



Survey about the Perceptions and Experiences of Research Participation in the HD Community

* 1. In what country do you live?

* 2. What is your gender?

☐ Female

☐ Male

☐ Other

* 3. What is your age?

☐ 18 to 24

☐ 25 to 34

☐ 35 to 44

☐ 45 to 54

☐ 55 to 64

☐ 65 to 74

☐ 75 or older

* 4. What is the highest level of education you have completed?

*** 5. What is your status regarding Huntington's Disease (HD)?**

- ☐ At risk of Huntington's Disease (You do not know if you carry the genetic mutation of Huntington's Disease and are at risk for inheriting the disease)
- ☐ Premanifest/Prodromal Stage of Huntington's Disease (You had a positive result in the genetic test for Huntington's Disease and do not show symptoms of the disease)

*** 6. Have you ever participated in research studies related to Huntington's Disease?**

- ☐ Yes
- ☐ No

*** 7. How do you rate your knowledge about research studies in Huntington's Disease?**

- | | |
|--|---|
| <input type="radio"/> Not good | <input type="radio"/> Good |
| <input type="radio"/> Should be better | <input type="radio"/> Excellent |
| <input type="radio"/> Satisfactory | <input type="radio"/> I do not want to know about HD research |

*** 8. What are the main sources for you to get information about research studies in Huntington's Disease?**

☐ Internet

☐ Television

☐ Press/Newsletters/Flyers/Booklets

☐ International/National/Local HD Associations and/or Support Groups

☐ Health Care Professionals

☐ Family Members

☐ I am not interested in HD research information

Is there anything you want to add?

*** 9. How important are the following reasons for getting involved in research studies in Huntington's Disease?**

| | Not Important | Slightly Important | Moderately Important | Important | Very Important |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I will benefit from the best treatments | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I will help to produce generalizable knowledge about HD | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My doctor thinks it is a good idea | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I will help to benefit future generations | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My family thinks it is a good idea | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I will help others | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I know other people that also participate in HD research | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I will gain easier access to health professionals and HD experts | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have few therapeutic options | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think it is interesting | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Is there anything you want to add?

*** 10. How important are the following reasons for not getting involved in research studies in Huntington's Disease?**

| | Not Important | Slightly Important | Moderately Important | Important | Very Important |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I do not want to get false hopes | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not think I can be of any help | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not think there will be any drugs available in my life time | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not want to be reminded about the future progression of my disease | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not have time in my life right now | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not trust the research team | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not want to go to clinical units | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not want to be examined | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not want to take drugs right now | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not feel emotionally stable | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I do not want to be seen as a "guinea pig" | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I fear that my personal data will not be treated as confidential information | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Is there anything you want to add?

*** 11. Which of the following factors would prevent you from participating in research studies in Huntington's Disease?**

- ☐ I would have to travel to the study site
- ☐ I would not have family support
- ☐ I would have personal expenses
- ☐ I would have to do motor exams
- ☐ I would have to find someone to take care of my sick parent
- ☐ I would have to skip work days/hours
- ☐ I would have to be involved in the study for a long time
- ☐ I would have to go through invasive procedures (e.g., lumbar puncture or surgery)
- ☐ I would have to do cognitive assessments
- ☐ I would have to find someone to take care of my children
- ☐ I would have to rethink my decisions about family planning
- ☐ None of the above

Is there anything you want to add?

*** 12. Which of the following factors would facilitate your participation in research studies in Huntington's Disease?**

- ☐ I would have assistance from a patient advocate
- ☐ I would have family support
- ☐ The researcher is my doctor/my family member doctor
- ☐ My personal expenses would be reimbursed
- ☐ I would get the chance to meet other HD families
- ☐ I would gain easier access to treatments, health professionals and HD experts
- ☐ I would have psychological and social care available
- ☐ I would not have to go through invasive procedures (e.g., lumbar puncture or surgery)
- ☐ I know and trust the study team
- ☐ I would have regular feedback about my health condition
- ☐ None of the above

Is there anything you want to add?