**EATING BEHAVIOURS IN HUNTINGTON'S DISEASE III – A Pilot Study of an Online Version of the Huntington's Disease Eating Attitudes Test (HD-EAT) in a Genotype Positive Huntington's Disease Population**

**Participant Information Sheet version 1.0**

 Before you take part in this research study, it is important for you to understand the reasoning behind why the study is being conducted and what it could involve for you. The sponsor for the study is the University of Hull, and when this information sheet references “we”, it refers to the research team and the University of Hull. Please take the time to read this information sheet carefully, and ask any questions you may have, ensuring that they are answered to your satisfaction before deciding whether or not to take part:

1. **What is the purpose of the research?**

Weight loss is a common issue for people living with Huntington’s Disease (HD). However, the cause of this is quite poorly understood, with evidence suggesting there could be multiple reasons for HD-related weight loss. This study aims to pilot a new questionnaire which we hope will be able to make it easier for a clinician to work out what may be contributing to HD-related weight loss in their patients.

1. **Why have I been invited to take part?**

You have been invited to take part because the research team understands that you have the gene expansion for Huntington’s Disease. Because of this, we believe that your experience gives you a unique insight into how HD affects people’s eating behaviours, including their weight, attitude towards food and meals, and eating activities. Therefore, the research team would like you to complete the survey to draw from your experiences.

1. **Do I have to take part?**

No. Your participation is entirely voluntary and you do not have to take part in the research if you do not wish to. You do not have to give a reason for not wishing to participate either.

1. **What will I have to do if I decide to take part?**

If you decide you would like to take part in the research, scan the QR code at the end of this information sheet to access the survey. You will be asked to confirm that you meet the criteria and that you have read this information sheet, and then you will be able to complete the survey. We expect it will take 30-45 minutes to complete the survey. For the research to be accurate and for us to be able to properly calculate the results of the questionnaires, it is required that you answer all questions within the survey.

1. **Expenses and payments**

Whilst we appreciate the time and effort required in order to take part in the research, there is no formal expenses procedure and no payment will be made for your participation or any costs incurred while participating.

1. **What are the possible risks of taking part?**

Some of the survey questions will focus on personal experiences of eating difficulties, and Huntington’s Disease, which some people may find distressing to answer. If you find that this happens to you during your interview, possible solutions are discussed below, in section 7.

In very rare cases it may be that a participant’s completion of a survey questionnaire provides some initial evidence of a potential eating disorder or other incidental finding. In these cases it may be that the research team needs to contact the participant to explain this to them and provide details of the relevant questionnaire involved, as well as the calculated or self-reported score given by the participant. We will ask you for some contact information before you begin the questionnaire, we will not use it unless for the sole purpose of contacting you about these incidental findings.

1. **What if there is a problem?**

If you are finding filling out the questionnaires difficult to do, or feel distressed, you are welcome to take a break, as many times and for as long as you need. If you do not feel this is sufficient and wish to stop completing the survey, simply close the survey without submitting it. If you continue to feel distressed, the research team can direct you to the Huntington’s Disease charity HDA for support, and you are encouraged to contact your GP.

1. **Will my taking part in the research be kept confidential?**

Yes, all participation in the research is confidential. Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR). Any data you provide will be solely used by the research team, and will not be shared with any third parties.

1. **How will you use information about me?**

We will need to use information from you for this research project. This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. If we decide to quote something you have answered whilst completing the survey, it will not be attributed to you, and any identifiable information would be changed or anonymised. For example, if you wrote something about your neighbour and mentioned them by name, we would remove the name and instead add “my neighbour”.

1. **Where can I find out more about how my information is used?**

You can find out more about how we use your information…:

* At [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
* Our leaflet available from <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/>
* By asking one of the research team
* By sending an email to the researcher at c.schofield-2019@hull.ac.uk
* By ringing the researcher on 07875 437057
1. **Data Protection Statement**

The data controller for this project will be the University of Hull. The University will process the data you provide for the purpose of the research outlined above. The legal basis for processing this data for research purposes under GDPR is a ‘task in the public interest’. You can provide your consent for the use of the data you provide in this study by completing the consent form that has been provided to you. Information about how the University of Hull processes data can be found at <https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx>

You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation. You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can also be sent to the University of Hull Data Protection Officer, dataprotection@hull.ac.uk. If you wish to lodge a complaint with the Information Commissioner’s Office, please visit [www.ico.org.uk](http://www.ico.org.uk).

1. **Who is organising the research?**

This research has been organised by Callum Schofield, a PhD Psychology student at the University of Hull, under the supervision of Dr David Smith (an academic at the University of Hull). Prof. Marie Reid, retired contributing professor, and, and Prof. Ivana Markova, an academic at the University of Hull and Honorary Consultant Psychiatrist with the Humber Teaching NHS Foundation Trust.

1. **Who has reviewed the research?**

This research has been reviewed and approved by the University of Hull’s Faculty of Health Sciences Research Ethics Committee (FHS REC), as well as by the Health Research Authority (HRA), NHS Research Ethics Committee (NHS REC) and by the NHS Research Sites who are acting as Participant Identification Centres (PICs) for this research. This means that the NHS Research Sites will let potentially eligible participants know about the research and give them some information, but will not conduct the research themselves. This means that your usual NHS HD research team is not involved in this research, it is only being conducted by the University of Hull.

1. **What will happen to the results of the research?**

The results of the research will be presented at research conferences and events related to Huntington’s Disease. However, the primary purpose of the research results is to allow the researchers to see how well this early version of the HD-EAT works and how scores on the HD-EAT relate to other, established questionnaires. This information will be used to update the HD-EAT, if needed, to then be tested at a larger scale in clinical settings.

1. **Can I withdraw from the study?**

Yes, you can withdraw at any time and without providing a reason for your withdrawal. If you wish to withdraw from the study after starting the survey, simply close the survey without submitting it, you will not have to do anything else. If you have already completed and submitted your survey and wish to withdraw after this, you can do so by contacting the researcher using the contact details in section 14.

1. **What if I have a complaint?**

If you wish to raise a complaint or have concerns about the appropriateness of this research, please contact the University of Hull Conduct and Complaints Office at conductandcomplaints@hull.ac.uk, or call 04182 346311, and ask to speak to a member of the Conduct and Complaints team.

1. **Who can I contact for more information**

If you have any questions or concerns about the research, or wish to obtain a copy of any research study materials, such as the Privacy Notice for Research Participants, please contact:

 Mr. Callum Schofield, MSc, MBPsS, AFHEA

 c.schofield-2019@hull.ac.uk

If you wish to contact the lead academic supervisor of this research, please contact:

Dr. David Smith

d.r.smith@hull.ac.uk

Room 178, Fenner Building, University of Hull, Cottingham Road, Hull, HU6 7RX

 If you have read this Participant Information Sheet and wish to take part in the research, please scan this QR code to access the survey, or visit <https://app.onlinesurveys.jisc.ac.uk/s/hull/the-hd-eat-pilot-study>: