Family Information Sheet

Brain Injury and Schools Research Study | Plymouth Marjon University

Ethics reference: EP294

What is this about?

This research is looking at how well secondary school teachers and support staff understand acquired brain injury (ABI), and whether a short free training programme can improve their knowledge. We also want to know whether better-informed educators make a difference to how children with ABI feel about school.

The study is being carried out by Louise Hawkley, a PhD candidate at Plymouth Marjon University. Louise is also a neurological rehabilitation case manager and has worked with children and families affected by brain injury for many years.

Could my child take part?

Your child may be eligible to take part if they:

- are aged 11 to 16 and currently attend a mainstream secondary school in England
- have a confirmed acquired brain injury (this includes traumatic brain injury, stroke, brain tumour, meningitis, or any other cause)
- have English as their first language

Your child may not be eligible if they have another diagnosis, such as autism or a significant learning difficulty, where that condition rather than the brain injury is the main explanation for any difficulties at school. If you are unsure, please get in touch and we can discuss it.

What would taking part involve?

If you and your child decide to take part, here is what happens:

1. **Your child completes a short questionnaire about how they are getting on at school.**

   This takes about 15 minutes and is done online. We will be available throughout to answer any questions. You would need to be at home during this session.

2. **You complete two questionnaires about your child.**

   As a parent or guardian, you will be asked to complete two short questionnaires at the start of the study. One asks about your child's communication and language (how they understand and use language day to day). The other asks about how your child responds to sensory information,

such as noise, light, or touch. Both can be completed online or on paper, in your own time. They take around 20 to 30 minutes in total.

3. **The school shares your child's attainment information.**
   As part of the study, we ask the school to share information about your child's academic progress. This is a required part of participation and is handled through a formal data-sharing agreement between the school and Plymouth Marjon University. Your child's information is kept confidential and is not shared beyond the research team.

4. **Your child's teachers and school staff receive the free training.**
   The training is a one-hour online programme about acquired brain injury, designed specifically for secondary schools. It is delivered to school staff, not to your child. Your school needs to agree to participate for this to happen.

5. **Your child completes the questionnaire again.**
   A short follow-up questionnaire (about 15 minutes) is completed after the training, so we can see whether anything has changed.

6. **Your child takes part in a small online focus group.**
   Up to five young people discuss their experience of school in an online session (via Microsoft Teams) lasting about an hour. Your child can join using a made-up name (no real name or account is needed). You would need to be at home throughout this session.

Your child's agreement matters

Before anything begins, your child will be invited to watch a short video about their rights as a research participant. We ask that you watch it together so you can talk through any questions they have. After that, if your child wishes to take part, they will complete an assent form in their own right. Your child's agreement, alongside yours, is required throughout the study.

What does my family get from taking part?

Taking part does not provide individual clinical assessments or recommendations for your child. The questionnaires are research instruments and the scores will not be fed back to the school. The direct benefit is that your child's school receives free, specialist training on brain injury at no cost. The wider benefit is that this research may help schools across England to better understand and support children with ABI in the future.

Privacy and confidentiality

All information is kept confidential and stored securely on Plymouth Marjon University's systems. Your child is never identified by name in any research output. Focus group participants use pseudonyms. There is one important exception: if anything shared during the research raises a safeguarding concern, this will be

passed on to the appropriate people. You and your child will be reminded of this at the start of each session.

You do not have to take part

Participation is completely voluntary. You can withdraw at any point during the study and for up to four weeks after your child's final session, without giving a reason. After that point, data will be anonymised and individual contributions cannot be removed. Declining will have no effect on any existing relationship with Louise Hawkley or Hawkley Rehab.

Interested, or want to find out more?

If you think your child may be eligible and you would like to know more, please get in touch. There is no commitment to taking part by making contact.

Email: Hawkley.L@pgr.marjon.ac.uk

If you agree to take part, you will be sent a full participant information sheet and a consent form before anything begins. You will also receive a copy of the child assent form for your child to read and complete.

This study has ethical approval from Plymouth Marjon University's Research Ethics Committee (reference EP294). Researcher: Louise Hawkley, Plymouth Marjon University. Supervisors: Jonathan Harvey and Dr James Tonks (Haven Psychology). Contact for ethics queries: ethicspanel@marjon.ac.uk