Web Version

PARTICIPANT INFORMATION BOOKLET (Child)
BEAT CF Platform

INTRODUCTION

We are doing a research project called BEAT CF because we want to find the best medicine to give you when you get sick from a lung infection. We are inviting you (with your parent's permission) to be added to our "Platform", which is basically a big computer database. We will be collecting lots of information about you so we can find out what medicines might work better for you and other kids with CF.

This Information Booklet tells you about the BEAT CF Platform. Please read this information carefully and ask your parent or an adult if you don't understand.

WHO IS DOING THE RESEARCH?

We are scientists, doctors and nurses from the University of Sydney. Because this is a big project we have help from other doctors, nurses and scientists across Australia.
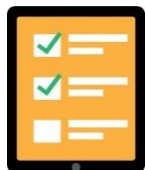
DO I HAVE TO BE INVOLVED IN BEAT CF?

If you do not want to be in this study, you do not have to. If you decide you want to and later change your mind, you can let your parent know or you can tell our BEAT CF nurse at any time.

WHY ARE WE DOING BEAT CF?

Some people with cystic fibrosis (CF) can get sick when they get an infection in their lungs. When this happens, they need to go to a doctor to get medicine to help fight the bugs in their lungs. We want to collect information to find out what medicines are usually given and how people get better after taking the medicine. We hope that we can use this information for the future BEAT CF trial because we want to give the best medicine (like antibiotics) to people when they get sick.

Treatments – we will look at what medicine your doctor gives you and what physiotherapy you get in hospital

Outcomes – we will look at the results of your blood tests or your mucus (if there are bugs in there), and any lung tests you do (where you blow into the tube as hard as you can). We will also ask you (or your parent) to answer some questions on a phone or computer when you are feeling well and every week when you are sick with a lung infection.

WHAT DO I NEED TO DO?

If you are involved in the study, your parent will give us permission to:

- collect information about you (like your birthdate)

- look at your test results (like your blood tests)

- look at what the doctors decide to do when you are sick. For example, whether you stay in hospital and what medicine you are given

- ask you some questions like how you are feeling and whether you have a cough. Your parent can help you answer these questions on their phone or computer.

You will not need to get any extra tests done. We are only collecting information on the tests you normally get.

WHERE WILL YOU STORE THIS INFORMATION?

All the information we collect about you will be safely stored in the BEAT CF Platform which is on a locked computer. Only the BEAT CF researchers can see it. We will also make it hard to tell that the information is yours by giving you a number instead of using your name.

WILL BEING INVOLVED HELP ME?

Being involved in the BEAT CF Platform might not help you right now but it might help you and other kids with CF in the future by helping us understand what doctors do when people get sick. This will also help the researchers to design the BEAT CF clinical trial where they will be testing different medicines to see which one works the best.

SHOULD I BE WORRIED ABOUT ANYTHING?

No. The worst thing that could happen is that people could break into our computer, but we have made it very hard for them to do this.

DO I NEED TO BE INVOLVED IN THE FUTURE STUDY WHICH IS TESTING MEDICINES?

Only if you want to be. We will ask you (and your parent) if you want to be involved in clinical trials when they are ready to start. At this stage, we are only asking you to be in the BEAT CF Platform which is just collecting your information.

ANY QUESTIONS?

If you have more questions, you can ask:

- Your parents

- A doctor or nurse at your hospital

CONTACT

Site Investigator

Study Team