

## PARTICIPANT INFORMATION SHEET

### **Implementation of clinical practice guidelines in Huntington's disease**

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being undertaken and what it will involve. Please take time to read the following information carefully and discuss it with others, if you wish.

Thank you for reading this.

#### **1. What is the purpose of this research project?**

At the beginning of 2020, new guidelines were published to guide physiotherapy practice for people with Huntington's disease (HD). The Physiotherapy Working Group of the European Huntington's Disease Network aims to support the HD community and plans to develop resources to support physiotherapists in their clinical work. In order to develop appropriate resources, we need to know the barriers and facilitators that physiotherapists may encounter when implementing the guidelines. The aim of this study is therefore to collect information from physiotherapists, via an online questionnaire, as to the barriers and facilitators to implementing the recently published clinical recommendations to guide physiotherapy practice for HD.

#### **2. Why have I been invited to take part?**

You have been invited because you are a physiotherapist who works or has worked with people with HD and will be able to provide information on what you perceive to be barriers and facilitators to implementing HD guidelines.

#### **3. Do I have to take part?**

No, your participation in this research project is entirely voluntary and it is up to you to decide whether or not to take part. If you decide to take part, we will discuss the research project with you and ask you to sign an electronic consent form. If you decide not to take part, you do not have to explain your reasons and it will not affect your rights. You are free to withdraw your consent to participate in the research project at any time, without giving a reason, even after signing the consent form.

#### **4. What will taking part involve?**

If you agree to take part in the study, you will use an electronic link to access an online questionnaire. The first page of the questionnaire will be the consent form for the study. The first section of the questionnaire will ask questions related to the country and healthcare setting where you work. Questions related to knowledge of accessibility to the guidelines will also be included. The questionnaire will provide the six action statements from the guidelines and ask you whether you agree or disagree with a list of barriers and facilitators to implementing the recommendations. Free text will also be available for you to add any further barriers and/or facilitators that you think are important.

The questionnaire will take approximately 15 minutes to complete.

#### **5. Will I be paid for taking part?**

There will be no payment for taking part in this study. You should understand that any data you give will be as a gift and you will not benefit financially in the future should this research project lead to the development of a new resources.

#### **6. What are the possible benefits of taking part?**

There is no direct benefit to you from taking part, but your contribution will help us develop resources for physiotherapists working with people with HD.

#### **7. What are the possible risks of taking part?**

There is a small risk that you may read new information about the physiotherapy management of HD and that this may cause you some concern in relation to your current clinical work. If you are concerned in any way, please contact the researcher to discuss these concerns. The contact details are at the end of this information sheet.

#### **8. Will my taking part in this research project be kept confidential?**

All information collected from or about you during the research project will be kept confidential and any personal information you provide will be managed in accordance with data protection legislation. Please see 'What will happen to my Personal Data?' (below) for further information.

#### **9. What will happen to my Personal Data?**

Personal data e.g. email addresses, will be managed according to the General Data Protection Regulation (GDPR). If you email the researcher, these will be kept by the principal investigator at Cardiff University and will not be shared with any other person or group.

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection, including:

- your rights
- the legal basis under which Cardiff University processes your personal data for research
- Cardiff University's Data Protection Policy
- how to contact the Cardiff University Data Protection Officer
- how to contact the Information Commissioner's Office

may be found at

<https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

Any emails received will be destroyed at the end of the study. The consent form will contain tick boxes and will therefore not contain personal data.

#### **10. What happens to the data at the end of the research project?**

Data collected from the questionnaire will be anonymised. At the end of the study, data will be downloaded and subsequently deleted from the survey software and stored on Cardiff University servers via a password protected computer. The data will be shared with the research team: Principal Investigator – Una Jones, Cardiff University, UK; Deb Kegelmeyer and Anne Kloos, Ohio State University, USA. Sharing will take place via University file sharing systems.

#### **11. What will happen to the results of the research project?**

The findings of the study will be disseminated via the Physiotherapy Working Group of the European Huntington's Disease network and potentially published via conference proceedings and peer reviewed journals. Participants will not be identified in any report, publication or presentation.

If you would like a copy of the findings, please contact Una Jones.

#### **12. What if there is a problem?**

If a problem arises, please contact Una Jones [jonesuf@cardiff.ac.uk](mailto:jonesuf@cardiff.ac.uk). If you feel that the issue has not been handled to your satisfaction, please contact the Chair of the School of Healthcare Sciences, Research Ethics Committee, Dr Kate Button [buttonk@cardiff.ac.uk](mailto:buttonk@cardiff.ac.uk).

If you wish to complain or have grounds for concerns about any aspect of the manner in which you have been approached or treated during the course of this research, please contact Dr Kate Button. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, you may have grounds for legal action, but you may have to pay for it.

**13. Who is organising and funding this research project?**

The research is organised by the Chair of the Physiotherapy Working Group of the European Huntington's Disease Network, Una Jones. Una Jones is from the School of Healthcare Sciences at Cardiff University.

**14. Who has reviewed this research project?**

This research project has been reviewed and given a favourable opinion by the School of Healthcare Sciences Research Ethics Committee, Cardiff University.

**15. Further information and contact details**

Should you have any questions relating to this research project, you may contact us during normal working hours:

Una Jones, [jonesuf@cardiff.ac.uk](mailto:jonesuf@cardiff.ac.uk), 00442920687789

School of Healthcare Sciences, Heath Park, Cardiff CF14 4XN

**Thank you for considering to take part in this research project.**