



# THE COMBAT PROJECT

Core post operative morbidity set for paediatric brain tumours

Information sheet for children aged 12-15yrs 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 unwanted 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 is something that aims to solve a problem. This is so we can make things better.



Surgery can help children get better when they are ill. Sometimes it can make you feel different afterwards. This includes both good things and things that aren't so good. These things are called 'outcomes'.

The things that aren't so good are called 'unwanted outcomes'. You may find that you can't do things that you could do before the surgery, or the same things as your friends or family. This can sometimes get better over time. Sometimes it can change how you feel or things you can do for a long time.

It is important that we know what unwanted outcomes are important to you. This is so we can make a list of the most important unwanted outcomes. All treatments and research will have to tell us how likely these outcomes are to happen. This is so we can tell children like you what to expect after surgery. It will also help us make sure children are getting the best treatment.

## Why have you asked me to take part?



We would like you to take part in this project because you had an operation. The aim of this operation was to make you feel better.

Because you are the one who had the operation you are the BEST person to tell us what it felt like.

We want to speak to you about how you felt after your operation.

## 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.

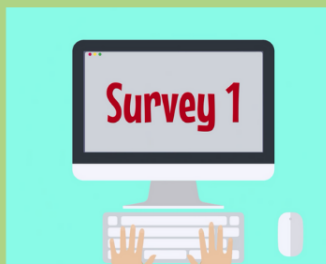
If you have any questions we can have a meeting to answer them. It will be a chance to say hello, for you to ask me any questions you have, and to check that you are happy to take part. You can have your parent or carer with you when we meet.



If you agree to take part we will send your parent/guardian details on how to do the survey. There are two surveys to complete in total. They shouldn't take longer than 30 minutes. You can do the survey by yourself or with your parent/guardian. We will send you and your parent/guardian clear instructions about how to complete the survey.

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)



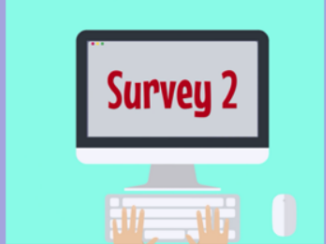
### **Survey 1**

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 or a number on a scale. 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 before you do Survey 2. 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 or a number on a scale. It will take 30mins to complete the questions.

It is very important that you fill out both surveys. By doing this we will know what outcomes are the most 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 write a report to let you know how the project is going. 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 and your parent or carer 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!**