Methods of Measuring Strength in Cystic Fibrosis: Current Evidence and Stakeholder Perspectives

Nicola Hodgson[1,2], Physiotherapist, Cystic Fibrosis Unit

Nicola.Hodgson@mft.nhs.uk

NIHR | Applied Research Collaboration Greater Manchester

Rationale

Cystic fibrosis is a multisystem genetic condition that causes respiratory and digestive problems, along with reduced muscular strength due to altered CFTR gene expression, recurrent chest exacerbations, inflammation, low physical activity, hospital admissions, nutritional factors, and steroid use (Troosters et al., 2008).

In recent years, advances in medical care have led to an ageing cystic fibrosis population. As a result, age-related declines in muscle strength have become an increasing focus and appear to be more pronounced in people with cystic fibrosis (Figure 1) (Wilkinson et al., 2018; Troosters et al., 2008). Whole-body muscle strength is therefore of particular importance in this ageing population.

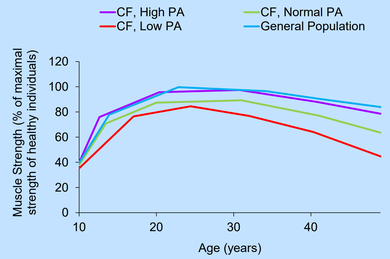


Figure 1. Hypothetical changes in muscle strength in people with cystic fibrosis (re-drawn from Gruet et al. (2021).

What are the implications of reduced whole-body muscle strength ?

A reduction in whole-body strength limits physical function, reduces quality of life, increases the risk of falls, contributes to greater morbidity and mortality, and leads to higher healthcare costs.

What is the problem?

- Whole-body strength is not routinely assessed in clinical practice, and no standardised method exists that is reliable, valid and feasible in people with cystic fibrosis.
- It's unknown how people with cystic fibrosis perceive strength assessments and their current experience.

Training

Table 1. Overview of formal and informal training

Formal	Informal
Scoping Review Training	Organisation skills
PPIE Workshops	Supervisory Team
Behaviour change course	Network/peer support
Clinimetrics Course: COSMIN	Resilience
Designing a communication plan	Understanding myself
Project management course	Practical PPIE experience
Introduction to R-studio	Navigating opinions

Scoping Review

To address *problem 1*, this study examined approaches to assessing muscle strength across diverse populations and settings through a scoping review with a systematic search design.

Aim: To review methods used to assess muscle strength in the literature.

Methods:

- A protocol was submitted to the Open Science Framework.
- Searches of PubMed, CINAHL Plus, Embase, and SPORTDiscus (Nov 24)
- Results were screened against eligibility criteria.
- Data extraction included strength construct, assessment method, population, setting, and country.

Key Results:

- A total of 2009 studies were included reflecting 68 countries and 251 unique settings, and 635 unique populations.
- Whole body assessments were rare with clinical populations (*n* = 3) but included the mid-thigh pull which was used 43 times in total (Figure 2).
- 1RM and hand grip test was most common in people with cystic fibrosis.
- Functional tests were also common.

Implications

- These findings suggest that strength assessments in people with cystic fibrosis are largely limited to single muscle group isometric or functional tests, while mid-thigh measurements may provide a practical means of evaluating whole-body muscle strength.

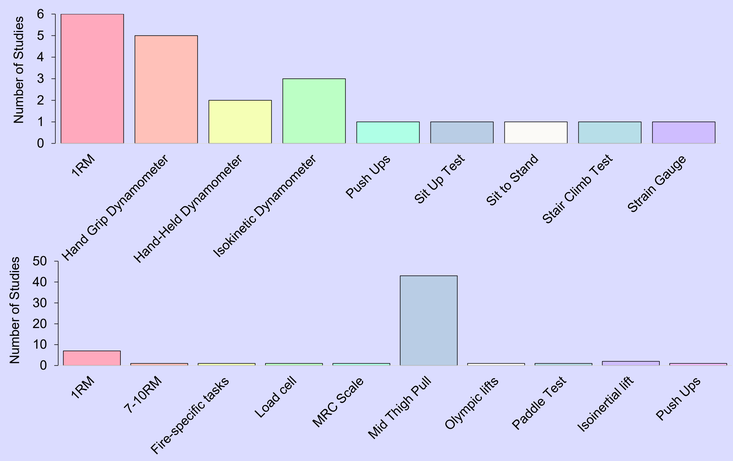


Figure 2. Example of the Shiny App being used to consolidate finding from the review for cystic fibrosis (top) and whole-body strength (bottom).

