BMJ Open

Survey of exercise testing and training in cystic fibrosis clinics in the UK: a decade of progress

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To cite: Tomlinson OW, Saynor ZL, Stevens D, *et al*. Survey of exercise testing and training in cystic fibrosis clinics in the UK: a decade of progress. *BMJ Open* 2023;**13**:e072461. doi:10.1136/bmjopen-2023-072461

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2023-072461).

Received 03 February 2023
Accepted 29 March 2023

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ABSTRACT

Objectives Regular exercise testing is recommended for people with cystic fibrosis (pwCF), as is the provision and regular review of exercise training programmes. A previous survey on exercise testing and training for pwCF in the UK was conducted over a decade ago. With the landscape of CF changing considerably during this time, this survey aimed to evaluate UK-based exercise testing and training practices for pwCF a decade on.

Design Cross-sectional, online survey.

Participants A survey was distributed electronically to UK CF clinics and completed by the individual primarily responsible for exercise services. Descriptive statistics and qualitative analyses were undertaken.

Results In total, 31 CF centres participated, representing ~50% of UK specialist clinics. Of these, 94% reported using exercise testing, 48% of which primarily use cardiopulmonary exercise testing. Exercise testing mostly occurs at annual review (93%) and is most often conducted by physiotherapists (62%). A wide variation in protocols, exercise modalities, normative reference values and cut-offs for exercise-induced desaturation are currently used. All centres reportedly discuss exercise training with pwCF; 94% at every clinic appointment. However, only 52% of centres reportedly use exercise testing to inform individualised exercise training. Physiotherapists typically lead discussions around exercise training (74%).

Conclusions These data demonstrate that the majority of respondent centres in the UK now offer some exercise testing and training advice for pwCF, representing a marked improvement over the past decade. However, continued efforts are now needed to standardise exercise practices, particularly regarding field testing practices and the translation of test results into personalised training programmes for pwCF.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This survey uses a mixed-methods approach to identify prevalence of exercise testing and training in UK cystic fibrosis (CF) centres, as well as barriers and facilitators to implementation.
⇒ This survey provides a comprehensive update on a previous UK-based survey, indicating that gold standard cardiopulmonary exercise testing is increasingly being performed.
⇒ Eliciting a single response per CF centre reduced the chance of multiple responses from the same clinical team, minimising the risk of response bias in analyses.

INTRODUCTION

Exercise testing and training are of clinical value in the management of people with cystic fibrosis (pwCF). Clinical endpoints used in exercise tests, such as peak oxygen (VO_{2peak}), can offer early warning signals to help predict mortality, transplantation need[1] and the risk of being hospitalised with pulmonary exacerbation,[2] while also providing new clinical endpoints for assessing intervention effectiveness in the era of modulator therapy.[3–5] Additionally, exercise testing can be used to determine the extent and mechanistic cause(s) of any exercise limitation, screen for exercise-induced adverse events and facilitate individualised exercise training.[6] Exercise training is important for pwCF as it can improve exercise capacity, quality of life and slow rates of decline in lung function in pwCF.[7]

Exercise testing has been adopted into clinical care guidelines for pwCF,[8 9] supported by expert statements in CF[6] and technical standards[10 11]—the purpose of which is to align and standardise test conduct and reporting globally. Annual review, including exercise testing, is recommended for all pwCF,[8 9] with various exercise testing protocols and modalities available, including field (eg, shuttle walks, step tests, sit-to-stand tests) and laboratory-based (eg, cycle or treadmill ergometer testing) tests. Cardiopulmonary exercise testing (CPET) on a cycle ergometer is recognised as the 'gold standard' exercise test for pwCF.[6] However, no audit of practice in the UK has taken place since this recommendation was made. Previous surveys of exercise practices for pwCF,[12–14] including a UK survey published over a decade ago,[15] demonstrated wide variations in practice,

which is not always in line with recommended guidelines. The previous UK data demonstrated that, although exercise testing was valued by CF clinical teams, only around 50% of respondents were using it, with only 8% being the gold standard cycle ergometer CPET.[15]

As well as interval exercise testing, advice and review of personalised structured exercise training regimens (including aerobic and resistance exercise) is also recommended standard care for all pwCF.[8 9] In 2010,[15] around 80% of responding UK CF clinics discussed 'exercise activity' with pwCF at every appointment. Available clinical guidelines from that time[16] have evolved, with updated versions now providing guidance on the benefits of exercise training, and how this can be implemented and individualised (via exercise testing) in clinical practice.[8 17 18] Any impact of more resources available to facilitate exercise training on the availability for pwCF in clinical practice also warrants investigation.

