

## The MoreLife with CF study



People with CF (PwCF) have been advised to eat a high calorie diet. This diet has helped them to become well-nourished and live longer. However, some PwCF have gained weight. This is because new treatments called Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) therapies are helping to treat CF, and reducing the need for a high calorie diet. As a result, some PwCF now need a diet lower in calories and become more active. This will help PwCF to adopt a healthy lifestyle and reduce the risk of developing additional health problems.

### What are we going to do ?

This study aims to co-design and test a programme with people living with CF, to support them to eat a healthy diet and become more active. It will be codesigned to be combined with an existing NHS weight management programme – called MoreLife. We will test the programme, to see if the CF programme used alongside an NHS weight loss programme is more acceptable to PwCF, compared to using an NHS weight loss programme only.

The study will have 3 stages ;

**Stage 1 – Planning the Programme** – we will aim to find out what PwCF eat and how active they are. We will also ask them about what influences their eating and activity and their experience of these since taking CFTR modulator therapy.

**Stage 2 – Co-designing the Programme with PwCF.** A group of PwCF, CF Health Care Professionals and weight loss experts will work together to design the CF programme.

**Stage 3 – Testing the Programme** The CF programme will be tested by a group of PwCF who are overweight and taking CFTR therapies. One group of 15 will be asked to use the CF programme as well as an NHS weight loss programme for 12 weeks (CF PROGRAMME+NHS MoreLife ). Another group of 15 people will be asked to use the NHS weight loss programme on its own for 12 weeks (NHS only).

Jo Barrett, CF Dietitian has been awarded NIHR (National Institute for Health and Care) Doctoral Fellowship. Jo's fellowship research will explore the eating habits and physical activity of people with CF who are taking CFTR modulator therapies and their experience of weight gain. This information will be used to co-design a weight management programme with people living with CF and this programme will then be tested.

Jo is seeking people with CF to work with her in making shared decisions on all aspects of this research project by joining the MoreLife with CF advisory group

### What is the MoreLife with CF patient advisory group?

The MoreLife with CF patient advisory group are a group of people who have lived experience of CF. They will work with Jo Barrett, CF Dietitian and Lead Researcher influencing how the research is done, contributing to the writing of participant information, feeding back views on the research findings and how these should be used to influence CF treatments and how this is communicated to patients and the public.

### **Who can apply to be a member of the More Life with CF Advisory Group?**

Anyone living with CF who attends the West Midlands and Sheffield Adult CF Centres can apply to be a member of the MoreLife with CF advisory group. Ideally, we are seeking people with CF who have unwanted weight gain due to CFTR modulators.

No prior experience is necessary, you will already be a 'expert' in CF. Further training, as required, can be undertaken while fulfilling the role.

### **What will I have to do**

As a member of the group, you will be invited to virtual meetings, comment on documents or just answer some quick questions. Jo will ask for your feedback and opinions on all aspects of the research and the groups feedback and opinions will be used to inform how the research is carried out.

### **What will be paid**

You will be paid for your time to attend meetings, any preparation time for the meetings and for your time to read and comment on any documents.

### **What difference this will make**

Being involved in undertaking this research will help us to understand the lived experience of people living cystic fibrosis from different background. Your involvement will be important to ensure this research is relevant for people with CF and is beneficial for helping them to manage their health.

If you would like to be involved or to find out more, please, contact: Joanne Barrett on 0121 424 41788 or email [joanne.barrett2@nhs.net](mailto:joanne.barrett2@nhs.net)

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