
 - c. Acquire medical equipment: _____
 - d. Increase proficiency and training for personnel: _____
 - e. Increase administrative assistance: _____
 - f. Increase other HCP support: _____
 - g. Other: _____

F. Future Capacity Outside your Unit

The objective of this section is to understand the **capacity outside of your Unit** (affiliated hospital, other neurology clinics etc) to manage HD patients should a DMT become available in the future.

Capacity reported should represent resources and infrastructure that is either immediately available for use or could be potentially accessible should a treatment become available (e.g. personnel tasks could be rearranged to free up time / space for additional activities). Please **do not** consider capacity (infrastructure/resources/personnel) that is:

- exclusively for research purposes and cannot be reassigned to clinical practice
- accessible with additional funding

Based on research plan template Version 3.0 released on 01 Jan 2020

There are six questions in this section.

1. **Outside of your centre**, are there any other HCPs within your department / hospital that would have accessible capacity to support HD care?
 - a. Yes
 - b. No
 - c. Unsure
2. [Sub-question] If yes, where would you anticipate this capacity to come from?
 - a. Affiliated neurology department
 - b. Other departments in the affiliated hospital
 - c. Outpatient/day hospitals
 - d. External outpatient/day hospitals
 - e. Infusion unit in the hospital
 - f. Other
 - g. Unsure
3. If a DMT was available, outside of your unit are you aware of any other HCPs that have accessible capacity to support HD care? Please consider personnel required for both intrathecal infusion and ancillary DMT activities.
 - a. Nurse in Neurology department
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
 - iii. Expected number of weeks per year: _____
 - b. Nurses in IV / IT units
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
 - iii. Expected number of weeks per year: _____
 - c. Nurse in day hospital (same hospital)
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
 - iii. Expected number of weeks per year: _____
 - d. Interventional Radiologists
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
 - iii. Expected number of weeks per year: _____
 - e. Anesthesiologists
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week _____
 - iii. Expected number of weeks per year: _____
 - f. IV unit doctors (same hospital)
 - i. Number of HCPs: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

- ii. Expected number of minutes each HCP could dedicate to HD patients per week
 - iii. Expected number of weeks per year: _____
 - g. Day hospital physicians (same hospital)
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week
 - iii. Expected number of weeks per year: _____
 - h. Other neurologist for HD clinical care
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week
 - iii. Expected number of weeks per year: _____
 - i. Psychiatrist for HD clinical care
 - i. Number of HCPs: _____
 - ii. Expected number of minutes each HCP could dedicate to HD patients per week
 - iii. Expected number of weeks per year: _____
 - j. Unsure
4. If a DMT was available, **outside of your** centre are you aware of any **rooms** would have **accessible capacity** to support HD care?
- a. Examination room in the broader Neurology department
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per room per year: _____
 - b. Examination room in the other department
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per room per year: _____
 - c. Dedicated room for intrathecal infusion
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per room per year: _____
 - d. IV infusion suite (with suitable bed for intrathecal infusion)
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per room per year: _____
 - e. Waiting room (for patient resting / walking after the procedure)
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per room per year: _____
 - f. Other
 - i. Number of resource: _____
 - ii. Expected number of minutes available for HD patients per room per week: _____
 - iii. Expected number of weeks per room per year: _____

5. If a DMT became available, would you consider referring your HD patient to other centres?

Based on research plan template Version 3.0 released on 01 Jan 2020

- a. Yes, only centre with high expertise in treating HD patients
 - b. Yes, any movement disorder centre
 - c. Yes, any neurologists
 - d. Yes, but only for the IT procedure / to administer the DMT
- No, I would not refer patients out of my centre
6. Which patients would you consider referring out?
- a. Only those that my centre will not be able to serve
 - b. Only patients that come from >2h driving distance
 - c. An anticipated % corresponding to _____%

G. Survey Close

The purpose of the study is to identify health care capacity to better plan for the future of care of Huntington's patients. In order to achieve this goal, we are aiming to capture the capacity within the Canadian health care system.

