



# THE COMBAT PROJECT

Core post operative morbidity set for paediatric brain tumours

Information sheet for children aged 8-11yrs participating in survey



Hello! My name is Sandhya. I'm a doctor. I work at a hospital called Alder Hey Children's Hospital in Liverpool.

I am doing a project. It is to make a list of the most important changes that happen after head surgery in children.



I would like to ask for your help to do this. This leaflet will help you decide if you want to!

## What is the project about?

A project can help us solve a problem. This is so we can make things better.



Surgery can help children if they are ill. It can sometimes lead to changes that you didn't want. You might not be able to do the same things as your friends or family. These changes are called 'unwanted outcomes'. They can make you feel sad or angry.

We want to know how you felt after your surgery. Did any changes happen to you? Which ones were most important? We need to know this so we can make things better for other children like you. It will help us to make new treatments better.

We need to make a list of the most important changes. To do this we need to know what you think. We hope you can help us to do this!



## Why have you asked me to take part?

When you were ill you had surgery. This was to make you feel better. How did you feel after it? Were there any changes?

You know what changes that happened to you that you didn't want. You are the best person to tell us about this!

## What will happen if I take part?

If you take part I will ask you to answer some questions. This will be in a survey.



If you have any questions we can have a meeting to answer them. It will be a chance to say hello, for you to ask me any questions you have, and to check that you are happy to take part. You can have your parent or carer with you when we meet.

When you are ready to take part I will send you the questions to answer. You can answer them by yourself, or with your parent or carer. The survey will be on the computer. It will have two parts. If you have any problems I can help you.

I will ask lots of different groups of people to answer the same questions. This includes children like you and their parents or carers. We will also ask people who look after children like you to answer the questions. This includes different types of doctors, nurses and therapists.

We have made a short video that you can watch here: [www.thecombatproject.org](http://www.thecombatproject.org)

### Survey 1



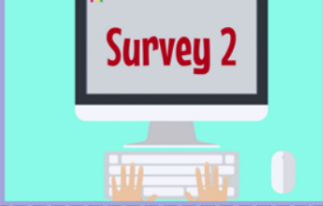
At the start we will ask you to fill in a form. It says you understand what will happen and that you are happy to take part.

We will ask you to answer the questions for the first time. We will ask you to tell us how important each item is for you. You can tell us by choosing a colour. Green means it is important to you. Red means it is not. It will take 30mins to complete the questions.

After everyone has finished the survey we will look at the results. We will send everyone a summary of the scores. You will also get a copy of your scores. No one else will know what your scores were.

We want you to look at the summary of what everyone has said. This is so you know what everyone thinks is important before Survey 2.

### Survey 2



We will ask you to fill out the same questions again. This is so we know if seeing the summary changes your mind. There are no right or wrong answers. You can change your score if you want or keep it the same.

We will ask you to tell us how important each item is for you. You can tell us by choosing a colour. Green means it is important to you. Red means it is not. It will take 30mins to complete the questions.

It is important you do both parts. This is so we know what is important to you.

### Do I have to take part?



No. If you don't want to take part if you don't want to. You can either tell your parent or carer and they will let me know, or you can tell me at our first meeting.

### Can I change my mind?

Yes! You can say yes now and then change your mind later, at any time in the project. You can tell your parent or carer, or you can let me know. You don't have to give a reason why you want to stop taking part.

### Will this project help me?



Taking part in this project will not change things for you. It will help other children like you in the future. We hope you will like helping us.

### Will anything bad happen if I take part?

Talking about when you were ill can be hard. It might make you feel sad. You can stop at anytime if you need to.

### Will you tell anyone else what I've said?



Only I will know what you've said. I will keep everything that you say safe and private. That means that I won't share it with anyone else.

I will need some details about you and when you were ill. I will ask your parent or carer about this. I will only use it in this project.

I will give you a special code number when you join. This is so when we talk about what you said, no one will know it was you. I won't use your name. The only time I might tell someone what you said is if we are worried about whether you are ok or not.

I will follow strict rules about the information you give me. If you want to know more about these rules you can find out more in a short video here:

<https://www.youtube.com/watch?v=Vll6V1MgZgY>

### **What happens after the project?**

This survey is the second part of this project!

I will look at what you, and everyone else have said. I will use this information to make a list of the most important unwanted outcomes.

At the end of survey we will ask some people to come to a meeting. This will be to discuss the results. It will help us decide what to include on our list.

Only a few people will come to the meeting. If you want to come then let us know by answering the question at the end of Survey 2.

I will let you know how the project is going. I will write a report. I will share this report with everyone who helped us with the project.

### **Who has checked that the project is safe?**

It has been checked by a group of people called a Research Ethics Committee. It is their job to check that the project is safe.



### **Where can I learn more?**

You can contact me, Sandhya, if you have any questions. You might also like to talk to your parent, carer or a friend about the project.

### **What are the next steps?**

If you want to take part, or have any questions let your parent or carer know. They can let us know! When we meet we can answer your questions.



Thank you for reading about our project!