Cystic Fibrosis Trust

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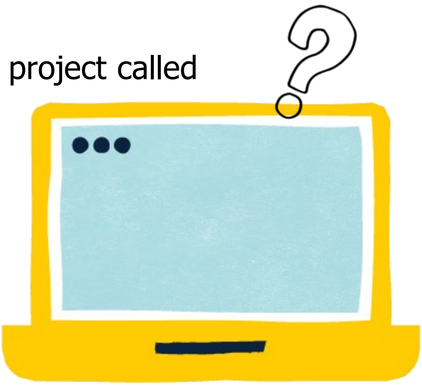
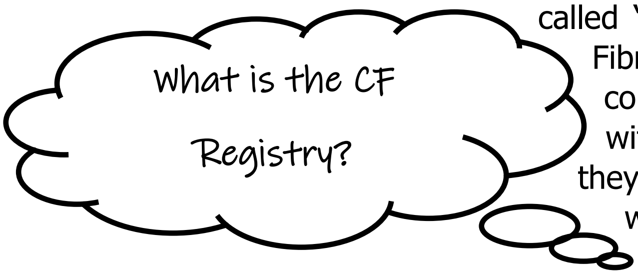
UK Cystic Fibrosis Registry

Information for children aged 6 to 12 years

We are asking if you and your family would like to take part in a project called a ‘Registry’. This leaflet will tell you a little bit about it. If you don’t understand anything, please ask a trusted adult to talk about it with you. You can say no if you want to.



The CF Registry collects information about people who have been told by their doctors and nurses they have something called ‘cystic fibrosis’. 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’.



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.

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.

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What will happen 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 UK CF Registry computer system.

You won't have to have any extra tests or hospital visits if you take part.

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.

Some information about you will be shared with others to help learn more about CF and how we can help everyone with CF now and in the future. Information that is given out does not include your name, so it can't be used to find out who you are.

If you have any more questions, talk to your mum, dad, carer or other grown up you trust. The doctors and nurses looking after you can also help you find out more about