Finally, 90% of pwCF are now eligible for highly effective cystic fibrosis transmembrane conductance regultaor (CFTR) modulator therapy, elexacaftor, in combination with tezacaftor and ivacaftor (ETI), with observed improvements in lung function and weight,[19 20] as well as fitness outcomes in small-scale studies.[21 22] The importance of exercise in a population of pwCF, with increasing life expectancy, and the potential to become overweight and develop age-related comorbidities,[23] has never been so great, thus warranting greater understanding of exercise services which have the potential to positively affect lifelong health in this population.

Therefore, the aim of the present study was to investigate exercise testing and training services within UK CF services.

METHODS

Survey distribution and design

This study was a cross-sectional survey disseminated by email link to the members of several professional bodies (the Association of Chartered Physiotherapists in CF, the UK CF and Exercise Technicians Network and the UK CF Medical Association), members of which are employed in CF centres throughout the UK. All email recipients were further requested to distribute the survey link to further contacts and colleagues, eliciting a 'snowballing' recruitment design. A follow-up email was sent after 3 weeks via these networks to remind non-respondents to complete the survey. This survey was then closed 1 week after this reminder, and therefore the survey was open for a full calendar month in total.

A single member of each CF multidisciplinary team (MDT), the person primarily responsible for exercise services, was requested to complete the survey on behalf of their centre. The survey was distributed in January 2021 and remained open for 6 weeks to maximise the response rate. This survey was hosted using an online platform (Qualtrics XM; Provo, Utah, USA), which is compatible with computers and smartphones and 'whitelists' IP addresses for compliance with data protection regulations.

The questions within this survey were based on a previous UK survey;[15] however, a number of questions were modified and/or updated to reflect changes in clinical practice. A total of 48 questions were asked in three distinct themes: (1) respondent characteristics; (2) exercise testing; and (3) exercise training. A further 13 questions were asked about the impact of the SARS-CoV-2 pandemic on clinical practice; however, these data have been reported separately.[24]

Questions included a mixture of multiple-choice checkboxes and free-text qualitative options. For some questions, participants were able to bypass particular sections based on prior responses. A full list of questions and an accompanying flow chart are provided in online supplemental file 1.

Ethics approval

This study was approved by the University of Exeter Sport and Health Sciences Ethics Committee (200708-A-01). All respondents provided consent to participate via a series of checkboxes, confirming they understood the study and were providing information on behalf of their centre. Respondents were free to withdraw at any time by simply closing the survey on their respective browser. This rendered the response as incomplete, and therefore only complete surveys were carried forward for analysis.

Patient and public involvement

As this was a survey of clinical staff only, and not people with CF themselves, there was no patient or public involvement in the design of this study.

Data analysis

For analysis, quantitative data are presented as frequency statistics. For qualitative data, free-text comments were imported into a Microsoft Excel (Microsoft; Redmond, USA) document and coded independently by two researchers (OWT, JA) using a broad-based coding scheme and subsequently grouped into common themes via an inductive approach, as possible themes had been identified previously.[15] Identified themes were subsequently reviewed by a third researcher (ZLS).

RESULTS

In total, 31 respondents completed the survey, representing approximately 50% of specialist CF centres in the UK.[25 26] Respondent characteristics are provided in table 1. Ten further responses were started, but not completed. Of these 10, six were lost preconsent and four made varied progress through the survey, ceasing responses at questions 8 (n=1), 18 (n=2) and 42 (n=1), respectively. All incomplete responses were excluded from analyses.

Exercise testing

The importance of exercise testing was perceived to be 'extremely important' for the majority of respondents,

Table 1 Characteristics of survey respondents and their cystic fibrosis centre

Demographic information	Sample number
Centre location	England (Midlands), n=5 England (North), n=8 England (South East), n=7 England (South West), n=5 Northern Ireland, n=0 Scotland, n=5 Wales, n=1
Centre type	Adult, n=11; paediatric, n=16; mixed, n=4; specialist CF, n=24; network, n=7.
Number of pwCF per centre	1–50, n=8 51–100, n=8 101–150, n=2 151–200, n=4 201–300, n=5 301+, n=4
Role within MDT	Physiotherapist (lead CF specialist), n=15 Physiotherapist (CF specialist), n=11 Physiotherapist (non-CF specialist), n=1 Therapy assistant/practitioner, n=2 Other (exercise therapist, exercise practitioner), n=2

CF, cystic fibrosis; MDT, multidisciplinary team; pwCF, people with CF.

