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ReDIRECT

Remote Diet Intervention to
REduce long COVID symptoms Trial

Public and Patient Involvement in a trial of remotely delivered weight management trial for people with Long Covid (ReDIRECT)

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**WORLD
CHANGING
GLASGOW**



**LONG COVID
SCOTLAND**

THE TIMES
THE SUNDAY TIMES
**GOOD
UNIVERSITY
GUIDE
2018**
SCOTTISH
UNIVERSITY
OF THE YEAR



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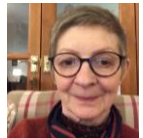
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Aims

- 1 To rapidly adapt and implement a remotely delivered supported weight management programme for people with Long COVID with personalised improvement goals
- 2 To determine the effectiveness and cost-effectiveness of this intervention

SUPPORTED BY

NIHR

National Institute
for Health Research



University
of Glasgow



LONG COVID
SCOTLAND

NHS
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Study Background

- People with Long COVID report frequently symptoms of fatigue, breathlessness, muscle aches, and joint pain.
- No established treatments for people with Long COVID.
- Links between weight, COVID: and Long COVID.
- Weight management programmes have helped reduce similar symptoms in other patient groups eg Diabetes.
- **Can a remote weight loss programme reduce or help manage symptoms for some people living with Long COVID?**

PPI – a central role



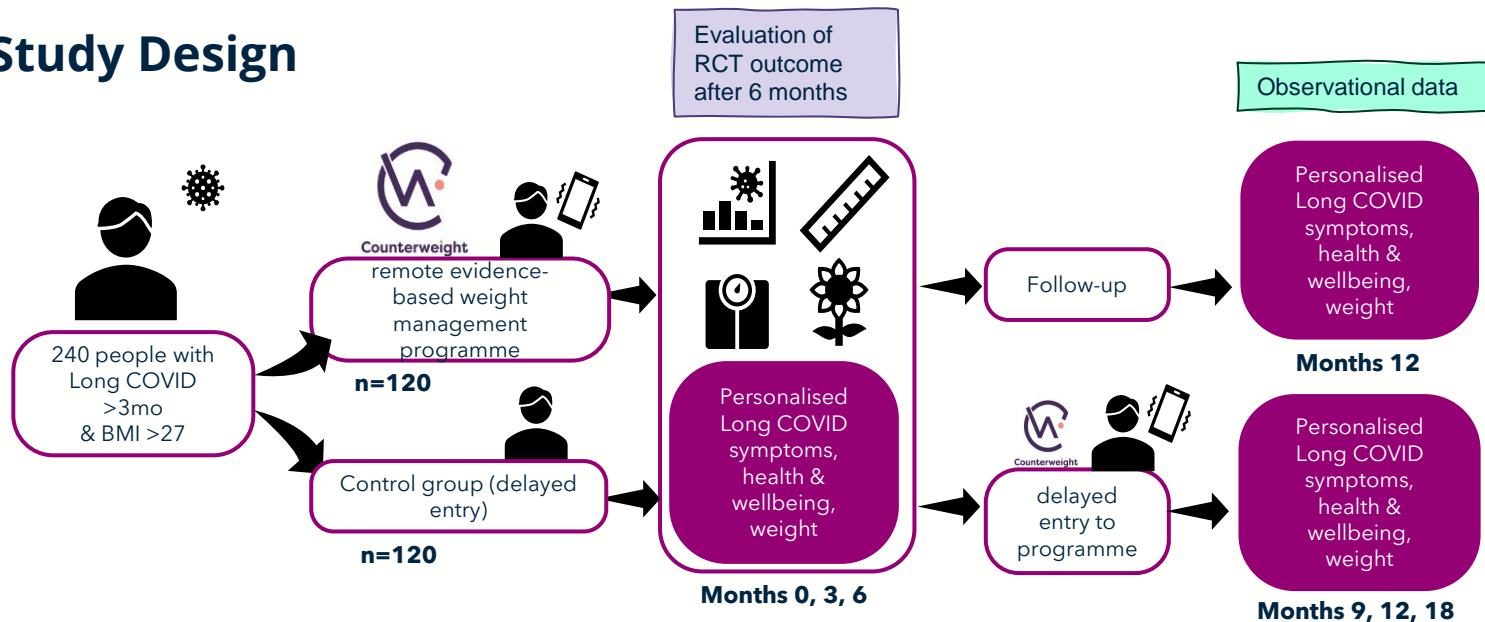
- As a new condition need to understand how people experienced Long COVID.
- Approached Patient Groups at an early stage (Long Covid Scotland, MVLS Long COVID PPI group).
- Establish strong PPI representation in study management, including **PPI lead** (Tracy Ibbotson), **Co-Investigator** (Jane Ormerod), Lived Experience member (Chris White) and PPI rep of Trial Steering Committee (Lesley Macniven).



