1 Survey Invitation Email for HD Patient Organizations

Dear XX,

The << *Huntington Society of Canada* or *Société Huntington du Québec* >> is working in partnership with Hoffmann-La Roche Ltd. to better understand Huntington's disease and its impact in Canada. You are being invited to participate in this research study because you are either a person living with Huntington's disease or the caregiver of a person diagnosed with Huntington's disease.

If you choose to participate, you will be asked a few questions about the impact of Huntington's disease on you, in terms of quality of life, direct and indirect costs, and healthcare resource utilization (e.g. visits to various healthcare appointments). This survey will take approximately 30-60 minutes to complete for the patient survey and approximately 20 minutes to complete for the caregiver survey. If you are a patient with Huntington's disease and you are unable to complete the survey on your own, a proxy (representative or helper) respondent may complete the survey on your behalf.

It is hoped that the needs of patients with Huntington's disease and their caregivers can be better understood as a result of this survey. Please note that only information required for this study will be collected and all responses collected will remain confidential and anonymous. The survey will be open for two months, or until 360 patient and 360 caregiver responses have been received. We thank you in advance for your participation.

If you reside in Alberta, please follow this link: <<*Insert survey link*>>

If you reside outside of Alberta, please follow this link: <<*Insert survey link*>>

Patients and caregivers residing in Newfoundland and Labrador will not be able to participate in this study at this time due to the nature of the Research Ethics Board approvals.

2 Informed Consent Form

2.1 Health Research Ethics Board of Alberta (HREBA) Informed Consent Form

Consent Form for Participation in a Research Study

Sponsor / Study Title:	**Hoffmann-La Roche Ltd / "Disease and Treatment Burden of Huntington's Disease on Patients and Caregivers in Canada Using Data from Patient and Caregiver Surveys"**
Principal Investigator:	**Tara Cowling, MA, MSc**
Telephone:	**403-460-2616**
Address:	**Medlior Health Outcomes Research Ltd.** **28 Quarry Park Blvd, Suite 210** **Calgary, AB, T2C5P9, Canada**

WHY AM I BEING ASKED TO TAKE PART IN THIS RESEARCH STUDY?

You are being invited to participate in a research study because you are either a person diagnosed with Huntington's Disease (HD) or a caregiver of a person diagnosed with HD. The purpose of this study is to help understand and characterize the impact of HD on patients and their caregivers in Canada.

This consent form provides information about the study to assist you with making an informed decision. Taking part in this study is voluntary. You may choose whether you take part. If you choose to participate, you may choose not to complete the survey at any time without giving reason or without penalty.

If you decide to participate in this study, your decision to answer survey questions or authorize a proxy to answer questions will be interpreted as an indication of your agreement to participate.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Up to 360 patients and 360 caregivers will take part in this study across Canada (excluding Newfoundland & Labrador)

WHAT WILL HAPPEN DURING THE SURVEY?

If you are a patient with HD or a caregiver of an individual with HD and choose to participate in the survey, you will be asked to answer a questionnaire. We expect this will take approximately 30 minutes to 60 minutes to complete for the patient survey and approximately 20 minutes to complete for the caregiver survey. If you are a patient with Huntington's disease and you are unable to complete the survey on your own, a proxy respondent may complete the survey on your behalf.

There is no cost to you for study participation.

WHAT ARE THE RISKS?

This study focuses on the impact of HD on adults diagnosed with HD as well as their caregivers in Canada. As such, we will be asking questions about the impact of HD on patients, the use of treatments and visits to various healthcare appointments, as well as personal expenses. Reflecting on your health could be upsetting for some individuals or too burdensome.

WILL I BENEFIT IF I TAKE PART?

This study is for research purposes only. There is no direct benefit to you from your participation in the study. However, based on the results of this survey, it is hoped that in the long-term, the needs of patients with HD and their caregivers can be better understood.

WILL I BE COMPENSATED FOR PARTICIPATING IN THIS STUDY?

There is no compensation for completing this survey. It is hoped that the results of this survey will contribute to a better understand the impact of Huntington's Disease on patients and their caregivers in Canada.

ALTERNATIVES TO PARTICIPATION

This research study is for research purposes only. The only alternative is to not participate in this study.

HOW WILL MY PERSONAL INFORMATION BE KEPT PRIVATE?

If you decide to participate, the researcher and study staff will only collect information they need for this study. They will do everything that they can to make sure that this data is kept private/confidential. The survey platform is GDPR (General Data Protection Regulation), and PIPEDA (Personal Information and Electronic Documents Act) compliant. All data is maintained on Canadian-based servers meeting provincial data protection requirements. No data relating to this study that includes your name will be released outside of the study site nor will it be published by the researcher. Every effort will be made to make sure that your information is kept confidential.

Representatives of the Health Research Ethics Board of Alberta (HREBA) (an ethics committee that reviewed the ethical aspects of this study to help protect the rights and welfare of study participants), may have access to the information collected for this study, at the study site.

All survey data collected will be anonymized: participants will be given a study number based on the order in which they completed the survey, but no personally identifiable data will be collected as part of this study.

Data collected from your participation in this research study will be de-identified and held in a Personal Information and Electronic Documents Act (PIPEDA)-secured database for data analysis by biostatisticians at Medlior Health Outcomes Research and Hoffmann-La Roche. Any future use of this research data is required to undergo review by a Research Ethics Review Board.

WHOM TO CONTACT ABOUT THIS STUDY

If you have any questions about taking part in this study, please contact the investigator or co-investigator. These persons are:

Tara Cowling, Medlior Health Outcomes Research Ltd.: (403) 612-0086
Eileen Shaw, Medlior Health Outcomes Research Ltd.: (403) 561-2332

If you have questions about your rights as a participant or about ethical issues related to this study and you would like to talk to someone who is not involved in the conduct of the study, please contact the Office of the Health Research Ethics Board of Alberta.

Telephone: (780) 423-5727 Toll Free: 1-877-423-5727

If you feel you need to talk about emotions triggered by completing this survey, please contact:

Huntington Society of Canada: info@huntingtonsociety.ca
Société Huntington du Québec: shq@huntingtonqc.org

AGREEMENT TO PARTICIPATE

Your decision to answer survey questions or authorize a proxy (representative or helper) to answer questions will be interpreted as an indication of your agreement to participate. You are free to withdraw from the study at any time.