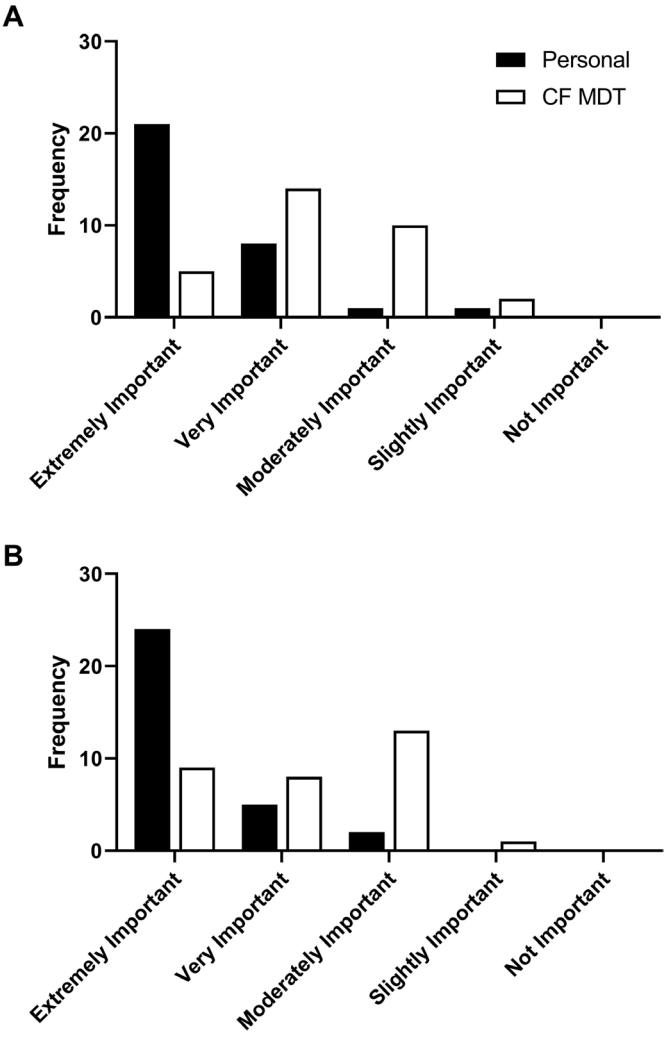

Figure 1 Relative importance of exercise testing (A) and training (B) for people with cystic fibrosis, as rated by survey respondents. 'Personal' importance is that assigned by respondent to survey in response to the question 'please indicate the importance you personally attach to the value of exercise testing in the healthcare of people with CF'. 'CF MDT' is importance assigned by wider multidisciplinary team in response to the question 'please indicate the importance your team attaches to the value of exercise testing in the healthcare of people with CF'. CF, cystic fibrosis; MDT, multidisciplinary team.

although it was recognised that the level of importance may vary among the wider CF MDTs (figure 1).

Consequently, in total, 29/31 (94%) of respondents stated that they used exercise tests to evaluate the health of pwCF, whereas 2/31 (6%) did not, although these centres stated they were considering incorporating exercise testing into their service. For centres performing exercise testing, tests were predominantly conducted by members of the CF MDT (24/29, 83%), including physiotherapists (n=18), therapy assistants/technicians (n=5) and clinical physiologists (n=1). Additionally, some tests were completed by supporting clinical teams (5/29, 17%), including respiratory physiology and anaesthesiology.

In centres that undertake exercise testing, 27/29 (93%) performed field tests, 14/29 (48%) used CPET, while 13/29 (45%) performed both. Reasons why exercise tests are undertaken and the number of tests performed per centre are displayed in figure 2. The types of tests conducted and outcome measures reported are presented in figure 3. The exercise testing equipment available in CF centres included pulse oximeters (n=28), cycle ergometers (n=11), treadmills (n=10) and ECG devices (n=8).

