**Parent/guardian information about the study**

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



Dear Sir/Madam

We would like to invite you and your child 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 if 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 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 has my child been invited?**

We are hoping to recruit adolescents between the ages of 14 and 25 years, who have survived a brain tumour in childhood. We would like to invite your child to take part because of their experiences and to learn more about how best to support these adolescents.

**Does my child have to take part?**

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

**What will happen if my child takes part in the study?**

If you and your child wish to participate, and you give consent/assent, then we will invite you and your child to complete some brief questionnaire measures online before speaking with the researcher via MS Teams. You and your child will then be invited to participate in weekly (for up to 3 weeks) executive function coaching sessions online via MS Teams. In the sessions, we will focus on your child’s strengths and needs relating to executive function. We will work towards goals they have around this. They will be asked to use a program called Brain in Hand to help them meet their goals. At the end of the intervention, we will ask your child 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 to them who have experienced the same thing OR a 1:1 interview with them and you OR a 1:1 interview by themselves. Your child can pick which one would be best for them. 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 your child to tell us about some of the difficulties they have and whether the sessions helped with this. We also want to ask them for their advice about how to make them better.

**Are there any risks to my child?**

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, your child experiences fatigue, then breaks for a rest will be given. In the unlikely event that your child becomes upset or distressed during the sessions or interviews then they will be stopped and your child will have the opportunity to discuss the reason for becoming upset with the researcher if they wish. Your child can then either stop the study or re-join the study.

**What are the potential benefits?**

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

**Will my child’s 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 child’s 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.

With your permission we will let your child’s GP know that they 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 or your child has given us, would be if potentially harmful behaviour to themselves or others was discussed. 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

If you have any concerns about the study or with to make a complaint, please speak with Gail Seymour, the University’s Research Ethics and Governance Manager, by email on G.M.Seymour@exeter.ac.uk or by phone 01392 726621

**Thank you for reading this information sheet.**