PPI importance in shaping and delivering the study

- What symptoms were most important to participants with Long COVID? (shaping the novel approach to **personalised primary outcome**).
- How can we deliver a remote weight loss programme to people living with Long COVID ?
- Input in all areas of the study, on the **data collection**, **intervention adaptation**, **study materials** (e.g. website), **recruitment**, **analysis** and **dissemination** (including publications).
- Evaluation informed by the GRIPP2-SF

Study Design



- **Remote delivery** of all aspects (recruitment, diet intervention, self-reported data collection)
- Recruitment from across the UK between Dec 2021 and July 2022
- Baseline data represents whole study population (n = 234)

Weight management:

- Professionally supported and evidence-based
- Very low energy formula diet 8-12 weeks
- Food reintroduction
- Weight maintenance until end of 12 months

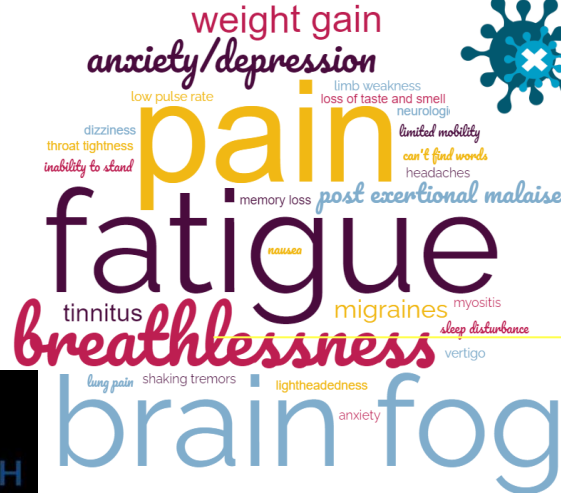
Data assessment:

- Primary outcome: Self-selected Long COVID symptom
- All non-selected Long COVID symptoms
- Body composition and health
- Demographics
- Quality of life
- Work productivity
- Healthcare utilisation
- Food expenditure

Raising awareness of Long COVID



LONG COVID SCOTLAND



It's really important for patients to be involved in the research

BBC Scotland



Public involvement had a huge impact on study design

Personalised primary outcome

Incentive for patients to take part in the study

Limited clinical knowledge of long COVID symptoms

The majority (55%) chose **Fatigue** as their dominant Long COVID symptom.

Weight management

Took into account Long COVID symptoms like brain fog

Flexible approach

Additional support resources eg Mental health

Social Media Criticism

Advice on plain language

Engage or withdraw?

Deterrent for future research
into Long COVID

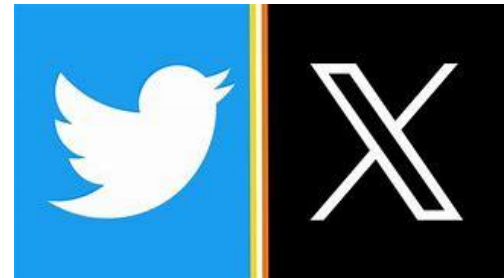
Challenge for safe public
scrutiny

What support can organisations
provide for patient groups ?

Lifestyle interventions for Long
COVID

Weight management
interventions for Long COVID

Personal attacks on researchers
and Long Covid Scotland





PPI Facilitators

- Increased **awareness of Long COVID symptoms** and patient groups.
- **Flexible remote programme** acceptable to patients with Long COVID
- Innovative approach to trial (**personalised**) **primary outcome** meaningful for patients with Long COVID.
- Involvement of **people with lived experience** of LC throughout.
- JO and CW **familiar with research** process



Barriers to PPI

- **Funding calls:** Concurrent funding calls for Long COVID research meant a lot of researchers looking for public involvement.
- **Involvement burden** of study: often complicated by LC-associated health problems (e.g. surgery for heart condition).
- **Social media criticism:** “I have Long COVID and I’m not overweight”.
- **Capturing the impact of PPI:** tracking the variety Long COVID PPI activities during the course of the study.
- **Timescales:** fastest we have ever dealt with!

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The views expressed in this publication are those of the author(s) and not necessarily those of NIHR or The Department of Health and Social Care.

- **Team and participants:**

Thanks to all the participants and to the study team.