A wide range of responses were also reported in relation to stopping criteria for exercise-induced SpO_2 desaturation (measured by pulse oximetry), ranging from conservative (an SpO_2 drop to below 90%) to liberal (no cut-off); normative reference values; and protocols employed (ramp incremental, n=11; step incremental, n=2; online supplemental file 2).

Multiple barriers to implementing exercise testing were identified, with physical space being the most common (see figure 4). Twenty-seven respondents provided qualitative feedback on how exercise testing could be enhanced (figure 4). Finally, free-text comments regarding exercise testing are provided in online supplemental file 2.

Exercise training

The importance of exercise training was perceived to be 'extremely important' for most respondents, as shown

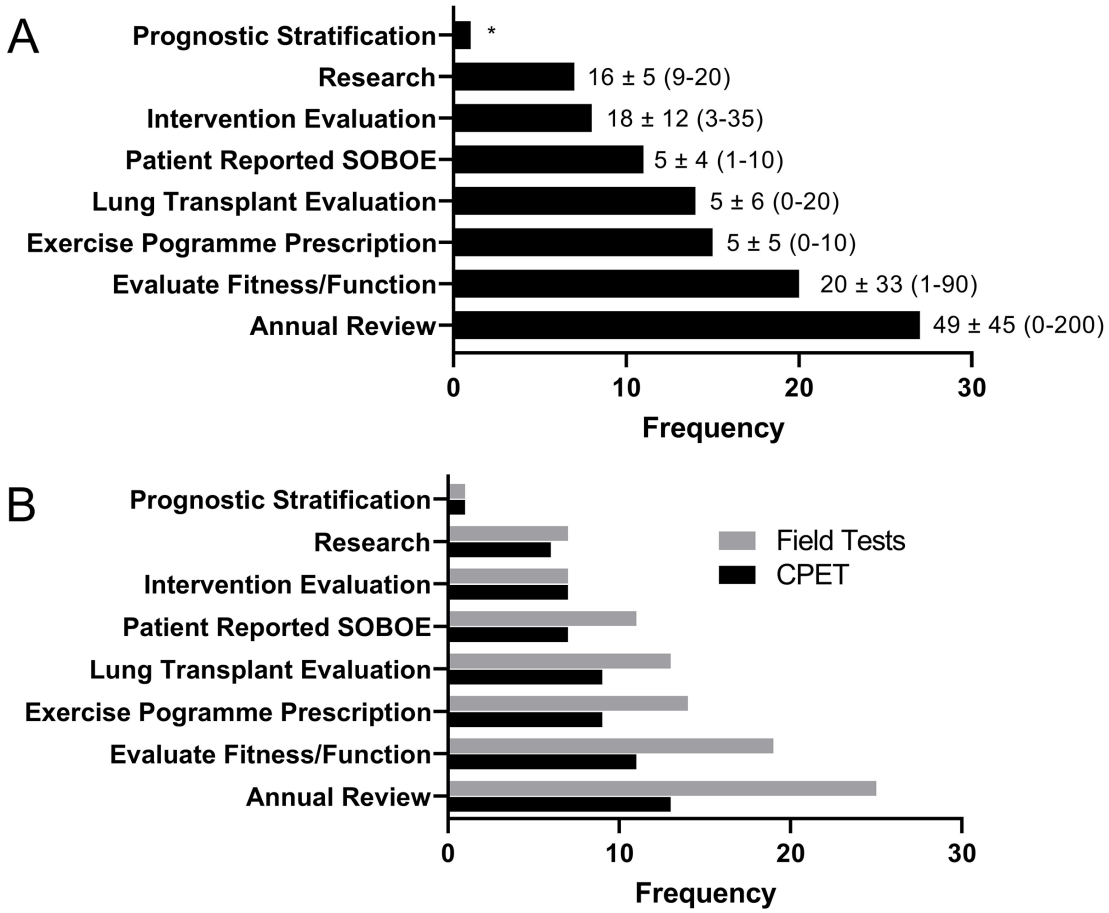

Figure 2 Reasons for, and number of, exercise tests undertaken in UK-based cystic fibrosis (CF) centres in 2019, when modality data are merged (A) and split (B). (A) Total frequency of number of CF centres using exercise testing (regardless of modality) for selected reason. The number accompanying the bar is mean number of tests (±SD (minimum–maximum)) which are undertaken for selected reason. Data are the total number of all tests presented in 2019, combining both field and laboratory tests. (B) Total frequency of number of CF centres selecting the reason for testing, split by cardiopulmonary exercise testing (CPET) and field testing. Data are not mutually exclusive (ie, centres may use CPET and field testing for same reason). *Denotes no number of tests reported, despite option being checked by respondent. SOBOE, shortness of breath on exertion.

