

Lay Summary of Results: The More Life with CF Study

The More Life with CF Study explored the diet and physical activity habits of people living with cystic fibrosis (PwCF) who also have overweight or obesity and how they manage their weight. The aim was to understand their real-life experiences so we can design a weight management programme that truly meets their needs.

What we did

We spoke to adults living with CF who were also living with overweight or obesity. We asked them to:

- Complete a 4 day food diary
- Wear a physical activity monitor for two weeks
- Take part in an interview about their experiences of diet, physical activity, and weight management

This helped us understand both what people *say* about their diet and physical activity habits and what they *actually do* day-to-day.

What we learned

1. Weight gain after new CF treatments

Many people told us that gaining weight—especially after starting treatments like **Kaftrio®**—was unexpected and difficult to manage.

They were used to eating high-calorie foods and snacks for most of their lives, so switching to a healthier diet felt like a big adjustment.

2. Diet patterns

Food diaries showed that the diets of PwCF are **very similar to the general UK population**, but with some key differences:

- **Higher sugar intake**, especially from cakes, biscuits, sweets, and snacks
- **Lower fruit and vegetable intake**
- A large amount of calories came from **dairy products and milky drinks**

3. Physical activity

Activity monitors showed that PwCF:

- Have **similar overall activity levels** to people without CF
- But often do **less activity that gets them out of breath**, which is important for fitness and health

What helped PwCF eat well and stay active

Participants said they were more able to make healthy changes when they had:

- Support and advice from their **CF Team**

- Opportunities to be active with **friends or family**
- A sense of being **ready** to make changes
- Diet strategies that helped them manage **diabetes or bowel symptoms**

What made healthy changes difficult

People also described several barriers, including:

- **Lack of time** due to busy lives
- **Health issues**, such as musculoskeletal pain or low mood
- Difficulty breaking long-standing habits of eating high-calorie foods
- Not knowing **which dietary changes** were right for them
- Not enjoying exercise or feeling uncomfortable getting out of breath

Why PwCF wanted to manage their weight

Participants were motivated by:

- Concerns about **body image**
- Wanting to protect their **future health**
- Benefits for **physical and mental wellbeing**
- Being a **healthy role model** for their children
- Managing **diabetes and bowel symptoms** more effectively

What's next

The findings from this study will now be used to **co-design a weight management programme for PwCF, with PwCF**.

This means people with lived experience will help shape the content, format, and delivery of the programme to ensure it is realistic, supportive, and tailored to their needs.