**Participant Information Sheet**

**Project Title:** The Hidden world of Huntington’s disease (Phase 2)

**Approval Number:** 2025-06278-Cruickshank

**Lead Investigators:** Dr Travis Cruickshank & Ms Melanie Clark

**Other Investigators:** A/Prof Julia Morris, MrsCassandra Barnes, Prof Angela Dew, Dr Christopher Kueh

**An invitation to participate**

You are invited to take part in a study exploring the lived experiences of people affected by Huntington’s disease (HD) through photovoice. In this study, you will capture photos based on different themes related to daily life with HD and share your thoughts about each image. This study is being undertaken with Huntington’s Australia, who financially contributed towards the work.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. If you decide to take part, you might want to talk about it with a relative or friend.

If you want to take part in the research project, you will be asked to sign a consent form. By signing the attached consent form, you are telling us that you:

* Understand what you have read;
* Consent to take part in the research project;
* Consent to be involved in the research described;
* Consent to the use of your personal information as described;
* Understand that you can withdraw at any time.

**What is the project about?**

You’re invited to take part in a study where you’ll use photos to share your experience of living with Huntington’s disease (HD). Each week, you’ll be given themes and prompts to guide you as you take photos that represent your daily life. You’ll also provide a brief explanation of what the photos mean to you. These will be shared with the research team via email, SMS, or WhatsApp. The goal is to raise awareness of HD and help others understand its impact. The team will look for common themes in your photos and comments to better understand the lived experiences of people affected by HD.

This is Phase 2 of a larger project using photovoice as a creative method for the HD community to show their hidden lived challenges to the wider community. The project has three phases:

**Phase 1**: Co-design a creative method to showcase hidden challenges experienced by people with HD.

**Phase 2**: Evaluate if the community can engage with and find the photovoice method useful for communicating their hidden challenges to the wider community.

**Phase 3**: Host a gallery event where photovoice pieces will be showcased to raise awareness and understanding of HD.

**In Phase 2**, you’ll be invited to take part by capturing photos based on weekly themes and prompts, sharing your experiences of living with HD.

**What does my participation involve?**

Taking Photos

You will be asked to take photos that represent your daily experiences with Huntington’s disease (HD) during May and June. These photos should capture aspects of your life that you want to share with others. Each week we will provide you with a theme to guide your photos along with some helpful prompts. If you need help, you can ask someone else to take the photos for you.

Writing About the Photos

For each photo, you’ll write a short explanation answering these questions:

* **"**What does this picture mean to you?"
* "What’s the story behind it?"
* "What do you want people to understand about HD?"

You can take your time to think about the photos and write your thoughts.

Sending Your Photos and Comments

Once you have taken your photos and written your explanations, you will send them to the research team using email, SMS or WhatsApp. We’ll provide clear instructions on how to do this.

Interview

We will invite you to take part in a short interview about your experience with the photovoice method. You’ll also be asked how you think this study can help raise awareness and make a difference for people living with HD.

Questionnaires

Before the study we will ask you to provide some basic information about you (e.g., age, date of HD diagnosis, relationship status, supports you receive). Before and after the study, we’ll also ask you to complete a brief questionnaire to see how participating in the photovoice process has affected your emotional wellbeing, quality of life and self-efficacy.

**Do I have to take part?**

Taking part in this study is completely voluntary and you do not have to participate if you don’t want to. If you decide to join and later change your mind, you can exit the study at any time. If you decide to take part, you will be asked to sign a consent form. You will also receive a copy of this information letter to keep. Your decision to participate or not will not affect your relationship with the research team in any way.

**Your privacy**

By signing the consent form, you agree to let the research team collect your photos and comments during the study. We will collect some personal information that could identify you, but this will only be accessible to the research team. Your photos and comments will only be used for this study and will not be shared with anyone outside the research team unless you give us permission or if required by law.

