

UK Cystic Fibrosis Registry

Information for patients aged 6 to 12 years

You are being invited to take part in a project to collect information about people who have cystic fibrosis. You are being invited to take part because you have cystic fibrosis. Before you decide whether to take part, it is important that you and your parents understand why this project is taking place and what it will involve.



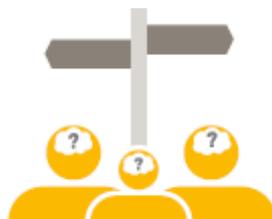
Why do you want to collect information about me?

Cystic Fibrosis (CF) is a very complicated condition. If we collect lots of information about you and other people with CF, doctors will be able to learn more about it and they may be able to help make it better in the future. We will store the information on a special computer system called the 'UK CF Registry'.



Do I have to take part?

No. It is up to you and your parents whether or not you decide to take part in the UK CF Registry. You do not have to say yes.



Can I change my mind later?

Yes. If at any time you decide you don't want to take part any more, just tell your parents or your doctor or a nurse. They will not be cross with you.

What do I have to do if I take part?

You don't have to do anything different if you take part. When you come to the hospital or when we visit you at home, we will write down your medical details as we do normally. Afterwards, people who work in your cystic fibrosis care team will put the data onto the CF Registry computer system.

Will anyone else see my medical details if I take part?

The only people who will see your medical details are your doctors and nurses and the people who are working on this project. They will not give your details to anyone else. Information that is given out does not include your name, so it can't be used to find out who you are.