Patient and Public Involvement

Manchester Metropolitan University | MANCHESTER 1824 The University of Manchester | MACFC MANCHESTER ADULT CYSTIC FIBROSIS CENTRE

Patient and Public Involvement: Strength Testing in Cystic Fibrosis

NJ Hodgson[1], J Ventre[3], A Parchment[3] and P Goodwin[2]

[1]Manchester University NHS Foundation Trust
[2]Department of Health Professions, Manchester Metropolitan University.
[3]Allied Research Collaboration Greater Manchester, University of Manchester

Aim of Patient and Public Involvement:

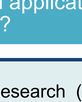
The aim was to understand the patient opinions and experience around muscle strength and testing via two discussion groups to inform future work to improve detection of muscle strength issues in this population group and to inform a PhD application.

Impact of Patient and Public Involvement

Topics	Outcome of discussion
Impact of new CF treatments on muscle strength	General agreement that muscle strength loss is a growing concern with increased life expectancy. Kaftrio impact: Some reported improved strength and stamina, while other felt no significant change Age-related decline: Many noted that muscle strength noticeably declined after age 40 or 60 years. Steroid use and comorbidities (e.g., diabetes, menopause) were identified as contributing to muscle weakness.
Personal experiences with muscle strength issues	Upper vs. lower body imbalance: Some reported strong legs but weak upper bodies, or vice versa. Functional limitations: Difficulty with daily tasks like lifting, gardening, or doing the stairs. Post-hospitalisation weakness: Significant muscle loss after inpatient stays. Exercise history: Those with consistent training routines noticed less decline.
Importance of muscle strength for the CF population	Strong consensus that muscle strength is important for quality of life, independence, and long-term health. Shift in priorities: From survival to thriving and maintaining function as people age. Preventative focus: Strength seen as key to avoiding future complications (e.g., falls, frailty).
Thoughts on muscle strength testing	Curiosity and openness to testing, especially if it's meaningful and actionable. Concerns about emotional impact: some feared demotivation if results were poor. Desire for context: Participants wanted to understand what the results mean and how to improve them.
Experiences with strength measures	Grip strength was the most used test, often by dietitians. Sit-to stand test was familiar to some, seen as useful but limited. Lack of consistency: many had never had formal strength testing or didn't know what was being measured. Interest in more comprehensive tools like isokinetic dynamometers or mid-thigh pull tests.
Usefulness of measuring muscle strength	Motivational tool: many said it would help track progress and encourage exercise. Personalised care: Participants wanted results to inform tailored exercise plans. Mixed feelings: some feared it could be discouraging without proper support or follow-up.
Considerations for measuring muscle strength	Clear communication: Explain purpose, results, and next steps. Sensitivity: Deliver results with empathy, especially if they're poor. Follow-up support: Provide guidance or referrals based on results. Accessibility: consider logistics, time, and physical limitations.
Frequency of muscle strength measurement	Annual or biannual testing was seen as reasonable. Linked to clinic visits: many preferred it to be part of the annual reviews or CPET appointments. Post-hospitalisation: some suggested testing after admissions to track recovery. Flexibility: some wanted the option to opt in more frequently if desired.

The group

n = 6 *n* = 4



Age range: 26-77 years

A variety of occupational & educational backgrounds

Recruited through Cystic Fibrosis Trust PPIE group and Manchester Cystic Fibrosis Unit clinic

2 discussion groups including 4-6 people each, via Microsoft Teams

Groups were audio-recorded and auto-transcribed *verbatim.*

NIHR | Applied Research Collaboration Greater Manchester

Perspectives of Public Involvement

These themes highlight the importance of muscle strength in the CF population, the positive reception towards strength testing, and the need for careful consideration in implementing these tests to ensure they are beneficial and supportive.

DCAF Application

Strength matters: clinical utility of the mid-thigh pull test in cystic fibrosis

Question 1

Is the mid-thigh pull a reliable assessment of lower-limb muscle strength in people with cystic fibrosis?

Question 2

Is maximal isometric strength from the mid-thigh pull associated with strength and functional tests in people with cystic fibrosis?

Question 3

Is it feasible to use the mid-thigh pull to prescribe exercise, assess its effectiveness, and evaluate its practical application in this context?

NHS Manchester University NHS Foundation Trust [1]

MACFC MANCHESTER ADULT CYSTIC FIBROSIS CENTRE [2]

Manchester Metropolitan University [3]

MANCHESTER 1824 The University of Manchester [4]

Nicola Hodgson[1,2] is supported by a National Institute for Health and Care Research (NIHR) Applied Research Collaboration Greater Manchester Pre-doctoral Fellowship. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

With special thanks to Dr Peter Goodwin[3], Dr Nick Dobbin[3], Dr Jodi Ventre[4], Dr Amelia Parchment[4]

I would like to extend my thanks to ARC-GM staff Dr R Atkinson, Dr P Davies, UoM library staff and public contributors.