If you decide to take part, you will take photos and share a short comment about each photo. You will send these to the research team via a private WhatsApp chat, email or SMS. You don’t have to share any personal details like your health history.

The photos and comments used for any research activity will not include personal details. They may be used in research reports or presented at conferences, but no personal information will be shared.

All your photos, comments, and personal information will be stored safely and securely for seven years. Thereafter, they will be securely archived according to Edith Cowan University and Western Australia Record Keeping Policies.

If you decide to leave the study at any time, you can. Please note that even if you leave, your photos and comments will still be part of the study. However, they won’t be linked to your personal details.

**Possible Benefits**

Taking part in this study may not directly benefit you, but the photos and comments you provide will help show the hidden experiences of people living with (HD). This will help improve awareness and understanding of HD in the wider community. The information from this study could have a positive social impact by changing how people think about HD, encouraging more support and better policies for those affected.

**Possible Risks and Risk Management Plan**

There are a few risks with taking part in this study. Talking about personal experiences with HD might make you feel upset and sharing photos could feel a bit uncomfortable. You can stop at any time if you want to and this will not affect your healthcare or relationship with researchers. We’ll be here to help you if you need it and make sure you’re okay during the study. There’s a small chance that your photos could show things that might make you easy to recognise (like your face or house number). We’ll talk to you about this and make sure you're okay with us using your photos in the study.

**What happens next?**

Once we've collected and looked at all the photos and comments, we’ll send you and the other participants a summary of the results. The next phase will also involve hosting a gallery event where participants can showcase their photos and comments to the general community. No photos or comments will be shown without permission. The aim of the gallery event is to raise awareness and understanding of HD. We plan to share the results in research journals and at conferences, both locally and internationally. Your personal information won’t be shared in any publication or presentation.

**Has this research been approved?**

This project has received the approval of Edith Cowan University’s Human Research Ethics Committee in accordance with the National Health and Medical Research Council’s *National Statement on Ethical Conduct in Human Research (2007)*. The approval number is 2025-06278-Cruickshank.

**Contacts**

If you would like to discuss any aspect of this project, please contact the following people.

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| **Lead Investigator**  Dr Travis Cruickshank  Chief Investigator  Edith Cowan University  E: [t.cruickshank@ecu.edu.au](mailto:t.cruickshank@ecu.edu.au)  P: 08 6304 3416 | **Lead Investigator**  Melanie Clark  Chief Investigator  Perron Institute  E: [melanie.clark@perron.uwa.edu.au](mailto:spin@ecu.edu.au)  P: 08 6457 0210 | **Independent Person** Research Ethics Advisor  Human Research Ethics Committee  Edith Cowan University  E: [research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au) P: 08 6304 2170 |

Approval to conduct this research has been provided by the Edith Cowan University’s Human Research Ethics Committee, approval number 2025-06278-Cruickshank, in accordance with its ethics review and approval procedures. If at any time you are not satisfied the research or wish to make a complaint about the research process, you may contact the Human Research Ethics team on 6304 2170 or by emailing them at [research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au).

**PARTICIPANT CONSENT FORM**

**Project Title:** The hidden world of Huntington’s disease

**Lead Investigator:** Dr Travis Cruickshank

I confirm that:

* I have read and understand the information and consent form.
* I understand the study will happen like it says in the information sheet, which I have a copy of.
* I've been told about the study and its possible effects.
* All my questions have been answered.
* I agree to take part in the study.
* Joining is my choice and I can leave anytime without giving a reason
* My data can be used in publications, but my name or identifying details won't be shared.

**Please review and check the following boxes:**

* I agree for my photos and comments to be **shared with Huntington’s Australia** to raise awareness and educate others.
* I would like to be contacted and give permission for my photos and comments to be **shared with Huntington’s Australia**.
* I do not want my photos and comments **shared with Huntington’s Australia**.

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| --- | --- | --- | --- |
| **Participant name:** |  | | |
| **Signature:** |  | **Date** |  |

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