1. Are you aware of any other neurology hospitals in your surrounding area which could provide capacity for this IT DMT administration? If yes, could you please provide the contact of a reference person?

H . Honorarium

Please review your Agreement in its entirety, and note the following information pertaining to Roche's tax reporting obligations:

As this project is being in part supported by Roche, they are be required by law to report payments made to you to the Canada Revenue Agency ("CRA"), and to issue tax statements to you, including, where applicable, a T4A Statement of Pension, Retirement, Annuity, and Other Income. This reporting will be done annually, and any tax slips will be mailed to you in February following the relevant tax year.

In scope for disclosure to the CRA are:

- Any fees for services paid to individuals (but not corporations)
- Any reimbursements paid to individuals (but not corporations) for out-of-pocket expenses (eg. reimbursed meals, mileage, taxi, parking, etc.)
- Grants and other financial support paid to individuals (but not to corporations)

Out of scope for disclosure to the CRA are:

- In-kind items and services (eg. flights, hotels, meals, etc. directly paid by Roche)
- Payments made to corporations instead of individuals
- GST/HST (or equivalent) paid (if any)

For more information on the requirements of CRA reporting, please contact Dina Shi by email at dina.shi@roche.com or by phone at 416-618-2947

Based on research plan template Version 3.0 released on 01 Jan 2020

1. Who should honorarium be made payable?

- a. Yourself
- b. Professional corporation
- c. Decline honorarium [*Exit survey*]

[If “a”, then] Please complete the following information below to receive the honorarium for this activity.

- 15. Title:
- 16. First Name
- 17. Last Name
- 18. Email Address
- 19. Admin/cc email address
- 20. Mailing address
 - a. Address
 - b. City
 - c. Province
 - d. Postal code
 - e. Institution/Hospital affiliation
- a. Telephone
- 2. Tax number:
 - a. Are taxes applicable?
 - i. Yes
 - ii. No
 - f. Please fill out if applicable:

Tax	Check if payable	Applicable rate*:	Tax ID
HST			HST #:
GST			GST #:
PST/QST			QST #:

* Tax rates subject to change in accordance with applicable tax regulations.

[If “b”, then] Please complete the following information below to receive the honorarium for this activity.

- 21. Title:
- 22. First Name
- 23. Last Name
- 24. Email Address
- 25. Admin/cc email address
- 26. Legal name of the professional corporation

Based on research plan template Version 3.0 released on 01 Jan 2020

27. Mailing address of the corporation
- a. Address

b. Province

c. Postal Code

a. Telephone
2. Tax number:
- a. Are taxes applicable?

i. Yes

ii. No

b. Please fill out if applicable:

Tax	Check if payable	Applicable rate*:	Tax ID
HST			HST #:
GST			GST #:
PST/QST			QST #:

* Tax rates subject to change in accordance with applicable tax regulations.

d.

Based on research plan template Version 3.0 released on 01 Jan 2020

APPENDIX 5 **Resource Centre (RCDs/Social Workers) (30 min)**

Resource centre (Social Workers) - HD capacity survey (30 min)

Thank you again for your participation in this assessment on the impact of the first Disease Modifying Treatment (DMT) for Huntington's disease (HD). The primary objective of this study is to assess and model the current and potential future health care capacity for the management of Huntington's clients across Canada.

The outputs generated could be used to influence policy, interagency collaboration, or research and development priorities at a local/provincial level potentially bettering the clinical care for HD clients.

The survey a total of seven sections:

- A. General questions
- B. Clients
- C. Current capacity
- D. Community network
- E. Future capacity
- F. Survey close
- G. Honorarium

Abbreviation Legend:

Disease Modifying Treatment (DMT)

Huntington's disease (HD)

Healthcare professionals (HCP)

Intrathecal (IT)

A. General questions

1. Name of HSC Resource Centre & HD or MD Clinic (if different/applicable): [free text]
2. Address: [free text]
3. Name: [free text]

B. Clients

In this section of the survey we will be asking you questions regarding the clients you support as a HSC Resource Centre Director.

