

PARTICIPANT INFORMATION



TITLE

How do people with Huntington's Disease and their family members feel about using digital devices to monitor and manage their lifestyle?

WHAT IS THE PURPOSE OF THIS STUDY?

The DOMINO-HD study will explore how lifestyle factors such as diet, physical activity and sleep may influence disease status. We are asking people with Huntington's disease (HD) to use wearable activity trackers (such as FitBit) at home for continuous registration of sleep and activity. We plan to use this information to develop lifestyle interventions for HD. As part of preparing for this study, we want to understand how HD family members feel about personal use of digital wearables. This survey has been developed to help us understand how best to use such devices within DOMINO-HD.

WHO CAN TAKE PART?

You can take part if you are over 18 years of age and are one of the following:

- Have a genetically confirmed diagnosis of HD.
- Are a family member or care for someone who has HD

WHAT WILL I HAVE TO DO IF I TAKE PART?

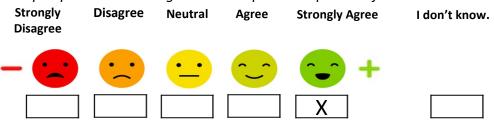


If you decide to take part, you will be asked to complete a questionnaire asking you what you think about using activity trackers (such as FitBit, Apple Watch or Garmin) in your daily life. We would expect it to normally take less than 15 minutes to complete this questionnaire and members of the DOMINO-HD team would be happy to help you.

HOW DO I ANSWER THE QUESTIONS IN THE QUESTIONNAIRE?

Please put a cross in the box under the face that best represents how you feel about each question if you have HD, <u>or how you think your family member / person you care for who has HD would feel given your experience if you do not have HD</u>.

Example question: Wearing a watch helps me keep track of the time.



WILL MY DATA BE PROTECTED?

If you decide to complete the questionnaire we will assume that you have given us permission to use the data collected. Cardiff University will be responsible for storing all data collected in a secure and safe way. We will not record any personal information about you that would identify you so it will not be possible to identify you in any results that we may publish from this research.



CONSENT STATEMENT



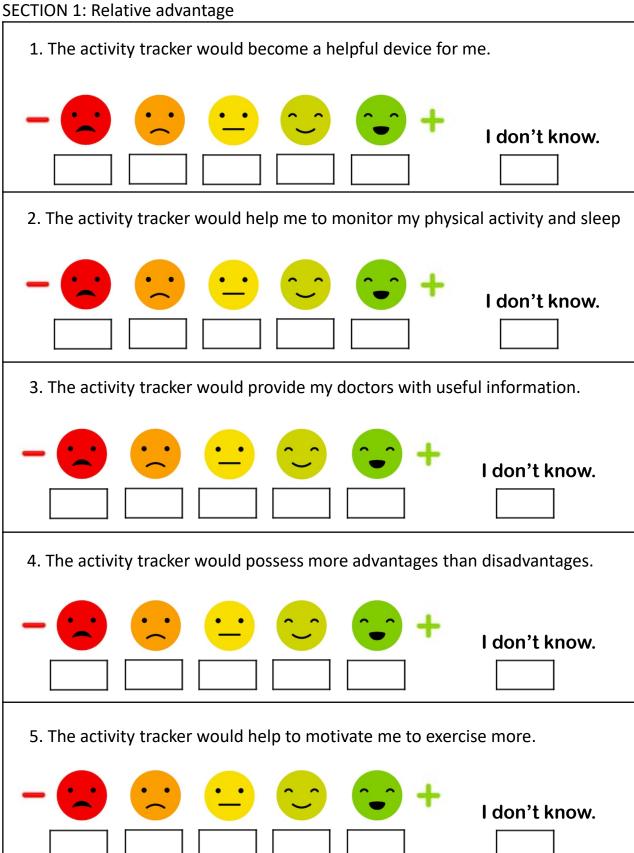
TITLE

How do people with Huntington's Disease and their family members feel about using digital devices to monitor and manage their lifestyle?

By answering the questions within the questionnaire, you are:

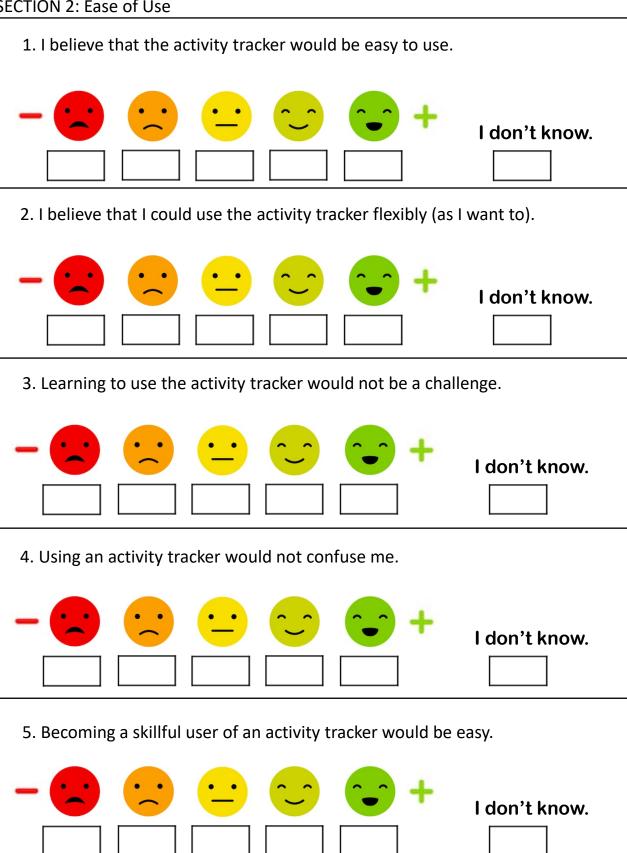
- 1. Confirming that you understand what the study is about and what is being asked of people taking part in the study.
- 2. Confirming that you understand that participation is voluntary and that you are free to withdraw at any time without giving any reason.
- 3. Providing your consent to take part in the above study.