in figure 1. As a result, exercise training was discussed with pwCF in all (100%) respondent centres, with 30/31 (97%) doing so at every appointment. No centres reported only discussing exercise training when raised by the pwCF, or solely on an annual basis. A total of 23/31 (74%) reported offering exercise training programmes, with training predominantly delivered by physiotherapists (n=23), therapy assistants/technicians (n=4) and 'other' roles (n=4, including exercise therapist and exercise practitioner). Alongside these individuals, physical activity and exercise training were also discussed by clinicians (n=17), dieticians (n=10), nurses (n=9) and clinical physiologists (n=3). Qualitative responses, providing further details regarding the types of programmes offered, are provided in online supplemental file 3.

In referring pwCF for exercise training programmes, 18/31 (58%) of centres use self-referral, 16/31 (52%) clinician referral and 9/31 (29%) other healthcare professionals, with a series of other pathways described in online supplemental file 3. People with more severe CF lung disease were prioritised for exercise training in 2/31 (6%) of centres and those postdischarge (for antibiotics) in 1/31 (3%). No system for prioritising pwCF for exercise referral was in place in 17/31 (55%) of centres, with all pwCF treated equally in 11/31 (35%) and all being offered an outpatient programme in 8/31 (26%) of centres. Outpatient exercise training programmes were fully supervised in a face-to-face capacity in 16/31 (52%) of centres, unsupervised in 11/31 (35%), fully supervised via telehealth/video calls in 9/31 (29%) of centres, partially supervised in 9/31 (29%), with 'other' methods given in 7/31 (23%; online supplemental file 3).

When discussing exercise training with pwCF, advice consisted of general encouragement regarding exercise (n=28), training recommendations that balance benefit and risk (n=27), individually tailored structured exercise training programmes based on exercise tests (n=17) and specific activities (n=22; online supplemental file 3). Some 68% of respondents reported using published resources to prescribe exercise for pwCF, with n=4 referring to WHO guidelines, n=4 to documentation from the UK CF Trust and n=3 referring to the American College

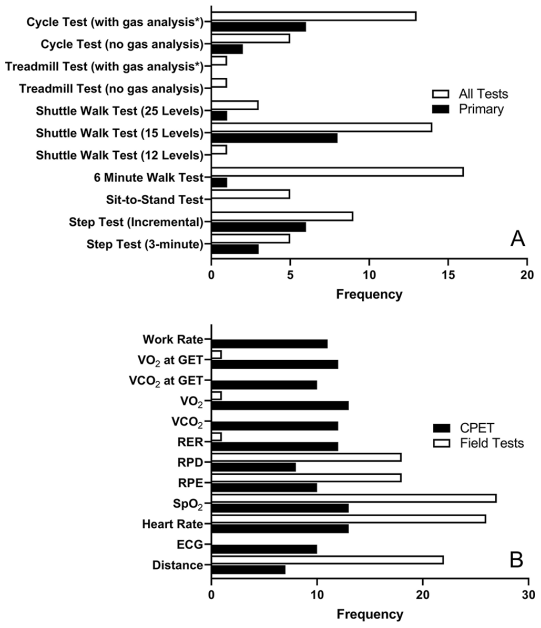

Figure 3 Frequency of exercise tests performed by cystic fibrosis (CF) centres (A) and outcome measures collected during tests (B). (A) Frequency of centres using each testing modality, displaying all tests used and the primary test used by respondent centres. (B) Frequency of outcome measures obtained by each CF centre, with separate responses for cardiopulmonary exercise testing (CPET) and field tests. *'gas-analysis' indicates CPET. GET, gas exchange threshold; RER, respiratory exchange ratio; RPD, rating of perceived dyspnoea; RPE, rating of perceived effort; SpO_2, transcutaneous arterial oxygen saturation; VCO_2, volume of carbon dioxide produced; VO_2, volume of oxygen consumed.

of Sports Medicine recommendations (online supplemental file 3).