3 Screening Questions

3.1 Alberta Version

Message provided to participants: *The following questions will be used to assess your eligibility and direct you to the correct survey.*

Participant Screening Questions

1) Are you a:
    a) Person diagnosed with Huntington's Disease (HD)
    b) Proxy responding on behalf of a patient diagnosed with Huntington's disease (HD)
    c) Caregiver for someone diagnosed with Huntington's Disease (HD)
    d) None of the above

If "A – Person diagnosed with Huntington's Disease (HD)" is selected:

2) Do you live in Canada?
    - Yes
    - No → *Direct to "Thank you" page and out of the survey*

3) Have you lived in Canada for at least the last 12 months?
    - Yes
    - No → *Direct to "Thank you" page and out of the survey*

4) Do you reside in Alberta?
    - Yes
    - No → *Direct to a message indicating the survey needs to be completed at a different link and provide a hyperlink to the Canada-wide survey page*

5) Are you 21 years of age or older?
    - Yes
    - No → *Direct to "Thank you" page and out of the survey*

6) What is your age? (Enter a whole number)
    - Years: ______
        i. *Survey flow options:*
            1. *If 21 years of age or older → Direct to* ***Self-Completed Patient Survey (Combined CSRI PD /Enroll HD CSRI + SF-36)***
            2. *If under 21 years of age → Direct to "Thank you" page and out of the survey*

Patient HD-Specific Screening Questions

7) What is your gender?
    - Male
    - Female
    - Other

8) Years since clinical Huntington’s Disease (HD) diagnosis:
   - o _______ years
   - o Not sure
   - o No diagnosis of HD → *Direct to “Thank you” page and out of the survey*

9) Have you received genetic testing results for HD?
   - o Yes → *If yes, years since genetic test results:* ______ years
   - o No

10) Which type of environment do you currently reside?
   - o Rural
   - o Urban

11) What, if any, symptoms have you experienced in the last month related to HD? (Select all that apply)

Movement/motor disorders:	
□	Involuntary jerking or writhing movements (chorea)
□	Muscle problems/posturing
□	Vision problems
□	Impaired gait, posture, and balance
□	Difficulty with speech or swallowing
□	Dropping objects
□	Bumping into objects/people/walls
□	Experiencing falls
Cognitive disorders:	
□	Difficulty organizing, prioritizing or focusing on tasks
□	Lack of flexibility or the tendency to get stuck on a thought, behavior, or action (perseveration)
□	Lack of impulse control that can result in outbursts, acting without thinking, and sexual promiscuity
□	Lack of awareness of one’s own behaviors and abilities
□	Slowness in processing thoughts or “finding” words

☐	Difficulty in learning new information
Neuropsychiatric disorders:	
☐	Feelings of irritability or angry outbursts
☐	Feelings of sadness or apathy
☐	Insomnia
☐	Fatigue/loss of energy
☐	Frequent thoughts of death, dying, or suicide

12) For each of the following statements, please select the response that you feel best describes your level of ability to perform common tasks.

Domain	Ability	Score
Occupation	Unable	0
	Marginal work only	1
	Reduced capacity for usual job	2
	Normal	3
	Do not know / not sure	**End Scoring**
Finances	Unable	0
	Major assistance	1
	Slight assistance	2
	Normal	3
	Do not know / not sure	**End Scoring**
Domestic chores	Unable	0
	Impaired	1

	Normal	2
	Do not know / not sure	**End Scoring**
Activities of daily living (i.e. self-care activities, such as self-feeding, bathing, dressing, grooming, etc.)	Total care	0
	Major impairment	1
	Minimal impairment	2
	Normal	3
	Do not know / not sure	**End Scoring**
Care level	Full-time nursing care	0
	Home with chronic care	1
	Home independently	2
	Do not know / not sure	**End Scoring**
IF 11-13 POINTS, CATEGORIZE STAGE 1 **IF 7-10 POINTS, CATEGORIZE STAGE 2** **IF 3-6 POINTS, CATEGORIZE STAGE 3** **IF 0-2 POINTS, CATEGORIZE STAGE 4**		

13) Have you transition to early stage motor onset (i.e. stage 1 or 2)?
   - Have not transitioned
   - Transitioned

14) Are you involved in any clinical trials for HD?
   - Yes – currently involved
   - Yes – previously involved/completed at least one clinical trial
   - Considering (researching/discussing with doctor) a clinical trial for HD
   - No

If "B – Proxy responding on behalf of a person diagnosed with Huntington's disease" is selected:

2) Does the person with Huntington's disease (HD) live in Canada?
   - Yes
   - No → *Direct to "Thank you" page and out of the survey*

3) Has the person with HD you lived in Canada for at least the last 12 months?

- Yes
- No → *Direct to "Thank you" page and out of the survey*

4) Does the person with HD reside in Alberta?
   - Yes
   - No → *Direct to a message indicating the survey needs to be completed at a different link and provide a hyperlink to the Canada-wide survey page*

5) Is the person with HD 21 years of age or older?
   - Yes
   - No → *Direct to "Thank you" page and out of the survey*

6) What is the age of the person with HD? (Enter a whole number)
   - Years: ______
     - i. *Survey flow options:*
       1. *If 21 years of age or older → Direct to **Self-Completed HD Screening Questions and Patient Survey (Combined CSRI PD /Enroll HD CSRI + SF-36)***
       2. *If under 21 years of age → Direct to "Thank you" page and out of the survey*

Patient HD-Specific Screening Questions

7) What is the gender of the person with HD?
   - Male
   - Female
   - Other

8) Years since their clinical HD diagnosis:
   - _______ years
   - Not sure
   - No diagnosis of HD → *Direct to "Thank you" page and out of the survey*

9) Has the person with HD received genetic testing results for HD?
   - Yes → *If yes, years since genetic test results:* ______ years
   - No

10) Which type of environment does the person with HD currently reside?
    - Rural
    - Urban

11) What, if any, symptoms have the person with HD experienced in the last month related to HD? (Select all that apply)

Movement/motor disorders:	
☐	Involuntary jerking or writhing movements (chorea)
☐	Muscle problems/posturing
☐	Vision problems

☐	Impaired gait, posture, and balance
☐	Difficulty with speech or swallowing
☐	Dropping objects
☐	Bumping into objects/people/walls
☐	Experiencing falls
Cognitive disorders:	
☐	Difficulty organizing, prioritizing or focusing on tasks
☐	Lack of flexibility or the tendency to get stuck on a thought, behavior, or action (perseveration)
☐	Lack of impulse control that can result in outbursts, acting without thinking, and sexual promiscuity
☐	Lack of awareness of one's own behaviors and abilities
☐	Slowness in processing thoughts or "finding" words
☐	Difficulty in learning new information
Neuropsychiatric disorders:	
☐	Feelings of irritability or angry outbursts
☐	Feelings of sadness or apathy
☐	Insomnia
☐	Fatigue/loss of energy
☐	Frequent thoughts of death, dying, or suicide

12) For each of the following statements, please select the response that best describes the level of ability of the person with HD to perform common tasks.

