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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
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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
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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: ______________________
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- 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 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: ___________
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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
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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
- requires a different source of funding for clinical use that is currently not available

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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
      b. Psychiatrist
      c. Social worker
      d. Neurologists
      e. Intrathecal proceduralists
      f. Neurologist-fellow/senior residents
      g. 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 DMT activities.
      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: _______
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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, 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)

   j. Blood pressure equipment
      i. Yes
      ii. No
      iii. Already used by the HD team (even if for non HD patients)
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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
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b. **I would** require additional medical training to support the clinical care of HD patients
   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 HD patients:
      0 - completely disagree
      1 - disagree
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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
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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: 

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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?
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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
1. Who should honorarium be made payable?
   a. Yourself
   b. Professional corporation
   c. Decline honorarium

[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:

<table>
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<th>Check if payable</th>
<th>Applicable rate*:</th>
<th>Tax ID</th>
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</thead>
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| 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
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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:

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<th>Check if payable</th>
<th>Applicable rate*</th>
<th>Tax ID</th>
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| HST      |                  |                  | HST #:
| GST      |                  |                  | GST #:
| PST/QST  |                  |                  | QST #:

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

d.