INFORMATION SHEET FOR CHILDREN aged 10-16 years

Exploring perceptions on the proposed cystic fibrosis (CF) screening protocol incorporating next generation sequencing (NGS)
IRAS: 307623

Who are we?

- We are a team of researchers (investigators) in England based at Universities, a hospital and the CF Trust.

What is our study about?

- You may already know that cystic fibrosis is caused by a faulty gene that affects the movement of salt and water in and out of cells. There are more than 2000 known faulty genes that can cause CF.
- You may also know that CF is normally diagnosed through a process called 'newborn bloodspot screening' – we will call this screening from now on. This process involves asking parents if a small amount of blood can be taken from their baby's heel when the baby is about 5 days old to test for some rare conditions including CF. At the moment, screening only tests for a small number of all the possible faulty genes that can cause CF.
- We would like to speak to a range of different people; we are asking you if you would be willing to speak to us as you are either:
    - A child with CF **OR**
    - A child who is a carrier of one of the faulty CF genes **OR**
    - A child who has been told they have something called CF screen positive, inconclusive diagnosis
- We would like to find out what you think of using something called 'next generation sequencing' or NGS as part of the screening process. NGS would mean it is possible to test for many more of the faulty genes that can cause CF than the current screening process.
- Hearing the views of lots of different people will provide important information about whether or not NGS should be used as part of screening for CF.

What does the study involve?

- If you decide to join our study you will ask you to take part in an interview (a chat) online with one of the researchers. We will ask you about your experiences of finding out about your CF status and also your opinions about using NGS as part of screening for CF. This should take about 30-45 minutes. You will receive a one off £20 voucher after the interview.

What will we do with the answers to our questions?

- Any answers you provide to the questions we ask will be kept safe and secure with us. We may use some of the things you have said when we write up our results but we will not share your name or any other details that might tell other people who you are when doing this. The only other time we would tell someone what you have said is if we were worried about your safety.
- At the end of the study, if you tell us we can contact you, we will tell you what we found.

Do I have to take part?

- No, it is up to you. Speak with your parent or carer about taking part in this study, and maybe other grown-ups you trust. You can also contact us if you have any questions
- If you decide that you would like to take part, please let your parents know and they can tell us. Also, below there is a form for you to sign if you would like to take part.
- If you do not want to take part, let your parents or carers know and they can tell us. Even if you decide to take part, you can stop at any time without telling us why.

Put a tick by the answer you want:

Yes, I want to take part in the study. ☐

No, I do not want to take part in the study. ☐

Your name: _____

Date: _____

For more information, please contact: Jane Chudleigh, jane.2.chudleigh@kcl.ac.uk or pru.holder@kcl.ac.uk