Domain	Ability	Score

Occupation	Unable	0
	Marginal work only	1
	Reduced capacity for usual job	2
	Normal	3
	Do not know / not sure	**End Scoring**
Finances	Unable	0
	Major assistance	1
	Slight assistance	2
	Normal	3
	Do not know / not sure	**End Scoring**
Domestic chores	Unable	0
	Impaired	1
	Normal	2
	Do not know / not sure	**End Scoring**
Activities of daily living (i.e. self-care activities, such as self-feeding, bathing, dressing, grooming, etc.)	Total care	0
	Major impairment	1
	Minimal impairment	2
	Normal	3
	Do not know / not sure	**End Scoring**
Care level	Full-time nursing care	0
	Home with chronic care	1

	Home independently	2
	Do not know / not sure	**End Scoring**
IF 11-13 POINTS, CATEGORIZE STAGE 1 **IF 7-10 POINTS, CATEGORIZE STAGE 2** **IF 3-6 POINTS, CATEGORIZE STAGE 3** **IF 0-2 POINTS, CATEGORIZE STAGE 4**		

13) Has the person with HD transition to early stage motor onset (i.e. stage 1 or 2)?
   - o Has not transitioned
   - o Transitioned

14) Is the person with HD involved in any clinical trials for HD?
   - o Yes – currently involved
   - o Yes – previously involved/completed at least one clinical trial
   - o Considering (researching/discussing with doctor) a clinical trial for HD
   - o No

If "C Caregiver for someone diagnosed with Huntington's Disease (HD)" is selected:

2) Do you live in Canada?
   - o Yes
   - o No → *Direct to "Thank you" page and out of the survey*

3) Have you lived in Canada for at least the last 12 months?
   - o Yes
   - o No → *Direct to "Thank you" page and out of the survey*

4) Do you reside in Alberta?
   - o Yes
   - o No → *Direct to a message indicating the survey needs to be completed at a different link and provide a hyperlink to the Canada-wide survey page*

5) What is your age? (Enter a whole number)
   - o Years: ______
      - *i. Survey flow options:*
         1. *If age is 18 years or greater → Direct to **Caregiver Survey (HDQoL-C)***
         2. *If age is less than 18 → Direct to "Thank you" page and out of the survey*

Caregiver HD-Specific Screening Questions

6) Are you employed as a caregiver (professional caregiver)?
   - o Yes → *Direct to "Thank you" page and out of the survey*
   - o No

7) What is the gender of the person diagnosed with HD in your care?
   - o Male
   - o Female
   - o Other

8) How many years has it been since the person in your care was clinically diagnosed with HD?
   - o _______ years
   - o Not sure
   - o No diagnosis of HD → *Direct to "Thank you" page and out of the survey*

9) Has the person with HD in your care received genetic testing results for HD?
   - o Yes→ *If yes, years since genetic test results:* ______ years
   - o No

10) Which type of environment does the person with HD in your care reside?
    - o Rural
    - o Urban

11) As a caregiver of the person living with HD, which, if any, of the following do you routinely do? (Select all that apply):
    - o Take them to medical appointments
    - o Discuss treatment options with their healthcare providers
    - o Help the person living with Huntington's Disease to make decisions about which treatment and medications to take
    - o Help with/monitor treatment
    - o Schedule and coordinate appointments with multiple healthcare providers
    - o Handling healthcare related paperwork (e.g. insurance claims)
    - o Selecting a physician or hospital, as appropriate

Respondents must select ≥ 3 tasks to qualify as a caregiver; otherwise, direct to "Thank you" page and out of the survey.

12) Thinking of one particular person living with HD for whom you are the primary caregiver, what, if any, symptoms have they experienced in the last month related to HD?

Movement/motor disorders:	
□	Involuntary jerking or writhing movements (chorea)
□	Muscle problems/posturing
□	Vision problems
□	Impaired gait, posture, and balance
□	Difficulty with speech or swallowing

☐	Dropping objects
☐	Bumping into objects/people/walls
☐	Experiencing falls
Cognitive disorders:	
☐	Difficulty organizing, prioritizing or focusing on tasks
☐	Lack of flexibility or the tendency to get stuck on a thought, behavior, or action (perseveration)
☐	Lack of impulse control that can result in outbursts, acting without thinking, and sexual promiscuity
☐	Lack of awareness of one's own behaviors and abilities
☐	Slowness in processing thoughts or "finding" words
☐	Difficulty in learning new information
Neuropsychiatric disorders:	
☐	Feelings of irritability or angry outbursts
☐	Feelings of sadness or apathy
☐	Insomnia
☐	Fatigue/loss of energy
☐	Frequent thoughts of death, dying, or suicide

13) For each of the following statements, please select the response that you feel best describes the level of ability of the person living with HD (for whom you care for) to perform common tasks.

Domain	Ability	Score
Occupation	Unable	0
	Marginal work only	1

	Reduced capacity for usual job	2
	Normal	3
	Do not know / not sure	**End Scoring**
Finances	Unable	0
	Major assistance	1
	Slight assistance	2
	Normal	3
	Do not know / not sure	**End Scoring**
Domestic chores	Unable	0
	Impaired	1
	Normal	2
	Do not know / not sure	**End Scoring**
Activities of daily living (i.e. self-care activities, such as self-feeding, bathing, dressing, grooming, etc.)	Total care	0
	Major impairment	1
	Minimal impairment	2
	Normal	3
	Do not know / not sure	**End Scoring**
Care level	Full-time nursing care	0
	Home with chronic care	1
	Home independently	2
	Do not know / not sure	**End Scoring**

IF 11-13 POINTS, CATEGORIZE STAGE 1

IF 7-10 POINTS, CATEGORIZE STAGE 2

IF 3-6 POINTS, CATEGORIZE STAGE 3

IF 0-2 POINTS, CATEGORIZE STAGE 4

14) Has the person living with HD transition to early stage motor on set (i.e. stage 1 or 2)?
    - o Have not transitioned
    - o Transitioned

15) Is the person living with HD for whom you care for involved in any clinical trials for HD?
    - o Yes – currently involved
    - o Yes – previously involved/completed at least one clinical trial
    - o Considering (researching/discussing with doctor) a clinical trial for HD
    - o No

If "D – None of the above" is selected:

- Participant directed to "Thank you" page and out of the survey

4 Patient and Caregiver Questionnaires

4.1 RAND Self-Completed Patient Survey (SF-36)

Choose one option for each questionnaire item.

1. In general, would you say your health is:

- 1 – Excellent
- 2 – Very good
- 3 – Good
- 4 – Fair
- 5 – Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?

- 1 – Much better now than one year ago
- 2 – Somewhat better now than one year ago
- 3 – About the same
- 4 – Somewhat worse now than one year ago
- 5 – Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐ 1	☐ 2	☐ 3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
5. Lifting or carrying groceries	☐ 1	☐ 2	☐ 3
6. Climbing **several** flights of stairs	☐ 1	☐ 2	☐ 3
7. Climbing **one** flight of stairs	☐ 1	☐ 2	☐ 3
8. Bending, kneeling, or stooping	☐ 1	☐ 2	☐ 3
9. Walking **more than a mile**	☐ 1	☐ 2	☐ 3
10. Walking **several blocks**	☐ 1	☐ 2	☐ 3
11. Walking **one block**	☐ 1	☐ 2	☐ 3

12. Bathing or dressing yourself	☐ 1	☐ 2	☐ 3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
13. Cut down the **amount of time** you spent on work or other activities	☐ 1	☐ 2
14. **Accomplished less** than you would like	☐ 1	☐ 2
15. Were limited in the **kind** of work or other activities	☐ 1	☐ 2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	☐ 1	☐ 2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	☐ 1	☐ 2
18. **Accomplished less** than you would like	☐ 1	☐ 2
19. Didn't do work or other activities as **carefully** as usual	☐ 1	☐ 2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- 1 – Not at all
- 2 – Slightly
- 3 – Moderately
- 4 – Quite a bit
- 5 – Extremely

21. How much **bodily** pain have you had during the **past 4 weeks**?

- 1 – None
- 2 – Very mild
- 3 – Mild
- 4 – Moderate
- 5 – Severe
- 6 – Very severe

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

- 1 – Not at all
- 2 – A little bit
- 3 – Moderately
- 4 – Quite a bit
- 5 – Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of pep?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
24. Have you been a very nervous person?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
25. Have you felt so down in the dumps that nothing could cheer you up?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
26. Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
27. Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
28. Have you felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
29. Did you feel worn out?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
30. Have you been a happy person?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
31. Did you feel tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

- 1 – All of the time
- 2 – Most of the time
- 3 – Some of the time
- 4 – A little of the time
- 5 – None of the time

How TRUE or FALSE is **each** of the following statements for you.

