

Participant Information Sheet

Identifying treatment Side effects in adults with an Intellectual Disability and Epilepsy:
Development of Patient-Reported Outcome Measure (PROM) for identification of Anti-
Epileptic Drug (AED) side effects (**SIDE-PRO**)



You are invited to take part in a study. It is being carried out by a team at Cardiff University. This information sheet is to answer some of your questions and help you decide if you want to take part.

What is the study about?



We would like to find out if you have any problems after you take your epilepsy medicine. We would like to help make it easier for the doctor to find out what problems you are having with your medicine.

Why have I been asked?

You have been asked to take part because you take medicine for your epilepsy.

Do I have to take part?



No. It is up to you if you want to take part in this study or not.



If you decide you would like to take part in the study you will be asked to sign a consent form stating you agree to take part in the study.



If you do take part, you can stop the study at any time. You will not need to tell us why you would like to stop.

What will happen to me if I take part and what do I have to do?



The study will happen in stages including focus groups, face to face interviews with the study team (home based) and questionnaires which we will post to you at home.

Participants do not have to take part in every stage of the study.

For this study we are looking to recruit people who meet the following criteria:

Participants:

- Live in the South Wales area
- Aged 18+
- Have a learning disability
- Have a diagnosis of epilepsy
- Currently taking antiepileptic medication

- Have an identified carer who is also willing to take part
- Have capacity to consent to participate in the study.
- Ability to complete the study questionnaires in English (supported by a carer if required)

We will give you a £10 high street gift voucher to thank you for giving up your time.

If you feel you do not want to answer the questions then you do not have to.

What will happen to the information I give?

NAME Some of what you say might be used in our report but your name or personal details will not be included.

What will happen to my personal details?

Your name, contact details and tape recording will be kept on a university computer which is password protected. Your details will only be seen by the research team and used to contact you.

Anything you tell us will be confidential. This means that no one outside the research team will know that you were in the study or what you said. We will not share your details with anyone and we will destroy them after 15 years.

What are the possible disadvantages and risks of taking part?

This study means you will be talking about your epilepsy with other people. It is possible that it may be upsetting. If you are upset please tell the research assistant.

Contact for further information:

If you would like to speak to someone on the Research Team about taking part please contact us below.

Andrea Meek

Research Assistant

South East Wales Trials Unit

Centre for Trials Research

Neuadd Meirionnydd, Heath Park

Cardiff University, CF14 4YS

Phone: **029 20687619**

FAX: 02030432358

Email: SIDEPRO@cardiff.ac.uk



Thank you for thinking about taking part in this study