1. How many clients have you supported over the past 12 months? Please list the number of clients by Shoulson-Fahn stage below.

Stage 1: Marginal engagement in occupation, having part-time voluntary or salaried employment potential AND maintains typical pre-disease levels of independence in all other basic functions, such as financial management, domestic responsibilities, and activities of daily living (eating, dressing, bathing, etc.); OR performs satisfactorily in typical salaried employment (perhaps at a lower level)

Based on research plan template Version 3.0 released on 01 Jan 2020

and requires slight assistance in only one basic function: finances, domestic chores, or activities of daily living.

Stage 2: Typically unable to work, requiring only slight assistance in all basic functions: finances, domestic, daily activities; OR unable to work and requiring different levels of assistance with basic functions (some are still handled independently).

Stage 3: Unable to engage in employment AND requires major assistance in most basic functions: financial affairs, domestic responsibilities, and activities of daily living. Care may be provided at home but needs may be better provided at an extended care facility.

Stage 4: Requires major assistance in financial affairs, domestic responsibilities, and most activities of daily living. For example, comprehension of the nature and purpose of procedures may be intact, but major assistance is required to act on them.

Stage 5: Requires major assistance in financial affairs, domestic responsibilities, and all activities of daily living. Full-time skilled nursing care is required.

g. **Prodromal:** Number of clients: _____

h. **Stage 1-2:** Number of clients: _____

i. **Stage 3:** Number of clients: _____

j. **Stage 4-5:** Number of clients: _____

a. Clients at risk for HD (total): _____

b. Client that are caregivers (total): _____

c. Other family members and supports (total): _____

1. How many of your clients in Stage 1-2 are not currently being followed by a HD center?

2. What percentage of your clients with HD live within 2 hours of driving their HD centre where they receive clinical care from their neurologist?

a. 0-25%

b. 25-50%

c. 51-75%

d. 76-100%

e. I do not know

3. What percentage of your clients that are in Stage 1 or Stage 2 are between ≥ 25 and ≤ 65 years of age:

a. 0-20%

b. 20-40%

c. 40-60%

d. 60-80%

Based on research plan template Version 3.0 released on 01 Jan 2020

- e. >80%
 - f. I do not have an estimate of the number
4. If a DMT were to become available for clients with HD, do you anticipate any increase to the number of clients you support?
- a. Yes, if so what is the percentage per stage
 - i. Stage 1 (%): _____
 - ii. Stage 2 (%): _____
 - iii. Stage 3 (%): _____
 - iv. Stage 4-5 (%): _____
 - v. At risk (%): _____
 - vi. Caregiver/Family (%): _____
 - b. No
 - c. I do not know

C. Current Capacity: Resources (personnel) and Infrastructure

In this section of the survey we will be asking you questions regarding your current resource capacity.

1. In total, how much time do you currently dedicate to clients with HD?
 - a. Time (min) per week: _____
 - b. Weeks per year: _____
2. On average, what percentage of your time do you spend helping clients in the HD community with the following tasks?
 - a. Identifying and accessing community resources for clients
 - i. Percentage of time: _____
 - b. Supporting clients in satellite/remote clinics (i.e. transient clinics set in rural communities)
 - i. Percentage of time: _____
 - ii. Percentage of time: _____
 - c. In-person or virtual emotional support
 - i. Percentage of time: _____
 - d. Support other HCPs (education, client information exchange)
 - i. Percentage of time: _____
 - e. Travelling to client meetings
 - i. Percentage of time: _____
 - f. Advocacy of services for clients
 - i. Percentage of time: _____
 - g. Disease education or education to the public
 - i. Percentage of time: _____
 - h. Education or support for other healthcare professionals
 - i. Percentage of time: _____
 - i. Other
 - i. Percentage of time: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

