



Participant Information Sheet

STAKEHOLDER PARTICIPATION

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

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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 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.

What type of data is being collected?

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. 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.

What will participation in focus groups involve?

There will be around six to eight people in each focus group with one facilitator. You will be asked to have a group conversation to express your views and form opinions. The group will be audio recorded and all information is kept confidential. The group will last for approximately 1 to 1.5 hours. For this study, we are interested in hearing your views about the social experiences of adolescents with ABI and to use your experiences to help us design an intervention programme which will aim to improve relationships with peers. There are no right or wrong answers to the questions we will ask you. The questions will aim to explore your experiences and views towards the research topic.

When will the focus group be?

It can be really difficult to arrange a time, date, and location for everyone to get together at the same time. We will propose a date in the near future and ask that you contact the researcher as soon as possible to confirm your attendance. If you cannot attend for any reason, please let us know as soon as possible. We ask that you arrive promptly to allow adequate time for the focus group. Refreshments will be provided on the day.

What will happen on the day?

You 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. You will then be asked to sign a consent form to state that you are happy to continue with the focus group. You will be unable to participate without this. The facilitator will ensure that everyone is seated and explain the group rules; these include not speaking over others, and to maintain confidentiality following the session. You will then be given the opportunity to ask questions. Once everyone is happy, the audio recording will begin and the group will commence. Following the group, you will be provided with debrief sheet which will contain further information about support if you require it.

What are the benefits of taking part?

This study offers an innovative approach which values the participation of 'experts by experience'. Your perspectives and consultation will allow for the development of an intervention programme to improve peer relationships for others experiencing ABI. You will have the opportunity to meet others in a similar situation to you and share experiences. As a thank you for sharing your time, we will give you a £10 Amazon voucher.

Are there any risks?

The questions are likely to talk about sensitive topics which may be difficult to share. If you become upset by the information spoken about within the focus group, there will be information provided about services where you could access support. You are able to withdraw from the study at any time with no consequence.

Will my information be kept private?



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 information remains private is important to us. We will do the following to protect your privacy in this research study:

- All personal and research related information about you 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 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 you, or someone else, was at risk of harm. In such cases, we would talk to you about this first and risk procedures will be followed. We may also make contact with appropriate local services for support. You will be reminded of this on the day of participation.

Further information

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

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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>