

Frequently asked questions

1. I am interested in taking part.
 - a. How can I get involved in the study?

Contact the research team, call or email us

Check out the participant information sheet available on the study webpage.

To take part in the study, we will need your agreement, and this will involve you giving your consent to take part in the online survey. We will ask for some personal details to confirm which stakeholder group you represent (such as patient group, professional group). We will require your contact details, essentially your email to all delivery of the Delphi Survey and any study contact, such as reminders.

We ask you to keep a copy of the participant information sheet.

- b. I am a healthcare professional working in the UK. Can I be involved in the study?

Yes, if you are involved in the support of women with epilepsy you can join the Delphi online survey. You will contribute your experience of what is important for women with epilepsy when planning a pregnancy.

2. Who can take part?

You can take part if you are:

Patients-

- Women with epilepsy
- People with personal experience of the condition; patients (women with epilepsy aged 16-50 years), patient spouse/ partner, parents, carers and service users.

Healthcare Professionals-

- Healthcare professionals with experience of preconception care to women with epilepsy
 - Neurologist/Epileptologist
 - Obstetrician
 - Midwives
 - GPs & GPs with a specialist interest in epilepsy
 - Neuropsychologist
 - Neuropsychiatrist (including those with a special interest in intellectual disability)
 - Epilepsy Nurse Specialist
 - Pharmacist
 - Family planning consultant/nurse
- Professional and lay representatives of International League Against Epilepsy; Royal College of Obstetricians and Gynaecologists, Royal College of Pharmacy; Royal College of General Practitioners; Epilepsy Nurse Specialist Association

Voluntary sector-

- Representatives of National Epilepsy Patient organisations (Epilepsy Action; National Epilepsy Society; Epilepsy Scotland; Epilepsy Wales; Epilepsy Action Northern Ireland; Epilepsy Action Isle of Man).
- Neurological Alliance; Brain Charity supporting patients with neurological conditions including epilepsy.

Exclusion criteria

- Women with epilepsy with significant intellectual disability who have permanent absence of capacity to consent to sexual activity to lead to pregnancy
- Patient groups or professional groups unable to provide, or refuse consent
- Healthcare professionals / voluntary sector not working/supporting women with epilepsy.

3. Will taking part in this study affect my care?

No. Taking part is voluntary. Taking part will not affect your care.

4. What is a Delphi survey?

Taking part in the online Delphi survey

A Delphi study is a research technique for reaching an agreement or consensus in a systematic manner.

In a Delphi study, researchers identify groups of people who are “experts” in the health condition they are interested in.

“Experts” are:

- People with personal experience of the condition, for example, patients, carers and service users (it doesn’t matter how long the person has had the condition for, their opinion is incredibly valuable)
- Health professionals with expertise in treating and caring for people with the condition
- Researchers
- Voluntary organisation representatives
- Healthcare commissioners

Experts taking part in a Delphi study are asked to give their opinion on what is most important the outcomes of care, through a series of structured stages, also known as rounds.

The aim is for the participants to contribute ideas, and then rank suggestions in successive rounds to reach a consensus about the content of the preconception care pathways and what the outcomes of preconception care are most important.

What are the stages of this Delphi Study?

The first stage, or round, we generated a long list of items relating to preconception care. We invited women with epilepsy, their partner, spouse, family and friends to participate in an interview or focus group. The research team analysed this data to develop the online survey.

The second stage, or round, involves taking part in the survey. We will send you a link to join the survey.

In two survey rounds, we will ask you to rank the items about preconception care into most and least important. The survey will ask what you think about the key stages of the preconception journey, and to rank the essential elements of preconception care along the pathway. We will ask your opinions of what you think are the critical outcomes of preconception care.

5. What is a consensus meeting?

At the end of the online survey rounds, the researcher team will invite a group of experts to get together in a virtual face-to-face meeting to discuss the results. This is known as a consensus meeting. This is optional, and attendance is voluntary for all those taking part in both online survey rounds. At the end of this process, the research team will produce a report on what the experts have agreed as the most important outcomes of the preconception care pathway for women with epilepsy in the UK.

a. Who can take part in the consensus meeting?

Participants completing both rounds of the online survey will be asked to confirm their interest in attending the consensus meeting. This is optional and participation is voluntary. We will invite representatives from each stakeholder group to attend.