

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 are now becoming overweight. 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, PwCF now need to adopt a diet lower in calories and become more active. This will help them to avoid becoming overweight and developing additional health problems such as heart disease, diabetes, and cancer.

What are we going to do ?

This study aims to co-design and test a CF-specific programme (CF PROGRAMME) with PwCF, to support them to eat a diet lower in calories and become more active. It will be co-designed to be combined with an existing NHS weight loss programme. 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 group). Another group of 15 people will be asked to use the NHS weight loss programme on its own for 12 weeks (NHS only).