**Participant information about the study (14-15 years)**

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



**We would like to ask you to take part in our research study. It is really important that we give you all the information you need before you say ‘yes’ or ‘no’. Please could you read the information on this page carefully about what you will be asked to do. If it is easier, you can ask someone else to read it with you, like your parents. You can always ask us for more information at any time. The contact details can be seen below.**

**What is the study about?**

**Sometimes, teenagers who have had a brain tumour can find it more difficult to do everyday things afterwards. This may be for a number of reasons, ranging from difficulties with memory, planning or solving day-to-day problems. This can affect you in school or work and make things harder for you. We would like to invite you to take part in 2 or 3 sessions of an intervention which we hope will support you with these things. You will be introduced to some technology to use in between the meetings too. We also want to hear about how you found it afterwards, along with others who are also taking part.**

**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?**

**No, you do not have to take part if you do not want to. It’s up to you and your parents. You can say yes or no. If you say yes, we will ask you to complete a form that says this called an assent form. Your parents will be asked to complete a form too.**

**What will happen in the study if I say yes?**

**If you say yes, we will give you and your parents more information on the study. If you are happy to continue, we will invite you to meet with the researcher on a weekly basis for up to 3 weeks for online sessions. In the sessions, we will talk about things you are good at and some things that are difficult for you. We will make goals on how to improve the difficult things. You can have someone with you for the sessions if you such as a parent. In between the sessions, we will ask you to use a program called Brain in Hand to help you with your goals. After all the sessions are finished, we will ask you to let us know how you found them. 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. We will use video recording to help us remember your answers. We will take out any personal data you say. 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.**

**What’s good about taking part?**

**You are the ‘experts’ in your experiences following a brain tumour and what you may need extra help with. You will be helping us to understand what it is like for you and what problems people like you might have. The sessions and the technology you use in between them will hopefully be interesting and helpful for you. Afterwards, you will be able to meet other people your age and share experiences. You will also get a £10 voucher as a thank you for coming along. You will also be able to access Brain in Hand for up to 3 months after taking part.**

**What’s not so good about taking part?**

**One possible bad thing about taking part is that some of the discussions in the sessions and in the group to talk about the sessions may be upsetting. If at any time you feel that you might be upset, you can stop. If you want to, there will be people there who you can talk to and further information about support will be provided. If you want to stop the sessions or leave the group at any point, you are more than welcome to.**

**What do I do if I no longer want to take part?**

You can stop taking part in the study at any time. You don’t have to give a reason if you don’t want to take part anymore. We will delete any information about you we have if this happens before the study is finished. We are not able to delete your information once the study is finished. Also, if you feel upset about anything when you are answering our questions, then we will stop. We might ask you if you want to talk about what made you feel upset. If this happens, you can either choose to carry on or you can stop - it is up to you.

**Will information be kept safe?**

**All the information you provide will be kept safe. We will give each person taking part a code so what they say is not linked to who they are. Group discussions and interviews will take place online via MS Teams and be video recorded so that we can hear the discussions at a later date. We will delete the video recording once we have a written record of what was said. This will be kept safe on a password protected computer After meeting you, we will not use your names, and no one will know that it is you talking. We will not record what is talked about in the online sessions. If you choose to discuss things as a group, you will be asked not to discuss what has been said with anyone else outside of the room. If you say something that worries us, we might have to tell someone else what you have said to keep you safe. If we do this, we will talk to you first.**

**When we write up the study, we will not use your names. We will use pseudonyms or ‘fake’ names.**

**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

**Thank you for reading!**