

Combined Participant Information Sheet and Consent Form for Anonymous Online Surveys for Adult Participants

Study Title: Benchmarking integrated care for people living with Huntington's Disease in England - Integrate-HD

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Ethics/ERGO no: 77725

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What is the research about?

My name is Sandra Bartolomeu Pires and I am a nurse doing a PhD (doctoral degree) at the University of Southampton in the United Kingdom.

I am inviting you to participate in a study regarding the changes that need to happen in the system to improve support and care for people living with Huntington's Disease (HD). People living with HD require the care from different professionals in health and social care. Their needs are complex due to the variety of symptoms involved and due to the different professionals needed for their care. This coordination is often difficult to achieve, and people report fragmented care and unmet care needs.

My project aims to understand how satisfied people living with HD are with the care they are receiving and how are the care and the resources different across England. I will identify what care people receive, what they need, and what needs to happen to meet the gap. I want to know what works well in care and what needs improvement.

This study was approved by the Faculty Research Ethics Committee (FREC) at the University of Southampton (Ethics/ERGO Number: 77725).

What will happen to me if I take part?

This study involves completing an anonymous questionnaire which should take approximately 20-30 minutes of your time, but you can take breaks and do it at your own pace. If you are happy to complete this survey, you will need to tick (check) the box below to show your consent. As this survey is anonymous, the research team will not be able to know whether you have participated, or what answers you provided.

Why have I been asked to participate?

You have been asked to participate because you are living in England and are:

- A person at risk of HD;
- A person diagnosed with HD;
- A person supporting someone living with HD (partner, spouse, son/daughter, sibling, friend, etc.);
- A person with former experience of supporting someone living with HD (partner, spouse, son/daughter, sibling, friend, etc.). You would have cared for a person with HD in the last 3 years.

I am aiming to recruit around 60 participants for this study.

What information will be collected?

The questions in this survey ask for information in relation to health and social care resources you use(d), and the ones you need. I am very interested in identifying what changes need to happen in the system to provide better support to people living with HD. I will ask for certain personal data, such as gender, age, and the county where you live/receive care. This will allow me to characterize the survey sample and map services

across England. I will ask for brief medical information, such as your history with HD.

Some of the survey questions contain textboxes where you will be asked to type in your own answers. Please note that in order for this survey to be anonymous, you should not include in your answers any information from which you, or other people, could be identified.

You do not have to answer all the questions if you do not wish to do so.

What are the possible benefits of taking part?

If you decide to take part in this study, you will not receive any direct benefits; however, your participation will contribute to knowledge in this area of research.

Are there any risks involved?

It is expected that taking part in this study will not cause you any psychological discomfort and/or distress, however, should you feel uncomfortable you can leave the survey at any time or contact the following resources for support:

PhD student name: Sandra Bartolomeu Pires

PhD student email: s.m.bartolomeu-pires@soton.ac.uk

Huntington's Disease Association

Webpage: <https://www.hda.org.uk/>

Email: info@hda.org.uk

Phone: 0151 331 5444

What will happen to the information collected?

All information collected for this study will be stored securely on a password protected computer and backed up on a secure server. If provided, your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you.

I will produce a lay report with the study results and send it to participants that consent to receive this report. If you would like to receive a copy of this report, you need to provide your contact details after you submit the survey. Only the researcher and their supervisors will have access to this information.

The information collected will be analysed and presented at conferences and published in journals as articles. Results will be disseminated on social media and via charities. Results will be part of the researcher's dissertation.

The University of Southampton conducts research to the highest standards of ethics and research integrity. In accordance with our Research Data Management Policy, The University of Southampton will keep identifiable information about you until the project is complete and the results have been published. Anonymised data from the survey will be deposited on the University repository, Pure, and made accessible to other researchers for 10 years

What happens if there is a problem?

If you are unhappy about any aspect of this study and would like to make a formal complaint, you can contact the Head of Research Integrity and Governance, University of Southampton, on the following contact details:

Email: rgoinfo@soton.ac.uk, phone: + 44 2380 595058.

Please quote the Ethics/ERGO number above. Please note that by making a complaint you might be no longer anonymous.

More information on your rights as a study participant is available via this link:

<https://www.southampton.ac.uk/about/governance/participant-information.page>