When guiding individualised prescription of aerobic exercise programmes, centres based this on (from highest to lowest proportion) field test results (16/31, 52%), target heart rates (15/31, 48%), symptom scores (14/31, 45%), SpO_2 measures (13/31, 42%), CPET results (7/31, 23%) and other methods (8/31, 26%; online supplemental file 3). Exercise training programmes are subsequently progressed on the basis of field test results in 13/31 centres (42%), target heart rates (13/31, 42%), symptom scores (13/31, 42%), SpO_2 measures (11/31, 35%), patient-oriented functional goals (11/31, 35%) and CPET results (4/31, 13%; online supplemental file 3).

Multiple barriers to implementing exercise training were reported (figure 4) and 24 respondents provided additional qualitative feedback on how to improve exercise services. Finally, open comments and opinions around exercise training for CF are provided in online supplemental file 3.

DISCUSSION

This study provides contemporary insight into exercise testing and training provision within UK-based CF clinics. Importantly, both exercise testing and training are perceived to be 'extremely valuable' by CF MDTs and, in line with this, the use of both has increased over the past decade.[15] The value of exercise testing is highlighted by the finding that 94% of centres (vs 53% in 2010[15]) perform an annual exercise test for pwCF and that 100% of CF teams discuss exercise training with pwCF. However, wide variation remains in the exercise tests used and a lack of standardisation for exercise testing. Multiple barriers (staffing, space, equipment, costs and expertise) to testing and training in clinical practice remain, reflecting similar findings to 2010.[15] There is staffing variation in this present survey also, with the emergence of dedicated exercise professionals (table 1) working with a number of CF teams.

In the current survey, 48% of responding CF centres reportedly have access to CPET (vs 8% in 2010[15]), an improvement that perhaps reflects, at least in part, the availability of supporting guidelines and technical standards.[6 10 11] Although interval exercise testing is recommended for pwCF,[6 8 9] it is most commonly (93%) performed alongside the CF annual review, aligning with published clinical standards of care.[8 9] This represents a step change from 2010,[15] when only 35% of centres reportedly performed an annual exercise test for pwCF.[15] It is encouraging to see the uptake of these recommendations, which may be being facilitated due to increased employment of exercise specialist staff,[27] and inclusion of exercise-oriented data into national registries[28]—prompting such testing to occur at annual review.

While the increased use of exercise testing in UK-based CF clinics is positive, a key indication for testing is to facilitate individualised exercise counselling (which some may also call exercise prescription).[29] At present, only 23% of centres report using CPET-derived data to prescribe individually tailored exercise training programmes for pwCF, with only 13% progressing programmes using CPET-derived data. It is possible that confidence and competence may play a part in why this application gap exists, as education, training and resources were noted as barriers to implementation of both testing and training (figure 4). Moreover, there remains a high level of disparity between CF centres in how and when exercise tests are implemented, including test frequency, modality, selection of protocol and outcome variables, normative reference data and the reasons for referral (figures 2 and 3, online supplemental figure 3). Despite CPET being the gold standard exercise test for aerobic function in pwCF,[6] the 6 min walk test is the most prevalent test performed in clinics in the UK across both paediatric and adult practice (figure 3). However, growing evidence suggests that given its submaximal nature, this test should be restricted to those with advanced CF lung disease and/or as part of lung transplant preassessment.[30] Considering this, although an increased uptake of exercise testing in pwCF is positive, further work is needed to promote and standardise appropriate exercise testing, with known clinometric properties, for those without access to CPET,

