

Participant Information Sheet (HD)

Hello, my name is Nicolò Zarotti and I am conducting this research as a PhD student at Lancaster University, Lancashire, UK.

What is the study about?

To explore how people positively tested for Huntington's disease regulate their own emotions and recognise emotions in others.

Why have I been approached?

You have been approached because you have the following characteristic:

- You tested positive for the HD gene mutation, but you have no formal diagnosis of HD yet.

Do I have to take part?

No. It's completely up to you to decide whether or not to take part in this study. Not taking part will have no negative repercussions on your treatment.

Will I be able to withdraw after participating?

No, as the data will be automatically anonymised, you will not be able to withdraw after you complete the survey. However, you can withdraw from the survey at any time before completing it.

What will I be asked to do if I take part?

If you decide to take part, you will be asked to complete an online survey consisting of a questionnaire on how you manage your emotions and a recognition task. For the latter you will be shown pictures of people expressing emotions and you will be asked to identify the expressed emotion. The survey will take approximately 20 minutes, although you can stop sooner if you wish.

Will my data be confidential?

The information you provide is confidential and anonymous. The data collected for this study will be stored securely and no one will have access to any non-anonymised data. The files will be encrypted, that is no one other than the research team will be able to access them.

What will happen to the results?

The results will be summarised and reported in a PhD thesis and are expected to be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Main researcher: Nicolò Zarotti, n.zarotti@lancaster.ac.uk (tel: 07922330167)

Research supervisors:

- Dr. Ian Fletcher, ij.fletcher@lancaster.ac.uk
- Dr. Jane Simpson, j.simpson2@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bruce Hollingsworth
Head of the Division of Health Research
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YD
Tel: +44 (0)1524 594154
Email: b.hollingsworth@lancaster.ac.uk

If you wish to speak to someone outside of the Division, you may also contact:

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine (Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YD
Tel: +44 (0)1524 593746
Email: r.pickup@lancaster.ac.uk

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

- Local Huntington's Disease Association support: www.hda.org.uk/hda/branches
- The Samaritans: www.samaritans.org