Developing EVIdence for AntidepreSsant ChoicE to Treat Depression in Huntington's Disease

Study Partner Information Sheet V3 13/03/2026

This leaflet explains what it means to be a study partner — someone who helps a friend or relative take part in a research study

The person you support has been invited to take part in a research trial on the impact of anti-depressants in Huntington's Disease. They will be asked to complete questionnaires throughout the study. There may be times when they might ask for support to complete the questionnaires.

We would like to know if you would be comfortable to be contacted and to support them in completing assessments. We will also be asking the person you support if they would be happy for you to support them in completing assessments.

A team member will go through this leaflet with you, explaining what your role in the study would involve and answering any questions before you make a decision.

IMPORTANT THINGS YOU NEED TO KNOW

- This trial is for people that carry the gene mutation that causes Huntington's Disease (HD) and a doctor has recently diagnosed the person you support with a new episode of depression
- HD causes difficulties with movement and thinking that get worse over time. Many individuals with HD also have depression
- Research has shown that depression in people with HD is different and anti-depressants may work differently because of that.
- We want to know how well anti-depressants do or don't work to improve depression in HD
- To do this we want to understand whether it is possible to run a Randomised Control Trial (RCT) looking at the effect of anti-depressants in people with HD.
- In this study, half of the people will receive the anti-depressant Sertraline, or an table with no medication (placebo). Participants will take the treatment daily for 6 months
- We may ask them to give some small samples of blood, but this is optional

- Throughout the trial we will ask the participant about their feelings of depression and how their disease is progressing.
- The research study will last for 6 months.

WE WOULD LIKE TO INVITE YOU TO HELP SUPPORT YOUR FRIEND OR RELATIVE IN TAKING PART IN THE RESEARCH STUDY

- We want the research to be accessible to as many people as possible. By having a study partner role in the research, we can include people who are not normally invited to take part in research. This means that the research will be more accurate.
- We will ask to collect your contact details (Name, telephone number) and we will keep those details stored securely at Cardiff University, only storing it on password-protected, secure servers.
- If we're unable to reach the person you support during the study, we may contact you to help us get back in touch with them about their participation.
- We may ask you to help the person you support to complete the assessments.
- You can discuss with the person you support who is being asked to take part in the research study before making a decision. You are free to decide whether you want to act in the support role or not.

HOW WILL WE USE THE INFORMATION ABOUT YOU

- If you decide that you want to take on the support role and then decide you no longer want to be involved you can stop acting in the support role without giving a reason. You can request that we destroy your contact details within 28 days of you telling us that you no longer want to continue in the study partner role, however we will delete this information as standard at the end of the trial
- All information collected about you will be kept strictly confidential in accordance with applicable Data Protection laws. Cardiff University is the sponsor for this study based in the United Kingdom. This means that we are responsible for looking after your information and using it properly. We will not share your information with any other organisations.
- If you have any concerns or want to find out more about how we use your information you can:
    - Email the research team DEVISEHD@Cardiff.ac.uk

- Have a look at the Cardiff University Data Protection Policy: www.cardiff.ac.uk/public-information/policies-and procedures/data-protection
- Contact the Cardiff University Data Protection Officer by email- inforequest@cardiff.ac.uk or in writing to:
  Data Protection Officer
  Compliance and Risk, University Secretary's Office
  Cardiff University
  42 Park Place
  Cathays, Cardiff
  CF10 3BB
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- If you remain unhappy and wish to complain formally, you can do this by contacting an NHS complaints advocate. Details can be obtained from https://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/
- If you decide you want to take on the support role, we will offer you a copy of this information sheet and ask you to sign a consent form to keep your contact details.
- Please let us know if there is anything in this leaflet that is not clear or if you would like more information. A member of our team will answer your questions. If you would like further information about the study please contact DEVISEHD@Cardiff.ac.uk or the hospital trial team.
- We know that helping to support someone with HD can be challenging. If you ever feel unsure, overwhelmed, or need to talk, please reach out to the research team. We're here to support you. You can also contact another organisations:

  Samaritans by calling 116 123

  Shout by texting 85258

  [INSERT LOCAL TRUST SERVICES OR LOCAL SUPPORT ORGANISATIONS]

  - <LOCAL SITE CONTACT DETAILS>

You don't need to be in crisis to reach out — these services are here to listen.