

The use of CFTR modulators and gut symptoms in Cystic Fibrosis

1. What is the purpose of the survey?

Gut symptoms in Cystic Fibrosis such as bloating, pain and sickness are common for people with Cystic Fibrosis (pwCF). Through a previous survey in 2018 we asked pwCF to tell us more about their gut symptoms to better understand the research priority question “How can we relieve gastro-intestinal symptoms, such as stomach pain, bloating and nausea in people with Cystic Fibrosis?” PwCF previously told us that these symptoms can be embarrassing and disruptive to everyday life with 2 in every 3 people missing either school or work because of them.

Since then, there has been a change in the landscape in the treatment of cystic fibrosis (CF) with the introduction of modulator therapy, which targets the faulty gene in CF rather than treating the symptoms. This has resulted in improvements in the respiratory function and symptoms for pwCF, but the effect on the gut is less well understood. The purpose of this survey is to better understand peoples experience of gut symptoms since starting on modulators and whether they have noticed any improvements or worsening of their bowel symptoms.

The results of this survey will also contribute to a wider body of work through the research study “CARDS-CF” which aims to develop a scoring system called a 'patient reported outcome measure'. This patient reported outcome measure will be used in the future by researchers in clinical trials to better assess gut symptoms in CF and the impact that they have on daily life as well as the effects treatments have on these.

2. Who can complete the survey?

- If you're a person with Cystic Fibrosis, have a friend or family member with CF or a healthcare professional caring for people with CF, please help us by taking part in our survey and answering the questions as honestly as you can.
- We would like to hear the views both of people who have and haven't taken a CFTR modulator.
- The survey is voluntary and completely anonymous which means you won't be identified from the answers you provide.
- If you are under the age of 16, please get the permission of a parent/ guardian before filling in the survey.
- If you leave your contact details for further information about related research activities such as being involved in other research related to the CARDS-CF research project or receiving a summary of the survey results this will be separated from your survey answers before your answers are looked at.

3. What will happen to my data?

All the information you give as part of the survey will be kept confidential by the University of Nottingham. We will keep all information you give safe and secure. The option to share personal data such as contact details are collected to share with you the survey results and

to let you know about further research opportunities relating to the research project CARDS-CF. We will not share your personal details with anyone else outside the study team and these will be destroyed at the end of the study. The data controller for the study in the University of Nottingham. They will store your answers securely for at least 7 years after the study finishes. After this, data will be destroyed confidentially.

By completing the survey, you are giving consent that the answers you give will be included within the study. Once you have submitted your survey answers you cannot withdraw this information. Your answers will remain on file and will be included as part of the survey analysis.

You can find out more about how we use your information:

- <https://www.nottingham.ac.uk/utilities/privacy.aspx>