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.
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)
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 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.
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)
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 patient care?

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 _____ %
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?