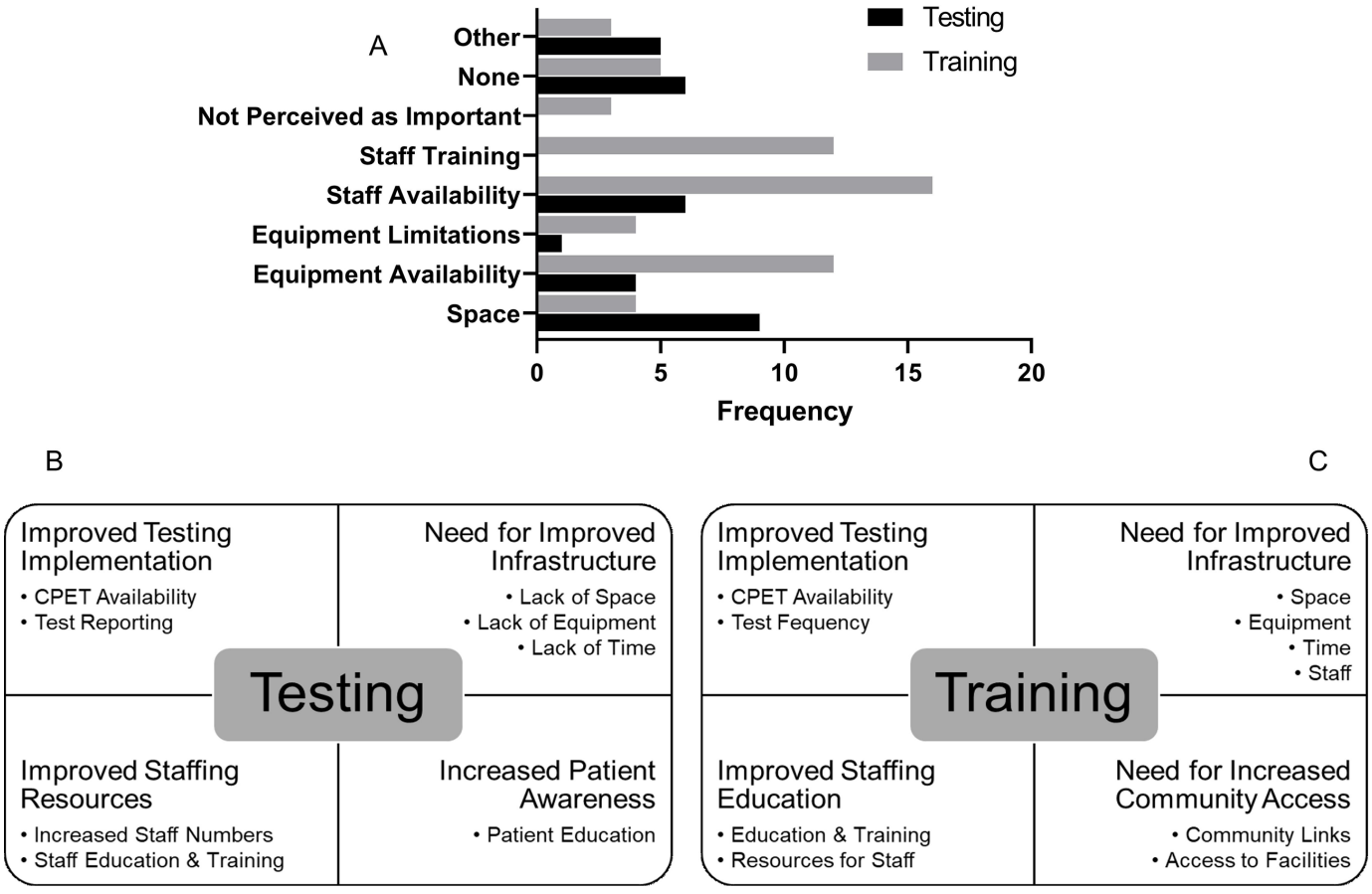

Figure 4 Predominant barriers to implementing exercise testing and training in UK-based cystic fibrosis clinics (A) and thematic analysis of factors that would enhance exercise testing (B) and training (C) provision. (A) Frequency of barriers to exercise testing and training. 'Other' responses for testing include patient engagement (n=3) and detailed combinations of factors (equipment, staffing and space; n=2) for testing; and case load priority (n=1), patient reasons (n=1) and no reason (n=1) for training. (B) Predominant themes from qualitative responses to '*What would enhance the role of exercise testing in your clinic?*'. (C) Predominant themes from qualitative responses to '*What would enhance the role of exercise training in your clinic?*'. CPET, cardiopulmonary exercise testing.

particularly considering the recent move to incorporate exercise testing data into national CF registries.[28 31]

In addition to an increased provision of exercise testing, the number of CF MDTs offering exercise training to pwCF in the UK has also increased. We report that 97% of centres discuss exercise at every clinic appointment, compared with 79% in 2010,[15] and 74% of centres report that their patients with CF have access to exercise training programmes (31% in 2010). These data highlight the increased recognition of a need to provide exercise services for pwCF (given benefits of exercise training[7]), a point illustrated by the high levels of perceived importance for training among CF MDTs (figure 1). However, a notable implementation gap exists, whereby the majority of responding centres (97%) discussed exercise training, yet 26% still did not offer structured training programmes, and therefore representing a clear direction in which to improve exercise services.

