



Information Sheet for Parents of Potential Participants

CHILD AND YOUNG PERSON (Aged 12-17 years)

Improving Peer Relationships in Adolescents Following Acquired Brain Injury: Designing an Intervention Programme Through Intervention Mapping.

Chief Investigator: Scott Ankrett, University of Exeter, U.K.

Research Supervisor: Dr Anna Adlam, University of Exeter, U.K.

Dear Sir / Madam

Purpose of the research

Acquired brain injury (ABI) in children and young people is a leading cause of disability worldwide. ABI can alter a child's developmental trajectory when compared to their peers, with developmental 'gaps' becoming increasingly apparent with age. This can cause a number of psychosocial impairments including mood, educational attainment, and friendships. Little is known about the social outcomes in adolescents with ABI. Even less is known about how social impairments can be improved.

Peer relationships are extremely important during childhood. They allow for continual social development, the sharing of experiences, and simple companionship. Those with social impairments are at risk of peer rejection, making it difficult to establish a supportive peer group. As a consequence, those with ABI can experience isolation, loneliness, inappropriate behaviour, anxiety, and aggression.

The aim of this study is to use an intervention mapping approach to address the gap in the literature and to design a suitable intervention aimed at improving peer relationships. The chosen methodology supports the co-design of an intervention with the involvement of various 'stakeholders' who have in some way experienced ABI in adolescence. This includes adolescents with ABI, parents, peers, practitioners, and researchers. The study is interested in hearing about the social experiences of those impacted by ABI, and use their consultation to help design a treatment programme.

We would like to ask your child to take part in the research study. It is really important that we give you all the information about what your child is expected to do before you provide consent for them to participate. You can always ask us for more information at any time. The contact details can be seen below.

Why is my child being asked to take part?

We would like your child to be in the study because they are the 'experts' we would like to hear from in the development of this intervention. We are asking both girls and boys between the ages of 12 and 17 years who have had a brain injury, or know a friend who has to take part and offer their expertise.

What type of data is being collected and how?

The study will be collecting data using questionnaires, surveys, and focus group discussions. The questionnaires are used to collect a number of characterisation and demographic data; this includes social skills, quality of life, social economic status, type of injury, and injury severity (children with brain injury only). Each questionnaire will come with a set of instructions on how to complete them.

A focus group is a group discussion around a particular 'focus' topic. Your child will be asked to attend a focus group at the University of Exeter to meet with others their age and with similar experiences (date to be confirmed). There will be between 3 and 6 people in their focus group with one group facilitator. They will be asked to have group conversations in response to some questions, there are no right or wrong answers. For this study, we are interested to hear about experiences of children with brain injury regarding their friendships with others, what needs to improve, and how teenagers would like it to be done so that is meaningful for them. This information can then help design an intervention. The group will be audio recorded and all information is kept confidential. The group will last for approximately **1 hour**, refreshments will be included.

What will happen on the day?

You and your child will be welcomed on arrival and offered refreshments whilst we are waiting for everyone to arrive. We will ask you to bring with you the questionnaires we will send to you **2 weeks** prior to the focus group (children with brain injury only). You will then be asked to sign a consent form to state that you are happy for your child to continue with the focus group. They will be unable to participate without this. The facilitator will ensure that everyone is seated and then explain the group rules; these include not speaking over others, and to maintain confidentiality following the session. Following the group, you and your child will be provided with a debrief sheet which will contain further information about support if you require it.

Do they have to?

No, they do not have to take part, it is completely up to you and your child. If you choose not to participate, that's okay. This will not impact your child's care.

What's good about taking part?

Your child is the 'expert' in social experiences following brain injury. They will be helping us to understand what it is like for teenagers and what problems they might have. They can talk to us about what is meaningful and important to teenagers when thinking about friendships. We can think together about how we might be able to help teenagers who have difficulties with their friends. Your child will be able to meet others their age and share experiences. They will also get a £10 Amazon voucher as a thank you for coming along.

What's bad about taking part?

One possible bad thing about taking part is that some of the discussions may be upsetting. If at any time your child feels that they are becoming upset, they can stop. If they want to, there will be people there who they can talk to and further information about support will be provided. If they want to leave the group at any point, they are more than welcome to, no problem.

Will information be confidential?

Due to recent regulatory changes in the way that data are processed (General Data Protection Regulations 2018 and the Data Protection Act, 2018), the University of Exeter's lawful basis to process personal data for the purposes of carrying out research is termed as a 'task in the public interest'. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection. If you have any concerns about how the data are controlled and managed for this study then you can also contact the Sponsor Representation, Pam Baxter, Senior Research Governance Officer (e: p.r.baxter2@exeter.ac.uk).

Making sure that your child's information remains private is important to us. We will do the following to protect their privacy in this research study:

- All personal and research information about your child will be stored on a secure password protected university server. No identifiable information will leave university premises.
- Only researchers at the University of Exeter will have access to your child's personal information (contact details, consent forms). This will be kept securely for 5 years before being destroyed.
- Once the research data has been analysed, all identifiable information will be anonymised. There will be no identifiable information published as part of this study. All transcriptions of focus group data will be anonymised.
- Confidentiality will be reiterated within the focus groups by the facilitator.

Risk and Confidentiality

The only time we would break confidentiality was if we felt that your child, or someone else, was at risk of harm. In such cases, risk procedures will be followed and we might have to tell you or someone else about what they have said in the interest of safety. We may also support you to make contact with appropriate local services for support. You will be reminded of this on the day of participation.



Thank you for reading!

Further Information

If you have any further questions about this research study, please contact the lead researcher via email: sa675@exeter.ac.uk

University of Exeter, College of Life and Environmental Sciences, Psychology,
Exeter, EX4 4QG.

Tel: 01392 72 2209.

To contact the Chair of Psychology Ethics, please contact Dr Nick Moberly (e: n.j.moberly@exeter.ac.uk t: 01392 724656)

Ethical approval number: <insert REC number>