	Definitely true	Mostly true	Don’t know	Mostly false	Definitely false

33. I seem to get sick a little easier than other people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
34. I am as healthy as anybody I know	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
35. I expect my health to get worse	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
36. My health is excellent	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4.1.1 Proxy Version

Choose one option for each questionnaire item.

1. In general, would you say the health of the person with HD is:

- 1 – Excellent
- 2 – Very good
- 3 – Good
- 4 – Fair
- 5 – Poor

2. **Compared to one year ago**, how would you rate the health of the person with HD in general **now**?

- 1 – Much better now than one year ago
- 2 – Somewhat better now than one year ago
- 3 – About the same
- 4 – Somewhat worse now than one year ago
- 5 – Much worse now than one year ago

The following items are about activities the person with HD might do during a typical day. Does **the health of the person with HD now limit them** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐ 1	☐ 2	☐ 3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
5. Lifting or carrying groceries	☐ 1	☐ 2	☐ 3
6. Climbing **several** flights of stairs	☐ 1	☐ 2	☐ 3
7. Climbing **one** flight of stairs	☐ 1	☐ 2	☐ 3
8. Bending, kneeling, or stooping	☐ 1	☐ 2	☐ 3

9. Walking **more than a mile**	☐ 1	☐ 2	☐ 3
10. Walking **several blocks**	☐ 1	☐ 2	☐ 3
11. Walking **one block**	☐ 1	☐ 2	☐ 3
12. Bathing or dressing themselves	☐ 1	☐ 2	☐ 3

During the **past 4 weeks**, has the person with HD had any of the following problems with their work or other regular daily activities **as a result of their physical health**?

	Yes	No
13. Cut down the **amount of time** they spent on work or other activities	☐ 1	☐ 2
14. **Accomplished less** than they would like	☐ 1	☐ 2
15. Were limited in the **kind** of work or other activities	☐ 1	☐ 2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	☐ 1	☐ 2

During the **past 4 weeks**, has the person with HD had any of the following problems with their work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the **amount of time** they spent on work or other activities	☐ 1	☐ 2
18. **Accomplished less** than they would like	☐ 1	☐ 2
19. Didn't do work or other activities as **carefully** as usual	☐ 1	☐ 2

20. During the **past 4 weeks**, to what extent have physical health or emotional problems of the person with HD interfered with their normal social activities with family, friends, neighbors, or groups?

- 1 – Not at all
- 2 – Slightly
- 3 – Moderately
- 4 – Quite a bit
- 5 – Extremely

21. How much **bodily** pain has the person with HD had during the **past 4 weeks**?

- 1 – None
- 2 – Very mild
- 3 – Mild

- 4 – Moderate
- 5 – Severe
- 6 – Very severe

22. During the **past 4 weeks**, how much did **pain** interfere with the normal work of the person with HD (including both work outside the home and housework)?

- 1 – Not at all
- 2 – A little bit
- 3 – Moderately
- 4 – Quite a bit
- 5 – Extremely

These questions are about how the person with HD feels and how things have been with the person with HD **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way they have been feeling.

How much of the time during the **past 4 weeks**...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did they feel full of pep?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
24. Have they been a very nervous person?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
25. Have they felt so down in the dumps that nothing could cheer them up?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
26. Have they felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
27. Did they have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
28. Have they felt downhearted and blue?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
29. Did they feel worn out?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
30. Have they been a happy person?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6
31. Did they feel tired?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6

32. During the **past 4 weeks**, how much of the time has the **physical health or emotional problems** of the person with HD interfered with your social activities (like visiting with friends, relatives, etc.)?

- 1 – All of the time
- 2 – Most of the time
- 3 – Some of the time

- 4 – A little of the time
- 5 – None of the time

How TRUE or FALSE is **each** of the following statements for the person with HD.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. They seem to get sick a little easier than other people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
34. They are as healthy as anybody they know	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
35. They expect their health to get worse	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
36. Their health is excellent	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4.2 Huntington's Disease Quality of Life Battery for Carers (HDQoL-C) Survey

SECTION 1

This section asks for information about yourself. Please answer all the questions and do not spend too much time on any one item.

1) What is your gender?
   - Male
   - Female
   - Other

2) What is the highest qualification you hold?
   - No qualifications
   - Diploma
   - University degree
   - Post-graduate degree

3) What is your marital status?
   - Single
   - Married
   - Partnership
   - Separated
   - Divorced
   - Widowed
   -

4) If the person with HD you care for is a family member, approximately how long have you known of the presence of HD in your family?
   - ________ Years

5) How long have you been caring for an HD affected family member that you primarily care for?

- ________ Years

6) Are you the main carer for the person with HD whom you primarily care for?
    - Yes
    - No

7) The affected person that you primarily care for is my:
    - Sibling
    - Spouse/Partner
    - Parent
    - Child
    - Other

8) Have you previously cared for any other HD affected person?
    - Yes
    - No

    a. If **yes**, what is / was their relationship to you? The affected person is my:
    - Sibling
    - Spouse/Partner
    - Parent
    - Child
    - Other

9) Do you have children at risk / symptomatic?
    - Yes
    - No

10) How many family members live in your household?
    - ________

11) Are you currently employed?
    - Yes
        - I. If yes to currently employed, what is your gross annual income?
            - 1 $10, 000 or less
            - 2 $10, 000 - 25, 000
            - 3 $25, 000 – 50-000
            - 4 $50, 000 – 75, 000
            - 5 $75, 000 – 100, 000
            - 6 $100,000 or more
        - II. If yes to currently employed, approximately how many hours do you spend each week on paid work?
            - _____ hours/week
        - III. If yes to currently employed, approximately how many hours per week were you absent from work due to caring for the person with HD (average in the past 6 months)?
            - _____ hours/week
        - IV. If yes to currently employed, has your income or work hours been reduced due to the COVID-19 pandemic?
            - Yes
            - No
    - No

I. If **no** to currently employed, have you ever been employed?
  - o Yes
    a. If yes to ever being employed, did you leave your job for reasons associated with caring for the person with HD?
      - o Yes
        1. If yes to leaving job to care for person with HD, when did you leave your job (year)?
          - o _____
        2. If yes to leaving job to care for person with HD, what was your gross annual income prior to leaving your job?
          - o 1 $10, 000 or less
          - o 2 $10, 000 - 25, 000
          - o 3 $25, 000 – 50-000
          - o 4 $50, 000 – 75, 000
          - o 5 $75, 000 – 100, 000
          - o 6 $100,000 or more
      - o No
  - o No

- o No due to the COVID-19 pandemic
  i. If **no due to the COVID-19 pandemic**, were you:
    - o Temporarily laid off (furloughed)
    - o Permanently laid off

12) Approximately how many hours do you spend on the following each week?
  - o hours caring for HD affected relative(s)/individual(s): ________

