

How do I know if my child or person I care for is able to provide their own consent to take part in this project?

This form can be translated to Welsh upon request

The decision about whether to take part in this study must be 'informed'. This means that anyone making the decision must understand exactly what is involved in the study, what will be required from participants and why. You need to decide whether your child/the person you care for can understand enough about the study to make an 'informed' decision independently about whether or not they would like to participate and to communicate this decision to you. If you are not sure whether or not your child/person you care for is able to make this then the following procedure may be helpful to you.

STEP ONE: Read the following statements to the person you care for:

1. The study is about collecting information from medical notes and investigations about your epilepsy and using stored samples of spinal fluid for research.
2. The study will involve your doctor answering questions about your epilepsy.
3. If you agree for me/your parents/your carers to be contacted by the research team, you may be invited to take part in other research in the future.
4. You do not have to agree to take part. If you agree to take part and change your mind at a later time that is OK. You just need to tell someone.
5. All information will be stored in a safe place and only the research team at Aston University will have access to your information.

STEP TWO: Ask the person you care for the following questions:

1. What is the study about?
2. What will you and your parents or carers need to do to take part in the study?
3. What will happen if you agree for me/your parents/your carers to be contacted again by the research team?
4. What do you need to do if you decide to take part and then change your mind?
5. Where will your information be kept?
6. Do you agree to take part in this study?

If your child/person you care for is able to answer each of the above questions correctly and without any support then it is likely that they have sufficient capacity to consent to take part in the research project. If this is the case, complete the Consent Form Appendix 5. If the person you care for has been unable to answer all of the questions above it is unlikely that they have sufficient capacity to consent to take part in the research project. If this is the case, please complete Consent Form Appendix 10.