

Participant Information Sheet

Study title: Understanding how brain injury affects development.

Researcher: Beverley Garrigan

We would like to invite your child to take part in our research study. Before you decide whether you would like them to take part we would like you to understand why the research is being done and what it would involve for your child.

What is the purpose of the study?

This study is part of a PhD project. The purpose of the study is to look at how young people with a brain injury develop compared to people of the same age who do not have a brain injury. We want to look at how young people develop and change as they get older, and investigate whether this is different for young people who have a brain injury. Damage to the brain can affect various aspects of peoples' lives and the more we know about this, the better we will be able to help young people with a brain injury.

Why has my child been invited to take part?

Your child has been invited to take part in this study because they are aged between 11 and 16 and have a brain injury. We want to compare a group of young people with a brain injury to a group of young people without a brain injury to investigate the effects of damage to the brain on different aspects of peoples' lives.

Does my child have to take part?

It is up to you and your child to decide to join the study. We will describe the study and go through this information sheet. If you agree for your child to take part, we will then ask you to sign a consent form. Your child will be free to withdraw at any time, without giving a reason.

What will happen to my child if I decide I want them to take part?

If you decide you would like your child to take part, your child will be given participant information and the study will be explained to them. They will also be asked to sign an assent form to confirm that they want to take part.

If your child takes part there will be two sessions. The first session will take about two hours in total. The second session will be two weeks after the first and will only take about 45 minutes.

Your child will first be asked some questions which measure how they think and work things out. This part will take about one hour. They will then be given a couple of short questionnaires to fill out which ask about different things such as how they behave and some questions about their family.

Your child will be shown some pictures which tell a story and they will be asked to make a decision about what they would do in that situation. The researcher will also ask your child some questions and ask them to explain their answers, which is to measure their reasoning. Their answers to this part will be recorded by the researcher using an audio recorder and later transcribed. Only the researcher will listen to and transcribe your child's answers and the recording will then be deleted once the study is over. Their answers will be anonymised and some of them will be sent to a research group in Canada for them to process. This group won't know your child's name.

Two weeks after completing the first sessions your child will be asked to complete some of the questions again, but not all of them. This second session will only take about 30 minutes.

You, or another parent or caregiver of your child will also be asked to complete a short booklet containing some questions about your child. A separate information sheet will explain this.

As part of this study the researchers would like to look at your child's NHS Trust and GP records in order to find out details about their brain injury. If you agree to your child taking part in the study, you will be asked whether or not you consent to the research team accessing these records. If you agree, you will be asked for details of your child's GP practice. Your child will also be asked whether they agree to the researchers accessing these records.

Some of the tasks your child will be asked to complete as part of this study may be tasks they have completed before with a clinician. You will be asked if you agree for the research team to access the scores to these tasks via your child's NHS Trust records. If your child has completed these tasks in the past year and the research team can access these scores, your child will not be asked to complete these tasks again in this study.

Your child will be asked about any police contact they may have had. If your child discloses any information about a crime which has not been reported to the police, or

for which they are currently under investigation, the researcher may have to pass this information onto the relevant authorities. This will be explained to your child.

Will my child's data be confidential?

All the information collected about your child will be confidential. Your child's responses will be kept under a number not your name and the consent forms containing names will be kept separately to their responses. All your child's responses will be confidential unless they disclose information which suggests they are at risk of harm, in which case the researcher will have to pass the information to the relevant people.

Expenses and payment

When your child has completed both sessions they will be paid £5 for their time.

What are the risks of taking part for my child?

The first session may take up to two hours. Your child will be able to have breaks at any time. If your child becomes upset answering any of the questions the researcher will stop the study and discuss this with your child.

What are the benefits of taking part for my child?

By taking part in this research your child will help us to learn more about how brain injury affects a child's development. The more we know about the effects of brain injury, the better we can help affected children and their families.

What happens when the research stops?

The data collected in this study will be analysed and a report detailing the findings will be produced. Your child's data will be kept in secure storage for 5 years and then destroyed.

If you would like to know how your child performed on the standardised measures then we can give you a brief report summarising your child's performance, and you can give a copy of this report to your child's school, GP, or other health professionals working with your child. We can also give you an overall summary of the study findings for your information.

You will be asked if you agree to be contacted directly by the researcher, Beverley Garrigan, about future studies conducted as part of her PhD. If you agree to be contacted about these studies you are not agreeing for your child to take part in any further studies, you are just agreeing to be contacted with information about them.

You will be asked whether you agree to your child being added to a Research Volunteer Register hosted by Dr Anna Adlam (Clinical Senior Lecturer) at the University of East Anglia to inform you of opportunities for them to participate in ethically approved studies conducted by her and her team. This is voluntary and you can withdraw this consent at any time.

Further information and contact details

If you would like any further information about the study please contact Beverley Garrigan (email: B.Garrigan@uea.ac.uk).

If you would like to discuss this study with someone who is not involved in the research then you can contact the Norfolk Community Health and Care NHS Trust Patient Advice and Liaison Services (PALS) on 0800 088 4449.