3. When meeting clients at a HD centre, do you utilize any of the following rooms for your clients?
 - a. Meeting room for in-person appointment
 - i. Yes
 - ii. No.
 - iii. If yes:
 - Time (min) per visit _____
 - iv. Visits per year, _____
 - b. Meeting room for virtual appointments
 - i. Yes
 - ii. No.
 - iii. If yes:
 - Time (min) per visit, _____
 - iv. Visits per year, _____
 - c. Other
 - i. Yes
 - ii. No.
 - iii. If yes:
 - Time (min) per visit, _____
 - iv. Visits per year, _____
4. Do you provide in-home supports for your clients?
 - a. If so, what are the average:
 - i. number of in-home client visits per week _____
 - ii. time (min) to travel to in-home client visit _____
 - iii. time (min) of in-home client visit _____
5. Prior to the COVID-19, did you provide support to any of your clients using telemedicine services? (phone calls, video call, email, text messages)
 - a. Yes, If so, % of HD clients: _____
 - b. No
6. [Sub-question], If no, do any barriers prevent you from offering telemedicine to your clients living with HD?
 - a. Patient familiarity/lack of experience with the technology
 - b. Physical issues (e.g. speech too unclear)
 - c. Lack of approved telemedicine systems in region
 - d. Patient reluctance to participate if expected to perform telemedicine from home

D. Community Networks

The objective of this session is to understand the **health care networks supporting the clients with HD**.

1. On average how many referrals to other HCPs do you facilitate on behalf of your HD clients? (average # of referrals per month)

Based on research plan template Version 3.0 released on 01 Jan 2020

- a. Psychiatrist_____
 - b. Psychologist:_____
 - c. Physiotherapist_____
 - d. Occupational therapist _____
 - e. Speech language pathologist _____
 - f. Dietician/nutritionist:_____
 - g. Home/personal care:_____
 - h. HD/MD clinic:_____
 - i. Genetics/Genetic counsellor: _____
 - j. Other :_____
2. Currently, when a client with HD requires care from another HCP how often are they able to access the care they require?
 - a. Psychiatrist
 - i. Always
 - ii. Sometime
 - iii. Never
 - b. Physiotherapy
 - i. Always
 - ii. Sometime
 - iii. Never
 - c. Occupational therapy
 - i. Always
 - ii. Sometime
 - iii. Never
 - d. Speech language pathology
 - i. Always
 - ii. Sometime
 - iii. Never
 - e. Other (dietician, psychologist, genetics, general practitioner (GP))
 - i. Always
 - ii. Sometime
 - iii. Never
3. What are the biggest barriers when referring HD patients to other allied healthcare professionals? Select all that apply
 - a. Capacity of the healthcare professional (e.g. waitlist)
 - b. Willingness of the healthcare professional to manage HD patients
 - c. Identifying a health care professional in close proximity to HD patient
 - d. Lack of private coverage and/or cost
 - e. Lack of healthcare professional education and experience
 - f. Lack of transportation or logistical challenges to get to the healthcare professional
 - g. High turnover of health care professional
 - h. Other
 - i. Unknown

Based on research plan template Version 3.0 released on 01 Jan 2020

E. Future Capacity

The objective of this session is to understand the **anticipated capacity within your HSC Resource Centre** required to manage clients **should a DMT become available in the future**. Capacity will be assessed in two parts: resources (personnel) and infrastructure.

In answering the questions below, please make the following assumptions:

- Injection interval: Two-loading doses (28 days apart), then every 8 weeks treatment thereafter
- Financial protection: No financial losses compared to the current status

Capacity reported should represent resources and infrastructure that is either immediately available for use or could be potentially accessible should a treatment become available (e.g. personnel tasks could be rearranged to free up time / space for additional activities). For the purpose of this survey, we will refer to this as **accessible capacity**. Please **do not** consider capacity (infrastructure/resources/personnel) that is accessible with additional funding.

