

A Comprehensive Approach To Relief Of Digestive Symptoms In Cystic Fibrosis (CARDS-CF) research study.

Recording gut symptom burden: A survey

To access the survey please scan the QR code or visit:

<https://www.surveymonkey.co.uk/r/CARDSCFresearch>



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). 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. We want to better understand how these symptoms impact on the daily of pwCF.

We are developing a scoring system called a 'patient reported outcome measure' that will allow pwCF to record their gut symptoms. When the scoring system is finished, we will ask pwCF to test it by using it to record gut symptoms on a smartphone app, every day, for two weeks. This patient reported outcome measure can be used in the future by researchers to better assess gut symptoms in Cystic Fibrosis (CF) and the impact that they have on daily life.

To help us develop questions for our scoring system we have brought together evidence from previous studies and have talked to pwCF about their experiences. They have helped us to create a list of possible questions which we may include in our final scoring system.

This survey will help us to decide which are the best questions to use.

2. Who can complete the survey?

- If you're a person with Cystic Fibrosis aged 12 years or over please help us by taking part in our survey and answering the questions as honestly as you can.
- The survey is voluntary and completely anonymous which means you won't be identified from the answers you provide.
- If you leave your contact details for further information about related research activities such as trialing our patient reported outcome measure in the future or receiving the study 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. Personal data such as contact details are collected to let you know

when we are trialling our scoring system in the app, or to share the study results. We will not share these with anyone else outside the study team.

The Sponsor and data controller for the study is Nottingham University Hospitals NHS Trust. They will store your answers securely for at least 5 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:

- our GDPR leaflet available on request from researchsponsor@nuh.nhs.uk; or by the following link www.nuh.nhs.uk/gdpr
- <https://www.nottingham.ac.uk/utilities/privacy.aspx>

[If you need help with any aspect of your CF please contact your usual CF care centre. There is also additional support available online through the CF Trust \(UK, <https://www.cysticfibrosis.org.uk/the-work-we-do/support-available>\) or CF Foundation \(US, <https://www.cff.org/support>\)](#)

Many thanks

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