13) Please specify any difficulties you experience caring for your HD affected relative(s) /individual(s) (e.g. dealing with behaviour, physical problems, emotional problems). Select all that apply:
  - o My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)
  - o Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)
  - o Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)
  - o Caregiving is confining (For example: helping restricts free time or I cannot go visiting)
  - o There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)
  - o There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)
  - o There have been other demands on my time (For example: other family members need me)
  - o There have been emotional adjustments (For example: severe arguments about caregiving)
  - o Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)
  - o It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)
  - o There have been work adjustments (For example: I have to take time off for caregiving duties)
  - o Caregiving is a financial strain
  - o I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)

14) Has the person with HD ever had to move from one home to another to directly meet their HD care-related requirements?
    - Yes
    - No
    - Unsure

15) Has the person with HD had major modifications done on the home due to their requirements? For example, major changes to the configuration of house layout and/or access (e.g. wheelchair access)
    - Yes
    - No

    a. If **yes** to major modifications, please indicate who paid for the modifications? Select all that apply:
    - Out of pocket (from the person with HD or you as the caregiver)
    - Government funding or government program
    - Private insurance coverage
    - Funding provided by community organization (Huntington Society of Canada and Société Huntington du Québec)
    - Other
    - Unsure

    b. If **yes** to major modifications, what was the estimated total expense on home modifications?
    - $_______ CAD

    c. If **yes** to major modifications, of the total expense on home modifications, what proportion were out-of-pocket (from the person with HD or you as the caregiver)?
    - _______ %

16) Approximately how often in an average month do you get to take part in a social activity or hobbies (e.g. eat out, go to church, visit a friend)?
    - _______ times

SECTION 2

We want to know how you feel about your role as a carer, your health and your quality of life.

Please select the number that most accurately represents your situation.

For example, a statement might read:

How satisfied are you with the SUPPORT YOU GET?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

You should select the number that best fits how satisfied you are with the support you receive. So if you are totally satisfied with the support you receive from others, you would circle number 10.

This first set of questions asks for information about different aspects of your role as a carer.

Please select the number that best describes your situation.

1) How often are you restricted by the need to maintain a regimented daily routine?

Almost never — **Almost always**

0 1 2 3 4 5 6 7 8 9 10

2) How often do you receive appropriate help from social services?

Almost never — **Whenever I need it**

0 1 2 3 4 5 6 7 8 9 10

3) How often do you have access to professionals that have specialised knowledge of HD and understand its implications?

Almost never — **Almost always**

0 1 2 3 4 5 6 7 8 9 10

4) How much support are you given by health care professionals?

None whatsoever — **As much as I need**

0 1 2 3 4 5 6 7 8 9 10

5) How often do the genetic consequences of HD impact upon your caring role?

Almost never — **Almost always**

0 1 2 3 4 5 6 7 8 9 10

6) How often do you have access to appropriate care facilities?

Almost never — **Almost always**

0 1 2 3 4 5 6 7 8 9 10

7) How often do you receive any practical support you need?

Almost never — **Almost always**

0 1 2 3 4 5 6 7 8 9 10

8) How often do you experience a conflict of interest between what you want and what your HD affected relative wants?

Almost never — **Almost always**

0 1 2 3 4 5 6 7 8 9 10

9) How often do you sleep well?

Almost never										**Almost always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

SECTION 3

The next set of questions asks how *satisfied* you are with different areas of your life.

Please select the number that best describes how *satisfied* you are with each area of your life.

1) How *satisfied* are you with your HEALTH?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

2) How *satisfied* are you with what you ACHIEVE IN LIFE?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

3) How *satisfied* are you with your CLOSE RELATIONSHIPS WITH FAMILY OR FRIENDS?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

4) How *satisfied* are you with HOW SAFE YOU FEEL?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

5) How *satisfied* are you with FEELING A PART OF YOUR COMMUNITY?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

6) How *satisfied* are you with YOUR OWN HAPPINESS?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

7) How *satisfied* are you with THE TREATMENT THAT YOUR HD AFFECTED RELATIVE RECEIVES?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

8) How *satisfied* are you with YOUR OVERALL QUALITY OF LIFE?

Dissatisfied										**Satisfied**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

SECTION 4

This next set of questions asks how you *feel* about different aspects of your life.

Please select the number that best describes how you *feel* about each area of your life.

1) I *feel* GUILTY

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

2) I *feel* FINANCIALLY DISADVANTAGED

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

3) I *feel* ISOLATED

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

4) I *feel* THERE IS HOPE for the future

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

5) I *feel* EXHAUSTED

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

6) I *feel* SUPPORTED

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

7) I *feel* SAD OR DEPRESSED

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

8) I *feel* STRESSED

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

9) I *feel* WORRIED ABOUT THE GENETIC CONSEQUENCES OF HD

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

10) I *feel* MY OWN NEEDS ARE NOT IMPORTANT TO OTHERS

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

11) I *feel* COMFORTED BY THE BELIEF THAT ONE DAY THERE WILL BE A CURE FOR HD

Never										**Always**
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

12) I *feel* THAT HD BROUGHT SOMETHING POSITIVE TO MY LIFE

Never **Always**

0 1 2 3 4 5 6 7 8 9 10

13) I *feel* COMFORTED BY MY BELIEFS

Never **Always**

0 1 2 3 4 5 6 7 8 9 10

14) I *feel* THAT I CAN COPE

Never **Always**

0 1 2 3 4 5 6 7 8 9 10

15) I *feel* THAT HD HAS MADE ME A STRONGER PERSON

Never **Always**

0 1 2 3 4 5 6 7 8 9 10

16) I *feel* THAT I HAVE HAD A "DUTY OF CARE" FORCED ON ME

Never **Always**

0 1 2 3 4 5 6 7 8 9 10

17) I *feel* LIKE I DON'T KNOW WHO I AM ANYMORE

Never **Always**

0 1 2 3 4 5 6 7 8 9 10

4.3 Healthcare Resource Utilization – Client Service Receipt Inventory (CSRI)

1 USUAL LIVING SITUATION

1) What is your usual/normal living situation now?
    - 1 Living alone (+/- children)
    - 2 Living with husband/wife (+/- children)
    - 3 Living together as a couple (not married)
    - 4 Living with parents
    - 5 Living with other relatives
    - 6 Living with others
    - 7 Not known

2) What kind of accommodation is it?
    - 1 Owner occupied apartment or house
    - 2 Privately rented apartment or house
    - 3 Rented from local authority/municipality or housing association/co-operative

3) How many adults (aged 18 or older) live in this accommodation? And how many children? (under the age of 18)
    - Adults: ___________ (Number)
    - Children: ___________ (Number)

