

## **What are the needs and educational support requirements for children with brain tumours on their return to school and throughout education?**

### **Participant Information Sheet (PIS)**

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being conducted and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

### **About the Research**

#### **Who will conduct the research?**

Katie Egan, Trainee Educational Psychologist, Doctorate in Educational and Child Psychology, University of Manchester.

Academic Supervisor: Prof Caroline Bond, Ellen Wilkinson Building, Oxford Road, University of Manchester.

#### **What is the purpose of the research?**

This research is being carried out as part of the Doctorate in Education and Child Psychology at the University of Manchester. The purpose of this research is to understand the needs and educational support requirements for children with brain tumours. We are keen to hear your experiences and views. Taking part in this research may help develop effective approaches and resources for schools to support children with brain tumours on return to school and throughout their time in education.

#### **Why have I been chosen?**

You are an education or health care professional who has experience supporting children with brain tumours on their return to school and / or throughout education.

#### **Who has reviewed the research project?**

This project has been reviewed by the University of Manchester's Research Ethics Committee.

#### **Will the outcomes of the research be published?**

The findings of this research will contribute to the Trainee's research product to fulfil the requirements of the Doctorate in Educational and Child Psychology Programme at University of Manchester. The data may be used to inform future research or may be published in a psychology journal.

## **What would my involvement be?**

### **What would I be asked to do if I took part?**

You would be asked to take part in a focus group with the researcher and other education and health care professionals via Zoom.

### **What is the duration of the research?**

The research will take between 60-90 minutes.

### **Where will the research be conducted?**

The research will take place virtually at a time and date that is convenient to you and the other participants at the end of March / start of April.

## **Data Protection and Confidentiality**

### **What will happen to my personal information?**

In order to undertake the research project we will need to collect the following personal information/data about you:

- Your role within your service
- Your first name
- An email address to contact you
- An audio recording of the focus group, which will be transcribed, anonymised and used to establish key themes and ideas.

Only the research team will have access to this information.

We are collecting and storing this personal information in accordance with the General Data Protection Regulation (GDPR) and Data Protection Act 2018 which legislate to protect your personal information. The legal basis upon which we are using your personal information is “public interest task” and “for research purposes” if sensitive information is collected. For more information about the way we process your personal information and comply with data protection law please see our [Privacy Notice for Research Participants](#).

The University of Manchester, as Data Controller for this project, takes responsibility for the protection of the personal information that this study is collecting about you. In order to comply with the legal obligations to protect your personal data the University has safeguards in place such as policies and procedures. All researchers are appropriately trained and your data will be looked after in the following way:

The study team at the University of Manchester will have access to your personal identifiable information, that is data which could identify you, but they will anonymise it within a month of the interview taking place. However your consent form and contact details will be retained for 5 years. Audio data will be transferred to the University within the audio recorder. All data will then be stored on the P drive within the university, which is a secure, encrypted drive. Once transcribed, the audio recording will be deleted, and the transcription will be saved on the encrypted drive.

## **What are my rights in relation to the information you will collect about me?**

You have a number of rights under data protection law regarding your personal information. For example you can request a copy of the information we hold about you, including audio recordings. This is known as a Subject Access Request. If you would like to know more about your different rights, please consult our [privacy notice for research](#) and if you wish to contact us about your data protection rights, please email [dataprotection@manchester.ac.uk](mailto:dataprotection@manchester.ac.uk) or write to The Information Governance Office, Christie Building, University of Manchester, Oxford Road, M13 9PL. at the University and we will guide you through the process of exercising your rights. You also have a right to complain to the [Information Commissioner's Office](#), Tel 0303 123 1113

## **Will my participation in the study be confidential?**

Your participation in the study will be kept confidential to the study team and those with access to your personal information as listed above. Audio recording will be used to create transcripts by the researcher. All personal information, such as your name and your organisation's name will be anonymised within the transcript. The audio recording will then be deleted, and the transcription will be kept for up to 5 years on the encrypted drive. Only those within the research team will have access to this data.

## **What happens if I do not want to take part or if I change my mind?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised and forms part of the dataset as we will not be able to identify your specific data. This does not affect your data protection rights. Consent for audio recording is essential for participation within this research; however you are free to terminate your participation in the focus group at any point.

## **Contact for further information**

If something goes wrong please contact:

Katie Egan (Trainee Educational Psychologist)

School of Environment, Education and Development, Ellen Wilkinson Building, Oxford Road, University of Manchester.

Email: [katie.egan@postgrad.manchester.ac.uk](mailto:katie.egan@postgrad.manchester.ac.uk)

## **Minor Complaints**

If you have a minor complaint then you need to contact the researcher(s) in the first instance:

My email: [katie.egan@postgrad.manchester.ac.uk](mailto:katie.egan@postgrad.manchester.ac.uk)

My supervisor's email: [caroline.bond@manchester.ac.uk](mailto:caroline.bond@manchester.ac.uk)

## **Formal Complaints**

**If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact:**

The Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: [research.complaints@manchester.ac.uk](mailto:research.complaints@manchester.ac.uk), or by telephoning 0161 275 2674.

## **What Do I Do Now?**

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s):

**Katie Egan (Trainee Educational Psychologist)**

**School of Environment, Education and Development, Ellen Wilkinson Building, Oxford Road, University of Manchester.**

**Email: [katie.egan@postgrad.manchester.ac.uk](mailto:katie.egan@postgrad.manchester.ac.uk)**