

Would you like to help us design a research study?

Who are we?

We are a group of clinical-researchers interested in developing neuropsychological treatments for children who have survived a brain injury (e.g., traumatic brain injury, stroke, infection, brain tumour).

We are interested in developing treatments that target everyday difficulties experienced by children who have survived a brain injury, and their families, such as, memory and attention difficulties, emotional and behavioural difficulties, peer and family relationship difficulties, and difficulties engaging in school and home activities.

The research team are: Dr Anna Adlam (University of Exeter), Dr Jennifer Limond (University of Glasgow), Professor Shari Wade (Cincinnati Children's Hospital), Dr Fiona Warren (University of Exeter), Dr Annie Hawton (University of Exeter), Professor Tamsin Ford (University of Exeter), and Theresa Pass (Children's Brain Injury Trust).

What are we doing?

We are currently writing an application for research funding (Research for Patient Benefit) in partnership with CBIT, to support a study to investigate whether we can deliver an online web-based therapy for teenagers who have survived a brain injury. The therapy will focus on problem-solving skills, communication, managing behaviour and emotion, and coping with attention and memory difficulties. Please see the 'further information about the proposed study' section for more details about the proposed research study.

We would like to design and conduct this study in partnership with families of children who have survived a brain injury. We are, therefore, inviting parents and teenagers to be members of a **Research Advisory Panel**.

Families who join the Research Advisory Panel **will not** be expected to participate in the research study, or any other studies conducted by the team. Membership of the panel only involves being **invited to** comment, provide feedback, or advise on the research study.

To be a member of the panel, parents and teenagers will be asked permission for Dr Anna Adlam to keep a record of their email address on a secure server at the University of Exeter. We recommend one email address per family with a parent/guardian as the named contact person. Anna can then contact members of the panel (separately to maintain confidentiality) about the various stages of the research to seek their advice on how to proceed. If members do not wish to respond, then they do not have to. Members can also request to be removed from the advisory panel at any time without any future work with CBIT or the research team being affected.

How can you help?

If you would like to support our research by joining the Research Advisory Panel, then please email Anna at ccnr@exeter.ac.uk. Please include 'Research Advisory Panel' in the email subject heading.

Further information about the proposed research study

Brain injuries are common in children. In the UK, it is estimated that every 30 minutes a child will acquire a brain injury. These injuries can be caused by accidents (known as traumatic brain injury), illnesses such as meningitis or encephalitis, or a stroke or tumour. Most children survive a brain injury, however, this can have a devastating and life-long impact on the child and their family. For example, brain injuries can affect cognitive skills (e.g., problem-solving), emotion, behaviour, and relationships. These difficulties can impact on the child's ability to engage with school, home life, future employment, and independence. Families caring for children with brain injury are also more likely to experience mental health difficulties, and parents who are married are more likely to separate. These family difficulties can further affect how well a child recovers. Over the past 10 years, members of the research team have developed a treatment for children who have survived a particular type of brain injury, traumatic brain injury. This internet-based treatment teaches general problem-solving skills in response to specific everyday difficulties experienced by the child and their family. The treatment is used at home for 8-10 weeks, with weekly therapist support (video conference). Research in the USA has shown that adolescents who completed treatment, compared with adolescents who were given general self-help, improved in their ability to plan, organise, and problem-solve. Adolescents who completed treatment also experienced fewer behavioural and emotional problems, and their families experienced lower stress and fewer mental health difficulties. Despite these positive results, a number of questions remain: for example, will the treatment have similar beneficial effects for all types of brain injury occurring in childhood such as stroke, infection, tumour? Will the treatment lead to other benefits such as improved quality of life? Finally, as the research has only been carried out in the USA, is the treatment good value for money for the NHS? Before conducting a large multi-site study to answer these questions, we first aim to conduct a smaller study to find out how feasible such a large study will be. We would like to find out: i) can we identify and recruit adolescents and families via the NHS? and ii) do adolescents and families find the treatment and research measures acceptable? It is hoped that the research findings will lead to effective, value-for-money, easy-to-access, treatments for adolescents who have survived brain injury, and their families.