2 EMPLOYMENT AND INCOME

1) What is your employment status?
   - o 1 Paid or self-employment
   - o 2 Voluntary employment (e.g. unpaid work with charities, foundations, advocacy groups, etc.)
   - o 3 Sheltered employment
      I. ***If employed (answers 1-3)***: state occupation:
         - o 1 Manager/administrator
         - o 2 Professional (e.g. health, teaching, legal)
         - o 3 Associate professional (e.g. technical, nursing)
         - o 4 Clerical worker /secretary
         - o 5 Skilled labourer (e.g. building, electrical etc.)
         - o 6 Services/sales (e.g. retail)
         - o 7 Factory worker
      II. 8 Other ***If employed (answers 1-3)***,do you work full-time (30 hours or more per week) or part-time (less than 30 hours per week)?
         - o 1 = full-time
         - o 2 = part-time
      III. ***If employed (answers 1-3)***, in the last 6 months, have you taken any time off work because of HD (e.g., due to symptoms, had a doctor's visit)?
         - o 1 Yes
            a. If ***yes***, please complete the following table:

Method	**Select 'No' or 'Yes'**	**Number of working days missed**
Took sick leave from work	No Yes	
Use your paid vacation time from work	No Yes	
Took unpaid leave from work	No Yes	
Just made up the time at work	No Yes	
Other	No Yes	

            b. If ***yes,*** have you lost any pay because of this time off work?
               - o 1 = Yes
               - o 2 = No
         - o 2 No
   - o 4 Unemployed
      I. ***If unemployed***, number of weeks unemployed within the last 6 months* (*assume 26 weeks = 6 months)
         - o ___________ Number of weeks
      II. ***If unemployed***, have you ever been employed?
         - o Yes
            a. If ***yes to ever being employed***, have you left your job for reasons due to HD?
               - o Yes
                  1. If yes to leaving job due to HD, when did you leave your job (year)?
                     - o _____
                  2. If yes to leaving job due to HD, what was your gross annual income prior to leaving your job?
                     - o 1 $10, 000 or less
                     - o 2 $10, 000 - 25, 000
                     - o 3 $25, 000 – 50-000

- 4 $50, 000 – 75, 000
- 5 $75, 000 – 100, 000
- 6 $100,000 or more

o No

- No

- 5 Student
- 6 Homemaker
- 7 Retired
- 8 Other

2) Is your current employment status a result of the COVID-19 pandemic?
    - Yes
    - No

3) What is your main income source?
    - 1 Salary/Wage
    - 2 Government benefits
    - 3 Pension
    - 4 Family support (e.g. from spouse)
    - 5 Other

4) What is your gross annual income?
    - 1 $10, 000 or less
    - 2 $10, 000 - 25, 000
    - 3 $25, 000 – 50-000
    - 4 $50, 000 – 75, 000
    - 5 $75, 000 – 100, 000
    - 6 $100,000 or more

5) Do you receive any government benefits (e.g., welfare, disability, provincial, universal drug benefit)?
    - 1 = Yes
    - 2 = No

    If yes: What benefits are received? *(Please tick all boxes that apply)*

Employment Insurance	☐
Sickness Benefits	☐
Disability Benefits	☐
Compassionate Care Benefits	☐
Parents of Critically Ill Children Benefits	☐
Housing Benefits	☐
Other	☐

6) Do you have any (private) insurance plan in addition to provincial insurance?
    - 1 = Yes

- 2 = No

If yes:

i. Medication – Does your private insurance plan include medication coverage?
   - 1 = Yes
   - 2 = No

   Total cost in last 6 months: _______
   Coverage %: _______
   Coverage amount: _______

ii. Medical aids – Does your private insurance plan include coverage for medical aids?
   - 1 = Yes
   - 2 = No

   Total cost in last 6 months: _______
   Coverage %: _______
   Coverage amount: _______

iii. Homecare and Nursing – Does your private insurance plan include coverage for homecare and nursing?
   - 1 = Yes
   - 2 = No

   Total cost in last 6 months: _______
   Coverage %: _______
   Coverage amount: _______

iv. Allied health professionals – Does your private insurance plan cover allied health professionals?
   - 1 = Yes
   - 2 = No

   Total cost in last 6 months: _______
   Coverage %: _______
   Coverage amount: _______

v. Dental – Does your private insurance plan cover dental costs?
   - 1 = Yes
   - 2 = No

   Total cost in last 6 months: _______
   Coverage %: _______
   Coverage amount: _______

3 HOSPITAL AND RESIDENTIAL SERVICES IN THE LAST 6 MONTHS

Please indicate if you have used the following services in the last 6 months (in person or virtually):

1) Neurology outpatient visit:
   - 1 = Yes

- 0 = No

Use in the last 6 months because of your HD: _______ [visits]

2) Other hospital outpatient visit (i.e. appointments at clinics located in a hospital):
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

3) Ambulatory or same day surgery (i.e. urgent care visits or surgery where you did not spend the night in hospital):
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

4) Nursing or residential home:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

5) Admission to inpatient hospital (i.e. hospital visits where you were admitted for at least 1 night):
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

6) Hospital admissions to intensive care unit (ICU; e.g. trauma, medical, or surgical intensive care unit) :
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

7) Hospital emergency room visits:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

8) Has your use of these services changed due to the COVID-19 pandemic?
    - Increased
    - Decreased
    - Stayed the same

4 PRIMARY AND COMMUNITY CARE SERVICES IN THE LAST 6 MONTHS

Please indicate if you have used the following services in the last 6 months (in person or virtually):

1) General practitioner (GP) or internist/family doctor:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

2) Telemedicine (i.e., telephone appointments with healthcare practitioners):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

3) Physical Therapist (PT):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

4) Occupational Therapist (OT):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

5) Psychiatrist:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

6) Psychologist/psychotherapist:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

7) Counselor:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

8) Family therapist/marriage guidance:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

9) Dietician/nutritionist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

10) Clinical geneticist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

11) Social worker:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

12) Practice nurse (nurse practitioner or physician assistant):
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

13) Home healthcare nurse:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

14) Speech therapist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

15) Home help/home care worker:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

16) Acupuncturist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

17) Homeopath:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

18) Herbalist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

19) Aromatherapy:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

20) Reflexologist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

21) Hospital day activity facility:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

22) Adult day care centre:
- 1 = Yes

- 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

23) Group therapy:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

24) Education classes:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

25) Social club:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

26) Palliative care:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

27) Other services:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

28) Has your use of these services changed due to the COVID-19 pandemic?
    - Increased
    - Decreased
    - Stayed the same

5 INVESTIGATIONS/DIAGNOSTIC TESTS IN THE LAST 6 MONTHS

Please indicate if you have used the following services in the last 6 months:

1) Genetic test:

- 1 = Yes
- 0 = No

Number in the last 6 months: _______

2) Magnetic Resonance Image (MRI):
    - 1 = Yes
    - 0 = No

Number in the last 6 months: _______

3) CT/CAT scan:
    - 1 = Yes
    - 0 = No

Number in the last 6 months: _______

4) Electroencephalogram (EEG):
    - 1 = Yes
    - 0 = No

Number in the last 6 months: _______

5) Blood test:
    - 1 = Yes
    - 0 = No

Number in the last 6 months: _______

6 INFORMAL CARE IN THE LAST 6 MONTHS

Please indicate if you have used the following services in the last 6 months:

1) Child care (select ‘no’ if you have no children):
    - 1 = Yes
    - 0 = No

Average number of hours per week: _______

2) Personal care (e.g. washing, dressing, etc.):
    - 1 = Yes
    - 0 = No

Average number of hours per week: _______

3) Help in/around the house (e.g. cooking, cleaning, laundry etc.):
    - 1 = Yes
    - 0 = No

