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)
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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%
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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: __________
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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)
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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
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: __________________
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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 disease. 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
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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 (e.g. 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 (e.g. 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:

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* 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:

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