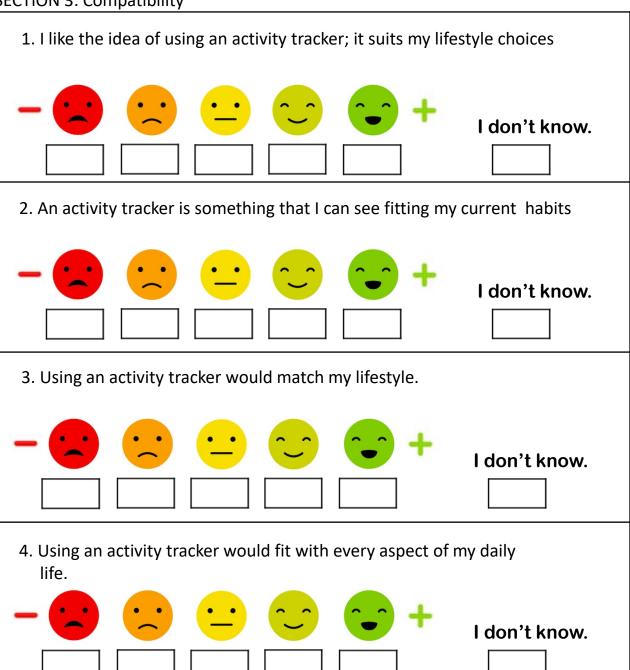


SECTION 2: Ease of Use



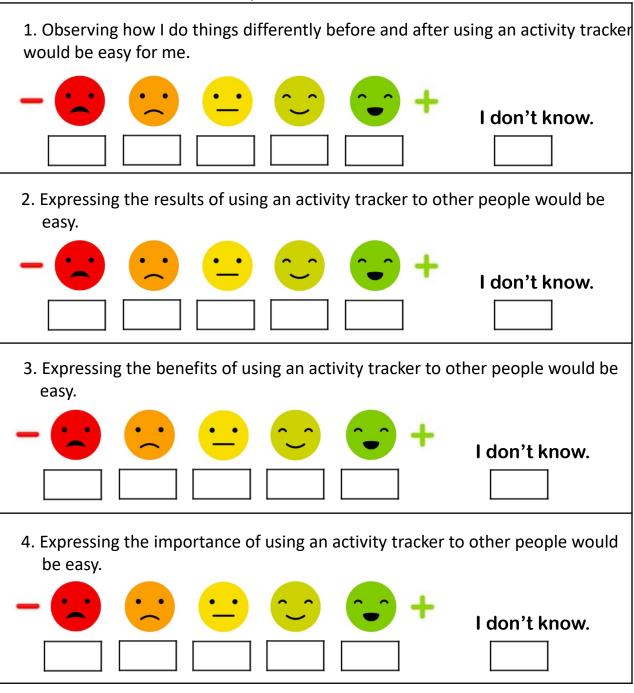


SECTION 3: Compatibility



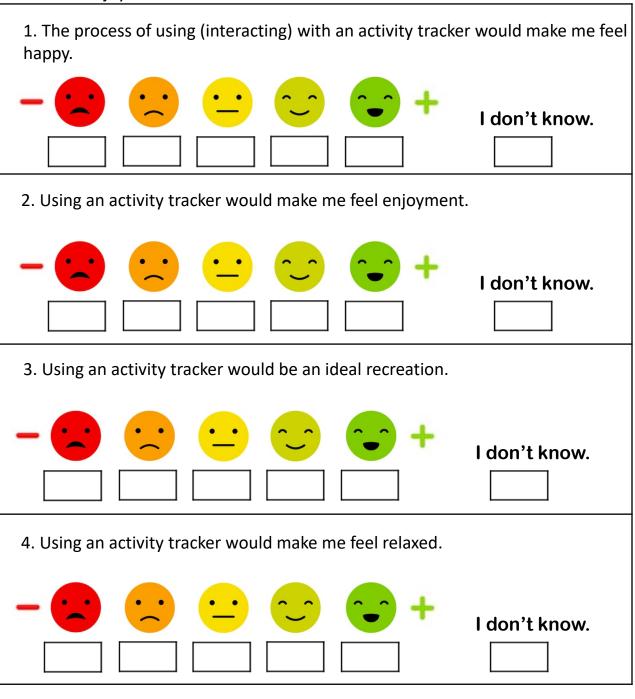


SECTION 4: Result Demonstrability

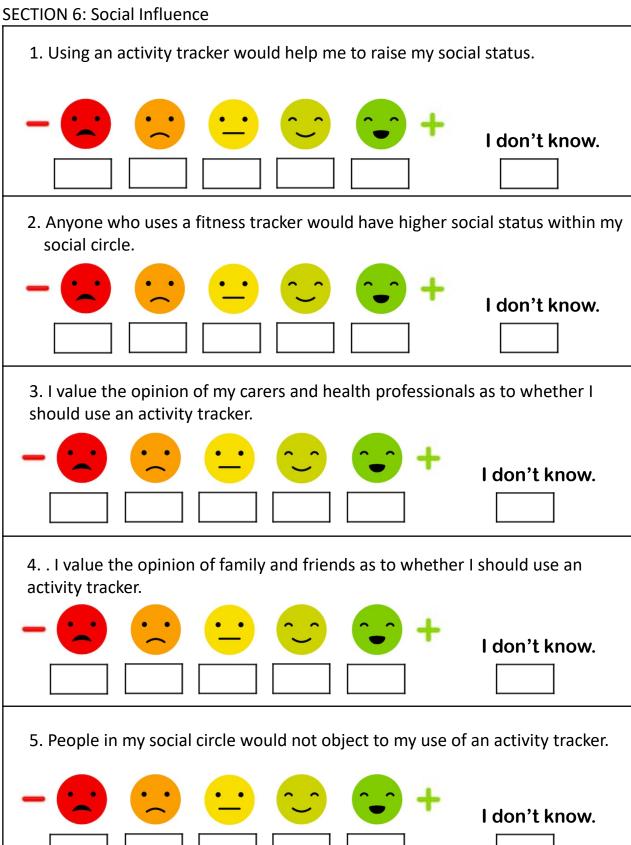




SECTION 5: Enjoyment

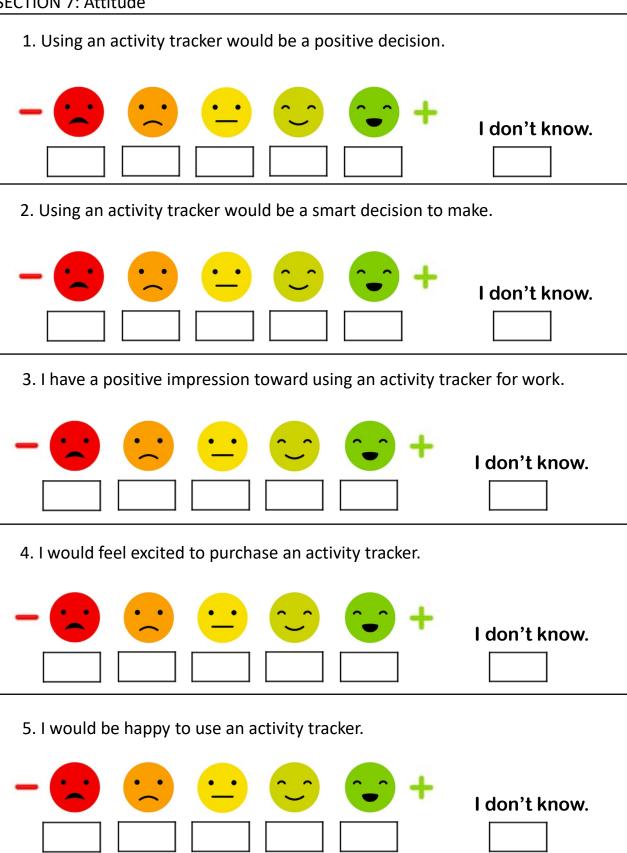








SECTION 7: Attitude





SECTION 8: Behavioural Intention

1. I would be willing to use an activity tracker.
-
2. I would be willing to use an activity tracker if I possess one.
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3. I would be willing to use the information provided by an activity tracker to manage my lifestyle (e.g. perform daily exercises or monitor sleep).
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About Me (Please indicate the option that best describes your involvement in HD:
I have a genetically confirmed diagnosis of HD
I am a HD family member or care for a person with HD
Other: (Please give details)

Please tick the age category that you, or the person you have completed this for, falls within:

24 years
or under
25 – 34 years
35 – 44 years
45 – 54 years

or under 25 – 34 years 35 – 44 years 45 – 54 years or older

55 years