**Participant information about the study (16-25)**

 **Adapting an executive functioning intervention for adolescents who have survived a paediatric brain tumour**



We would like to invite you to take part in a research to help us design a new intervention to support executive functions in adolescent who have survived a paediatric brain tumour. Before you decide to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others such as a parent if you wish. Please do not hesitate to contact us if there is anything that is not clear or if you would like more information (contact details can be found at the bottom of this sheet). Thank you for reading this.

**Purpose of the research?**

A brain tumour and subsequent treatment in childhood can lead to long-standing problems with planning, organising, and problem-solving (i.e., executive function). This can cause further difficulties with learning, academic achievement, behaviour, emotion, and relationships. Such difficulties can result in problems in everyday life, including school, which can impact on the quality of young people’s lives and that of their families. This study aims to better understand the everyday difficulties that children who have had brain injury, and their families, experience and to work with children and families to identify and develop interventions that might be helpful.

**Why am I being asked to take part?**

We would like you to be in the study because you are the experts. We are asking young people between the ages of 14 and 25 who have had a brain tumour when they were younger to take part.

**Do I have to take part?**

No, it is up to you whether you wish to take part. If you decide not to take part, we will respect your decision. If you do decide to take part, we will ask you first to sign a consent form before you begin the study. We will give you a copy of the forms and this information sheet to keep. You are free to change your mind and you can withdraw from the study at any time without giving reason. You are able to request that your data is destroyed. However, this will not be possible after the study has been written up.

**What will happen if I take part in the study?**

If you wish to participate, and you give consent, then we will invite you to complete some brief questionnaires online via Qualtrics. Once this is done, the researcher will contact you to organise the next steps via MS Team. As part of the next steps, you will then be invited to participate in weekly (for up to 3 weeks) executive function coaching sessions online via MS Teams. In these sessions, we will explore your strengths and needs. We will learn more about the type of difficulties you may have and make goals on how to improve these. In between sessions, you will be asked to use a program called Brain in Hand to help you work towards your goals. At the end of the intervention, we will ask you to give us feedback on your experience of the sessions and the delivery of the intervention. This can either happen as a group discussion with other young people of a similar age who have experienced the same thing OR a 1:1 interview with your parent with you OR a 1:1 interview by yourself. You can pick which one would be best for you. We will ask you some questions about the intervention and there are no right or wrong answers. It will be video recorded so the answers can be transcribed later. Any personal data revealed in the interview will be removed at the transcription stage. The group or interview will last for around one hour. In the group or interview, we will ask you to tell us about some of the difficulties you have and whether the sessions helped with this. We also want to ask you for your advice about how to make them better.

**Are there any risks to taking part?**

No, there are no significant risks to participating in the study. The questionnaires, discussion group, and intervention sessions are designed to optimise levels of motivation and minimise fatigue. If, however, you do feel tired, then breaks for a rest will be given. In the unlikely event that you become upset or distressed during the sessions or following interview then we will stop and you will have the opportunity to discuss the reason for becoming upset with the researcher if you wishes. You can then either stop the study or re-join the study, it is up to you.

**What are the potential benefits?**

By participating in this study, you will be helping us to design an intervention for everyday difficulties experienced by young people, like yourself, who have had a brain tumour. We will also give you a £10 gift voucher upon completing the study, as a token of our appreciation. You will be able to keep using Brain in Hand for 3 months after the study.

**Will my information be kept confidential?**

The group and individual discussions will be video-recorded for transcription purposes, which will be used for later analysis by the research team. Your comments will be kept anonymous. All recordings and written text will be stored at the University of Exeter for a maximum of 10-years and will be kept secure either in a locked filing cabinet (written text) or a password protected University of Exeter server (electronic files). If you agree to have your contact details added on to the Research Volunteer Register, then we will contact you before 5 years elapses to ask if you wish to remain on the Register. If you feel more comfortable, you can turn your camera off during the recording. The transcripts of the focus groups will be stored on a secure password-protected University computer and only the research team for this study will have access to these. Your personal details will be stored separately from other data, also on a password-protected University computer. Only the research team will have access to these, and all personal data will be deleted 6 months after the end of the study.

The responses to the questionnaires and the interviews will be kept anonymous, and data will be stored separately from any identifiable information. All video recordings will be deleted following transcription and the anonymised transcribed text will be stored at the University of Exeter for a maximum of 10-years and will be kept secure on a password protected University of Exeter server. If you agree to have your contact details added on to the Research Volunteer Register, then we will contact you before 5 years elapses to ask if you wish to remain on the Register.

With your permission we will let your GP know that you are participating in this study. This is in case you would like to discuss the study with the GP. No results will be shared with the GP. The only time we would disclose any of the information that you share would be if potentially harmful behaviour to yourself or others was made known. We would, however, aim to discuss this with you first.

The University of Exeter processes personal data for the purposes of carrying out research 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 informationgovernance@exeter.ac.uk. or at http://www.exeter.ac.uk/ig/

**What will happen to the results of the study?**

The results will also be submitted to peer-reviewed journals and presented at conferences and meetings. Your name (and any other identifiable information) will not be included on any research outputs, and all data will be presented anonymously.

**Further information**

If you have any further questions relating to the study, please do not hesitate to contact the lead researcher, Sarah Hester on sh1042@exeter.ac.uk

Any concerns about the study can be raised with the University’s Research Ethics and Governance Manager, Gail Seymour by email on G.M.Seymour@exeter.ac.uk or by phone 01392 726621