1. If a DMT would become available, how do you expect it to impact the time you dedicate to **your existing tasks**?
 - a. Identifying and accessing community resources for clients
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - b. Supporting clients in satellite/remote clinics (i.e. transient clinics set in rural communities)
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - c. In-person or virtual emotional support
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - d. Support other HCPs (education, client information exchange)
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - e. Travelling to client meetings
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - f. Advocacy of services for clients
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - g. Disease education or education to the public
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - h. Education or support for other healthcare professionals
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____
 - i. Other
 - i. Impact (increase, decrease, none): _____
 - ii. Percentage change: _____

Based on research plan template Version 3.0 released on 01 Jan 2020

2. If a DMT would become available, how do you expect it to impact the time you dedicate to **your potentially new tasks**? Please provide answers per client, per visits
 - a. Scheduling of intrathecal infusion appointments
 - i. Yes
 - ii. No
 - iii. If yes, expected time (min per client) _____
 - b. Coordinate transportation to intrathecal infusion site
 - i. Yes
 - ii. No
 - iii. If yes, expected time (min per client) _____
 - c. Client support for financial/reimbursement of treatment
 - i. Yes
 - ii. No
 - iii. If yes, expected time (min per client) _____
 - d. Coordinating referrals to genetic clinics
 - i. Yes
 - ii. No
 - iii. If yes, expected time (min per client) _____
 - e. Other
 - i. Yes
 - ii. No
 - iii. If yes, expected time (min per client) _____
3. If a DMT would become available, how much **accessible** time could you allocate to new tasks associated with intrathecal DMT?
 - a. Minutes per week _____
 - b. Weeks per year _____

F. Survey Close

The purpose of the study is to identify health care capacity to better plan for the future of care of clients with Huntington's . In order to achieve this goal, we are aiming to capture the capacity within the Canadian health care system.

1. Are you aware of any other resource centre in your surrounding area? If yes, could you please provide the contact of a reference person?

G. Honorarium

Please review your Agreement in its entirety, and note the following information pertaining to Roche's tax reporting obligations:

As this project is being in part supported by Roche, they are be required by law to report payments made to you to the Canada Revenue Agency ("CRA"), and to issue tax statements to you, including, where

Based on research plan template Version 3.0 released on 01 Jan 2020

applicable, a T4A Statement of Pension, Retirement, Annuity, and Other Income. This reporting will be done annually, and any tax slips will be mailed to you in February following the relevant tax year.

In scope for disclosure to the CRA are:

- Any fees for services paid to individuals (but not corporations)
- Any reimbursements paid to individuals (but not corporations) for out-of-pocket expenses(eg. reimbursed meals, mileage, taxi, parking, etc.)
- Grants and other financial support paid to individuals (but not to corporations)

Out of scope for disclosure to the CRA are:

- In-kind items and services (eg. flights, hotels, meals, etc. directly paid by Roche
- Payments made to corporations instead of individuals
- GST/HST (or equivalent) paid (if any)

For more information on the requirements of CRA reporting, please contact Dina Shi by email at dina.shi@roche.com or by phone at 416-618-2947

1. Who should honorarium be made payable?
 - a. Yourself
 - b. Professional corporation
 - c. Decline honorarium [Exit survey]

[If “a”, then] Please complete the following information below to receive the honorarium for this activity.

1. Title:
2. First Name
3. Last Name
4. Email Address
5. Admin/cc email address
6. Mailing address
 - a. Address
 - b. City
 - c. Province
 - d. Postal code
 - e. Institution/Hospital affiliation
 - f. Telephone
7. Tax number:
 - a. Are taxes applicable?
 - i. Yes
 - ii. No
 - b. Please fill out if applicable:

Tax	Check if payable	Applicable rate*:	Tax ID
HST			HST #:

Based on research plan template Version 3.0 released on 01 Jan 2020

GST			GST #:
PST/QST			QST #:

* Tax rates subject to change in accordance with applicable tax regulations.

[If “b”, then] Please complete the following information below to receive the honorarium for this activity.