Despite exercise being recommended as an integral part of the clinical management of pwCF,[8 9] a number of barriers to integrating exercise testing and training within clinical service pathways in the UK remain, including a lack of personnel and their time, facilities and equipment and appropriate training. These barriers are unchanged from 2010.[15] The prevalence and provision of these services has, however, encouragingly increased, with postulated contributory factors including the growing evidence base of benefit for exercise in pwCF,[1 7] increased availability of guidelines[6 8 10] and exercise specialists working within healthcare,[27 32] combined with increased recognition of the importance of exercise testing and training among MDT members.

The introduction of specialist exercise staff into CF MDTs (therapy assistants, therapy practitioners, exercise therapists, exercise practitioners) may be contributing to the increased provision of exercise services for pwCF. Professionals whose roles and responsibilities are to deliver exercise testing and training,[27 32] alongside physiotherapy assistants within CF MDTs, can prove useful[33] by relieving physiotherapy pressures while adding exercise expertise to the wider service.[34] The importance of experienced and qualified staff is recognised in recent clinical exercise testing guidelines,[11] and supported by a nationwide effort in the UK to establish clinical exercise

physiologists within the healthcare workforce.[35] Considering this increased value of exercise professionals is alongside increasing recognition for the health benefits associated with exercise by society in general, perceived benefit of CFTR modulator treatments on perspectives on quality of life and health status[36] and the recognised benefit of exercise professionals by pwCF themselves;[37] CF MDTs should consider the incorporation of exercise specialists[27] or clinical exercise physiologists[35] into their teams.[38] These roles exist in countries outside of the UK,[39–41] and it is likely their prevalence will increase within the National Health Service, given a recent charter and push for standardised roles.[35]

We must acknowledge several limitations with this survey, including the response rate, which accounts for around 50% of specialist CF centres within the UK, and while this leaves a further approximate 50% unrepresented, this rate matches that of the original survey.[15] Therefore, this likely reflects the opinions and behaviours of a large proportion of the CF clinical teams in the UK, although due to the nature of the target population, this work will be of predominant interest to UK CF professionals only. Moreover, several methods were employed to reduce bias, including only having the survey completed by one representative per centre, thus ensuring no chance of duplicate responses biasing the sample. However, in contrast, we cannot guarantee whether the respondent centres in this survey matched those from the 2010 survey,[15] due to the anonymised nature of responses. Furthermore, there is a possibility of responder bias, whereby those clinical teams who value exercise may have been more likely to complete the survey, although the risk of this is no higher than when this survey was first implemented.[15] Future surveys may consider shorter questions/surveys or financial incentives, both of which have been shown to increase response rates.[42]

CONCLUSION

Exercise testing and training for pwCF remain highly important, and their role in clinical care of CF has never been more prominent. The anticipated health gains for people on ETI, along with the potential for weight gain, are expected to lead to an increased focus on exercise for its management of CF, such as promoting airway clearance therapy,[43] and the multitude of extrapulmonary health benefits.[38] This study demonstrates a shift in availability of exercise testing and training for pwCF over the past decade but also highlights that the progress made requires to be built on with improvements still being required in regard to test selection, test standardisation and offering tailored exercise programmes to people with CF. It would be good to see these outstanding issues being tackled quickly to meet this prescient need.

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Acknowledgements The authors thank Dr Caroline Elston and the UK CF Medical Association; Thomas Kent, Lisa Morrison and the Association of Chartered Physiotherapists in CF; and Dr James Shelley, UK CF and Exercise Technicians Network, for assistance with distribution of the survey. Finally, all respondents are thanked for their time in completing the survey.

Contributors OWT, ZLS, DS, DSU and CAW conceived and designed the study. OWT and CAW coordinated the delivery of survey and collation of results. OWT analysed the results and drafted the manuscript with support on qualitative analysis from JA and ZLS. OWT, ZLS, DS, JA, DSU and CAW critically revised the manuscript. OWT, ZLS, DS, JA, DSU and CAW approved the final manuscript for publication. OWT and CAW act as guarantors for study.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the University of Exeter Sport and Health Sciences Ethics Committee (200708-A-01). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Please contact the corresponding author to arrange access to study data.

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