Average number of hours per week: _______

4) Help outside the house (e.g. shopping, transport, etc.):
   - 1 = Yes
   - 0 = No

Average number of hours per week: _______

5) Other:
   - 1 = Yes
   - 0 = No

Average number of hours per week: _______

6) What transportation options have you used:
   i. Private vehicle (driver):
      - 1 = Yes
      - 0 = No

      Cost of this: _______

   ii. Private vehicle (passenger):
      - 1 = Yes
      - 0 = No

      Cost of this: _______

   iii. Public transit:
      - 1 = Yes
      - 0 = No

      Cost of this: _______

   iv. Para transit:
      - 1 = Yes
      - 0 = No

      Cost of this: _______

   v. Taxi/ Uber:
      - 1 = Yes
      - 0 = No

      Cost of this: _______

   vi. Door-to-door (escort) service:
      - 1 = Yes
      - 0 = No

      Cost of this: _______

   vii. Other:
      - 1 = Yes
      - 0 = No

      Cost of this: _______

7 EQUIPMENT, AIDS, DEVICES, & ADAPTATIONS TO THE HOME

Please indicate if you currently and/or have used the following services in the last 6 months:

1) Medication reminder dispenser:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

2) Calendar clock:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

3) Falls detector/falls alarm:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

4) Community/personal alarm (including pull-cord and pendant alarms):
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

Adaptations to the Home

5) Outdoor railing:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

6) Grab rail/stair rail:
    - Yes
    - No

    In the last 6 months?

    - Yes

- No

7) Stairlift:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

8) Handrails:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

9) Ramps:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

10) Shower/ bath relocation:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

11) Walk-in shower/shower cubicle replacing bath:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

12) Over-bath shower:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

13) Bath / shower seat:

- Yes
- No

In the last 6 months?

- Yes
- No

14) Transfer bench to get into the shower:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

15) Full body dryer:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

16) Toilet relocation:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

17) Commode (chair with bedpan):
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

18) Continence pads
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

19) Redesign kitchen:
    - Yes
    - No

In the last 6 months?

- Yes
- No

20) Kitchen stool:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

21) Chair raises/special chair:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

22) Bed moved downstairs:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

23) Hospital bed:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

24) Other:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

Aids or Devices

25) Walking stick:
    - Yes
    - No

In the last 6 months?

- Yes
- No

26) Zimmer (walking frame):
- Yes
- No

In the last 6 months?

- Yes
- No

27) Wheelchair (manual or electric):
- Yes
- No

In the last 6 months?

- Yes
- No

28) Bath board:
- Yes
- No

In the last 6 months?

- Yes
- No

29) Pressure relieving cushions/mattress:
- Yes
- No

In the last 6 months?

- Yes
- No

30) Adapted eating utensils:
- Yes
- No

In the last 6 months?

- Yes
- No

31) Bed lever/rail:
- Yes
- No

In the last 6 months?

- Yes

- No

32) Toilet frame/raised toilet seat:
  - Yes
  - No

  In the last 6 months?

  - Yes
  - No

4.3.1 Proxy Version

1 USUAL LIVING SITUATION

1) What is the usual/normal living situation now for the person with HD?
   - 1 Living alone (+/- children)
   - 2 Living with husband/wife (+/- children)
   - 3 Living together as a couple (not married)
   - 4 Living with parents
   - 5 Living with other relatives
   - 6 Living with others
   - 7 Not known

2) What kind of accommodation is it?
   - 1 Owner occupied apartment or house
   - 2 Privately rented apartment or house
   - 3 Rented from local authority/municipality or housing association/co-operative

3) How many adults (aged 18 or older) live in this accommodation? And how many children? (under the age of 18)
   - Adults: ___________ (Number)
   - Children: ___________ (Number)

2 EMPLOYMENT AND INCOME

1) What is the employment status of the person with HD?
   - 1 Paid or self-employment
   - 2 Voluntary employment (e.g. unpaid work with charities, foundations, advocacy groups, etc.)
   - 3 Sheltered employment
     I. ***If employed (answers 1-3)***, state occupation of the person with HD:
        - 1 Manager/administrator
        - 2 Professional (e.g. health, teaching, legal)
        - 3 Associate professional (e.g. technical, nursing)
        - 4 Clerical worker /secretary
        - 5 Skilled labourer (e.g. building, electrical etc.)
        - 6 Services/sales (e.g. retail)
        - 7 Factory worker
        - 8 Other

II. ***If employed (answers 1-3)***, does the person with HD work full-time (30 hours or more per week) or part-time (less than 30 hours per week)?
  - 1 = full-time
  - 2 = part-time

III. ***If employed (answers 1-3)***, in the last 6 months, has the person with HD taken any time off work because of HD (e.g., due to symptoms, had a doctor's visit)?
  - 1 Yes
    a. If ***yes***, please complete the following table for the person with HD:

Method	**Select 'No' or 'Yes'**	**Number of working days missed**
Took sick leave from work	No Yes	
Use their paid vacation time from work	No Yes	
Took unpaid leave from work	No Yes	
Just made up the time at work	No Yes	
Other	No Yes	

    b. If ***yes***, has the person with HD lost any pay because of this time off work?
      - 1 = Yes
      - 2 = No
  - 2 No

- 4 Unemployed

I. ***If unemployed***, number of weeks unemployed within the last 6 months for the person with HD* (*assume 26 weeks = 6 months)
  - ___________ Number of weeks

II. ***If unemployed***, has the person with HD ever been employed?
  - Yes
    a. If ***yes to ever being employed***, have they left their job for reasons due to HD?
      - Yes
        1. If ***yes to leaving job due to HD***, when did they leave their job (year)?
          - ______
        2. If yes to leaving job due to HD, what was their gross annual income prior to leaving their job?
          - 1 $10, 000 or less
          - 2 $10, 000 - 25, 000
          - 3 $25, 000 – 50-000
          - 4 $50, 000 – 75, 000
          - 5 $75, 000 – 100, 000
          - 6 $100,000 or more
      - No
  - No

- 5 Student
- 6 Homemaker
- 7 Retired
- 8 Other

2) Is the person with HD's current employment status a result of the COVID-19 pandemic?

- Yes
- No

3) What is the main income source for the person with HD?
   - 1 Salary/Wage
   - 2 Government benefits
   - 3 Pension
   - 4 Family support (e.g. from spouse)
   - 5 Other

4) What is the gross annual income source for the person with HD?
   - 1 $10, 000 or less
   - 2 $10, 000 - 25, 000
   - 3 $25, 000 – 50-000
   - 4 $50, 000 – 75, 000
   - 5 $75, 000 – 100, 000
   - 6 $100,000 or more

5) Does the person with HD receive any government benefits (e.g., welfare, disability, provincial, universal drug benefit)?
   - 1 = Yes
   - 2 = No

   If yes: What benefits are received? *(Please tick all boxes that apply)*

Employment Insurance	☐
Sickness Benefits	☐
Disability Benefits	☐
Compassionate Care Benefits	☐
Parents of Critically Ill Children Benefits	☐
Housing Benefits	☐
Other	☐

6) Does the person with HD have any (private) insurance plan in addition to provincial insurance?
   - 1 = Yes
   - 2 = No

   If yes:

   i. Medication – Does their private insurance plan include medication coverage?
      - 1 = Yes
      - 2 = No

      Total cost in last 6 months: _______
      Coverage %: _______
      Coverage amount: _______

   ii. Medical aids – Does their private insurance plan include coverage for medical aids?