1. Title:
2. First Name
3. Last Name
4. Email Address
5. Admin/cc email address
6. Legal name of the professional corporation
7. Mailing address of the corporation
 - a. Address
 - b. Province
 - c. Postal Code
 - d. Telephone
8. Tax number:
 - a. Are taxes applicable?
 - i. Yes
 - ii. No
 - b. Please fill out if applicable:

Tax	Check if payable	Applicable rate*:	Tax ID
HST			HST #:
GST			GST #:
PST/QST			QST #:

* Tax rates subject to change in accordance with applicable tax regulations.

11.8

Based on research plan template Version 3.0 released on 01 Jan 2020

APPENDIX 6 - DISCUSSION GUIDE FOR PHONE INTERVIEWS

A. General questions

1. Name of centre & hospital (if different/applicable): [free text]
2. Address: [free text]
3. Name: [free text]
4. Profession of respondent: [free text]

B. HD patient population and journey

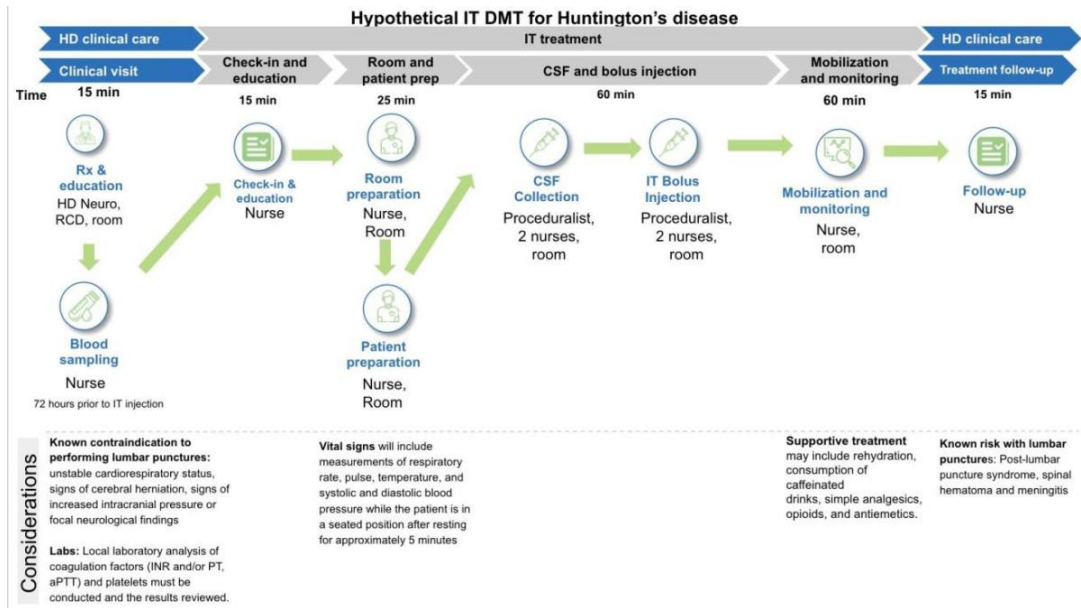
In this section of the discussion guide we'll be asking you questions as a follow-up to the online survey you completed regarding your current Huntington's patients and patient journey. There are four questions in this section.

As a reminder, in answering the questions below, please make the following assumptions:

- Injection interval: Two-loading doses (28 days apart), then Q8W treatment thereafter
- Sufficient expertise: Training on how to carry out an IT injection has been carried out if necessary
- Financial protection: No financial losses compared to the current status
- Patient population assumed to be stage 1-2, ages 25-65

Below is a diagram of the hypothetical treatment flow of intrathecal disease-modifying treatment for Huntington's disease developed by the steering committee of this study. Please take this into account when answering the following questions.

Based on research plan template Version 3.0 released on 01 Jan 2020



Capacity reported should represent resources and infrastructure that is either immediately available for use or could be potentially accessible should a treatment become available (e.g. personnel tasks could be rearranged to free up time / space for additional activities). For the purpose of this survey, we will refer to this as **accessible capacity**. Please **do not** consider capacity (infrastructure/resources/personnel) that :

- is exclusively for research purposes and cannot be reassigned to clinical practice
- requires a different source of funding for clinical use that is currently not available

1. In the survey you indicated that your current HD patient population to be *[insert survey response]*. How do you anticipate an IT DMT will impact patient volume? What factors do you feel will contribute to this change?

