# Participant Information Sheet (PIS)

# Exploring how people with Huntington’s Disease experience communication with professionals about assisted dying in the UK

**Name, position, and contact details of Researcher:**

Karolina-Tereza Harris, Trainee Clinical Psychologist, kts11@leicester.ac.uk

**Name, position, and contact details for Supervisor:**

Dr Sarah Gunn, Clinical Psychologist, sarah.gunn@leicester.ac.uk

We would like to invite you to join our research project. Before you decide, it is important you understand why we are doing this study, and what it would involve for you. Please read this information and discuss it with friends or family if you wish.

If anything is unclear, or if you would like more information, please do not hesitate to contact the lead researcher (Karolina) with the details above.

# What is the purpose of the research project?

We know that people with Huntington’s disease (HD) quite often think about the future, and sometimes think about death and dying. Some people might think about the possibility of ending their life, and some express the wish to access an assisted dying process (which is currently not legal in the UK, but it is in other parts of the world).

We want to learn about whether people who carry the HD gene feel able to talk to their healthcare professionals about death and assisted dying. This would include whether they feel able to talk about it at all, and how those conversations have gone if they have tried. We both (Karolina and Sarah) have worked with people with HD, and we feel strongly about supporting people with HD to express their feelings about death and dying.

# Who can take part?

We would like to speak with people living in the UK who have a positive genetic test for HD, and who would like to share their experiences or thoughts about discussing assisted dying with healthcare professionals. We would like to interview up to 20 people in total.

# Do I have to take part?

No, it is completely up to you. If you do decide to take part, please read this information sheet and the privacy notice, which explains how your data will be collected, used, and stored. We will then ask you to fill in a consent form, to show that you are happy to participate and understand what the study involves. If you decide to take part you are still free to withdraw for up to a month after the interview without giving a reason by contacting the researcher.

# What will happen to me if I take part?

If you join the project, the lead researcher (Karolina) will invite you for an interview. This will generally last up to an hour. You can choose whether you would like your interview via online video call using Microsoft Teams (we can help you access this if you haven’t used it before), or by phone. If you live fairly close to Leicester, you also have the option of the interview happening at your home. We will ask your permission for the interview to be recorded, so we can analyse your data afterwards. We know that death and dying is a sensitive subject, so there will be time to chat after the interview if you wish and we can direct you to sources of support if you would like.

# What are the possible disadvantages and risks of taking part?

Because we will be asking your thoughts about death and assisted dying, it is understandable that the conversation could feel upsetting at times. It’s really important to us that you feel emotionally supported during the conversation. If you do become distressed, the interviewer will invite you to either take a break, or pause and rearrange the interview for another day. You also always have the option to withdraw from the study completely, if it is feeling too distressing to talk about. Our priority is ensuring that you feel as well-supported and comfortable to speak as possible. We designed the interview questions with support from people affected by HD, to ensure that we approach the questions as sensitively as possible, and we are relying on our experience of working with people with HD to help us too.

# What are the possible benefits of taking part?

It’s unlikely that you will personally benefit from taking part, although sometimes people do find it helpful to have a safe and confidential space to talk through difficult thoughts and feelings. We hope also that the study findings could benefit people with HD in future, helping healthcare workers understand how people with the HD gene might think about death and assisted dying.

# What data will you collect about me?

We will ask for basic demographic details, such as your age, marital status, and HD status. As mentioned above, we will also record your interview (video-recorded if using Teams, or audio-recorded if by phone or in person) so we can analyse it later. We will use the recording to create a transcript (written version of the interview) for analysis. We will store all your data on the secure University of Leicester Research Drive where they can only be accessed by the research team.

# Will what I say in this research project be kept confidential?

We take confidentiality extremely seriously, and will only break it under very specific conditions. This would include if you told us that you or someone else was at risk of harm, or if you told us information about a criminal offence (present or historical). For example, as you will be aware, assisted dying is not currently legal in the UK. This means that if you told us you had a specific plan to undertake assisted dying imminently, then we would be legally compelled to report it. This does not necessarily reflect our own views about assisted dying, but it is something that we legally have to do, so it’s important you know this before speaking to us. You can, however, tell us how you feel about assisted dying, whether you might in theory consider using it one day or not, and why.

# How will you look after the data you collect about me?

### The Privacy Notice we have given you provides further details about what will happen to the data we collect about you and your legal rights. Your normal rights under the Data Protection Act and the General Data Protection Regulation apply. However, we need to manage your records in specific ways for the research project to be reliable. This means that we can’t always let you see or change the data we hold about you.You can stop being part of the research project and withdraw your data for up to a month after the interview without giving a reason.

To ensure confidentiality, we will remove any identifying details from your transcript that might disclose who you are (e.g., names of people, places and services). The transcript will be kept on a secure University of Leicester drive, only accessible by us (Karolina and Sarah) and the University of Leicester administrator for research drives. Your consent form will be stored separately from your transcript, so once the transcript is de-identified, no one can link you to your transcript.

We will destroy your identifiable data (original recordings, consent forms) once the study is complete. We will keep your contact details for as long as is needed to complete actions that you have agreed we can do – paying you for study involvement, sending a summary of results if you have asked for one, or keeping you on our future studies mailing list if you have asked to join (you can leave this at any time). We will keep the de-identified transcripts indefinitely. At all times this research study will comply with the General Data Protection Regulations (GDPR, 2018) approved by the EU parliament on 14 April 2016 and passed into UK law with effect from 25 May 2018*.*

# What will happen to the results of the research project?

The results will be submitted as part of a thesis for the lead researcher’s Doctorate in Clinical Psychology at the University of Leicester. We will publish the results in a peer-reviewed journal, and present the findings at relevant conferences. We will never publish quotes or data that could identify you; they will always be anonymous or with a “pseudonym” (false name) attached. We will send project summaries to HD organisations such as the Huntington’s Disease Association, and if you ask for a study summary on the consent form, we will send one to you too.

# What should I do if I want to take part?

If you would like to join the study, please contact the lead researcher (Karolina) at the email address provided below. You will be asked to complete an Informed Consent Form to confirm you understand how your data will be processed, protected, and reviewed for research purposes. We will then contact you to arrange your interview.

# Who is organising and funding the research project?

This project is a part of a University of Leicester, School of Psychology Doctorate in Clinical Psychology course. All project funds are provided by the course. We are grateful for the support and help of HD Voice in developing this project.

# What if something goes wrong?

In the unlikely event of you being harmed by participating in this research project, there are no special compensation arrangements. If you are harmed due to someone’s negligence, then you may have grounds for legal action but you may have to pay for it.

# Who has reviewed the research project?

This study has been approved by the University of Leicester Psychology Research Ethics Committee.

### Contact for Further Information

If you have any questions about the project, please do not hesitate to contact the lead researcher in the first instance (Karolina: kts11@leicester.ac.uk) or the project supervisor (Sarah: sarah.gunn@leicester.ac.uk). Please note that advice or guidance cannot be given as part of this study.

If you have any concerns or queries about how this research project has been conducted, please contact the Chair of the University Research Ethics Committee at ethics@le.ac.uk.

If you wish to find out more GDPR data protection information then you can access this via the University’s Information Assurance Services (University of Leicester, University Road, Leicester, LE1 7RH; tel: +44 (0)116 229 7945; email: dpo@le.ac.uk).

### Thank you very much for reading this information sheet and for considering joining our study!