- 1 = Yes
- 2 = No

Total cost in last 6 months: _______
Coverage %: _______
Coverage amount: _______

iii. Homecare and Nursing – Does their private insurance plan include coverage for homecare and nursing?
   - 1 = Yes
   - 2 = No

Total cost in last 6 months: _______
Coverage %: _______
Coverage amount: _______

iv. Allied health professionals – Does their private insurance plan cover allied health professionals?
   - 1 = Yes
   - 2 = No

Total cost in last 6 months: _______
Coverage %: _______
Coverage amount: _______

v. Dental – Does their private insurance plan cover dental costs?
   - 1 = Yes
   - 2 = No

Total cost in last 6 months: _______
Coverage %: _______
Coverage amount: _______

3 HOSPITAL AND RESIDENTIAL SERVICES IN THE LAST 6 MONTHS

Please indicate if the person with HD has used the following services in the last 6 months (in person or virtually):

1) Neurology outpatient visit:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [visits]

2) Other hospital outpatient visit (i.e. appointments at clinics located in a hospital):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

3) Ambulatory or same day surgery (i.e. urgent care visits or surgery where you did not spend the night in hospital):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

4) Nursing or residential home:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

5) Admission to inpatient hospital (i.e. hospital visits where you were admitted for at least 1 night):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

6) Hospital admissions to intensive care unit (ICU; e.g. trauma, medical, or surgical intensive care unit) :
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

7) Hospital emergency room visits:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [days]
Use in the last 6 months for other reasons: _______ [days]

8) Has the use of these services by the person with HD changed due to the COVID-19 pandemic?
   - Increased
   - Decreased
   - Stayed the same

4 PRIMARY AND COMMUNITY CARE SERVICES IN THE LAST 6 MONTHS

Please indicate if the person with HD has used the following services in the last 6 months (in person or virtually):

1) General practitioner (GP) or internist/family doctor:
   - 1 = Yes

- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

2) Telemedicine (telephone appointments with healthcare practitioners):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

3) Physical Therapist (PT):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

4) Occupational Therapist (OT):
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

5) Psychiatrist:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

6) Psychologist/psychotherapist:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

7) Counselor:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

8) Family therapist/marriage guidance:
   - 1 = Yes
   - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]

Use in the last 6 months for other reasons: _______ [contacts]

9) Dietician/nutritionist:
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

10) Clinical geneticist:
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

11) Social worker:
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

12) Practice nurse (nurse practitioner or physician assistant):
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

13) Home healthcare nurse:
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

14) Speech therapist:
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

15) Home help/home care worker:
  - 1 = Yes
  - 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

16) Acupuncturist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

17) Homeopath:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

18) Herbalist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

19) Aromatherapy:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

20) Reflexologist:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [contacts]
Use in the last 6 months for other reasons: _______ [contacts]

21) Hospital day activity facility:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

22) Adult day care centre:
- 1 = Yes
- 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

23) Group therapy:
- 1 = Yes

- 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

24) Education classes:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

25) Social club:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

26) Palliative care:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

27) Other services:
    - 1 = Yes
    - 0 = No

Use in the last 6 months because of your HD: _______ [visits]
Use in the last 6 months for other reasons: _______ [visits]

28) Has the use of these services by the person with HD changed due to the COVID-19 pandemic?
    - Increased
    - Decreased
    - Stayed the same

5 INVESTIGATIONS/DIAGNOSTIC TESTS IN THE LAST 6 MONTHS

Please indicate if the person with HD has used the following services in the last 6 months:

1) Genetic test:
    - 1 = Yes
    - 0 = No

Number in the last 6 months: _______

2) Magnetic Resonance Image (MRI):
    a. 1 = Yes

b. 0 = No

Number in the last 6 months: _______

3) CT/CAT scan:
   a. 1 = Yes
   b. 0 = No

Number in the last 6 months: _______

4) Electroencephalogram (EEG):
   a. 1 = Yes
   b. 0 = No

Number in the last 6 months: _______

5) Blood test:
   a. 1 = Yes
   b. 0 = No

Number in the last 6 months: _______

6 INFORMAL CARE IN THE LAST 6 MONTHS

Please indicate if the person with HD has used the following services in the last 6 months:

1) Child care (Select 'no' if they have no children):
   a. 1 = Yes
   b. 0 = No

Average number of hours per week: _______

2) Personal care (e.g. washing, dressing, etc.):
   a. 1 = Yes
   b. 0 = No

Average number of hours per week: _______

3) Help in/around the house (e.g. cooking, cleaning, laundry etc.):
   a. 1 = Yes
   b. 0 = No

Average number of hours per week: _______

4) Help outside the house (e.g. shopping, transport, etc.):
   a. 1 = Yes
   b. 0 = No

Average number of hours per week: _______

5) Other:

a. 1 = Yes
b. 0 = No

Average number of hours per week: _______

6) What transportation options have they used:
   a. Private vehicle (driver):
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

   b. Private vehicle (passenger):
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

   c. Public transit:
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

   d. Para transit:
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

   e. Taxi/ Uber:
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

   f. Door-to-door (escort) service:
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

   g. Other:
      i. 1 = Yes
      ii. 0 = No
      Cost of this: _______

7 EQUIPMENT, AIDS, DEVICES, & ADAPTATIONS TO THE HOME

Please indicate if any of the following applies to the person with HD currently and/or in the last six months:

1) Medication reminder dispenser:
   - Yes
   - No

   In the last 6 months?

- Yes
- No

2) Calendar clock:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

3) Falls detector/falls alarm:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

4) Community/personal alarm (including pull-cord and pendant alarms):
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

Adaptations to the Home

5) Outdoor railing:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

6) Grab rail/stair rail:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

7) Stairlift:
   - Yes
   - No

   In the last 6 months?

- Yes
- No

8) Handrails:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

9) Ramps:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

10) Shower/ bath relocation:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

11) Walk-in shower/shower cubicle replacing bath:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

12) Over-bath shower:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

13) Bath / shower seat:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

14) Transfer bench to get into the shower:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

15) Full body dryer:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

16) Toilet relocation:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

17) Commode (chair with bedpan):
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

18) Continence pads
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

19) Redesign kitchen:
   - Yes
   - No

   In the last 6 months?

   - Yes
   - No

20) Kitchen stool:
   - Yes

- No

In the last 6 months?

- Yes
- No

21) Chair raises/special chair:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

22) Bed moved downstairs:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

23) Hospital bed:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

24) Other:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

Aids or Devices

25) Walking stick:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

26) Zimmer (walking frame):
    - Yes

- No

In the last 6 months?

- Yes
- No

27) Wheelchair (manual or electric):
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

28) Bath board:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

29) Pressure relieving cushions/mattress:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

30) Adapted eating utensils:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

31) Bed lever/rail:
    - Yes
    - No

    In the last 6 months?

    - Yes
    - No

32) Toilet frame/raised toilet seat:
    - Yes
    - No

    In the last 6 months?

- Yes
- No