2. Of the patients who would be potentially eligible for treatment, what factors do you think would impede their access to treatment? (if needed patient population defined has age 25-65, SF scale stages 1-2)

Based on research plan template Version 3.0 released on 01 Jan 2020

3. How do you anticipate a DMT will impact the patient journey? How would this change in the patient journey impact how you currently manage HD patients? *Questions to prompt if not addressed* please Clinical visits: do you anticipate this being performed on the same day as the intrathecal infusion? Follow-up: Do you anticipate any challenges in terms of clinical or IT treatment follow-up? Aside from the intrathecal infusion, how will the advent of a treatment for HD impact how patients are managed within your HD centre?

4. Should a DMT become available, how willing are you to performing IT injections? Would you be willing to recruit someone who could perform and or support intrathecal infusion?

C. Referral

In this section of the discussion, we will be asking to better understand the **referral networks** in your region and how they may be impacted by the introduction of a DMT. There are two questions in this section.

1. Can you please describe the catchment area of your centre? What are the main HD centres in your area / region / province? How are you connected to these centres?

2. How would the introduction of a DMT impact referral patterns to your centre?

D. Skills and training

In this section of the discussion, we will be asking questions to better understand the **skills and training** required following the introduction of a DMT. There are **three questions** in this section.

1. For yourself, would you need additional training to perform intrathecal infusions regularly? If so, please elaborate.

Based on research plan template Version 3.0 released on 01 Jan 2020

2. For yourself, outside of training for intrathecal infusion, are there any other aspects of HD care where you would require additional training should a treatment become available? If so, please elaborate.

3. For other members of your centre, what training / skills would be required to support a change in how you deliver care to your patients with HD?

E. Barriers

In this section of the discussion, we will be asking to better understand the **barriers for patients and for your centre** following the introduction of a DMT. There are three questions in this section.

1. What are the barriers to patients being referred or accessing specialized HD care? *Please explain*

2. [If other was selected in Survey, please follow-up in phone interview with the following question] From your point of view, what do you anticipate to be the top barriers to coordination of HD patient care upon the introduction of an intrathecal disease modifying therapy?

3. Are there any unique barriers that exist for patients in rural or urban areas? What alternative access to care is provided to them (e.g. telemedicine, local HCPs, transportation services)?

4. For your centre, what are the most important barriers that may limit your centre's ability to provide access to disease modifying therapy? (e.g. provincial policies, institutional barriers, professional barriers)

Based on research plan template Version 3.0 released on 01 Jan 2020

F. Solutions

In this section of the discussion, we will be exploring solutions to meet to address the capacity gaps should a DMT become available for HD patients. There are four questions in this section.

1. With the arrival of a disease modifying therapy for Huntington's Disease, which of the following capacity dimensions (personnel, training, infrastructure, referrals) do you expect to be most important in your centre?

2. To ensure HD patients have access to an intrathecal disease modifying therapy, how much time (in weeks or months) on average would it take to implement the required changes? What factors would you anticipate to influence this number?

3. Are there any personnel, training or/and infrastructure requirements that you believe are required that have not been outlined in our discussion or in the survey that would support HD patientcare?

4. What additional support would your HD centre require to implement change?

5. Which patients would you consider referring out?
 - a. Only those that my centre will not be able to serve
 - b. Only patients that come from >2h driving distance
 - c. An anticipated % corresponding to _____%

Based on research plan template Version 3.0 released on 01 Jan 2020

G. Wrap Up

1. Are you aware of any other centres that may have capacity to support the management of HD patients? (e.g. affiliated outpatient clinics or neurologists). If available provide contact information?

2. Are there any other topics that we did not cover in the survey or today's discussion that would be important to consider when assessing the current and future health care capacity for HD in Canada?
