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

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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.

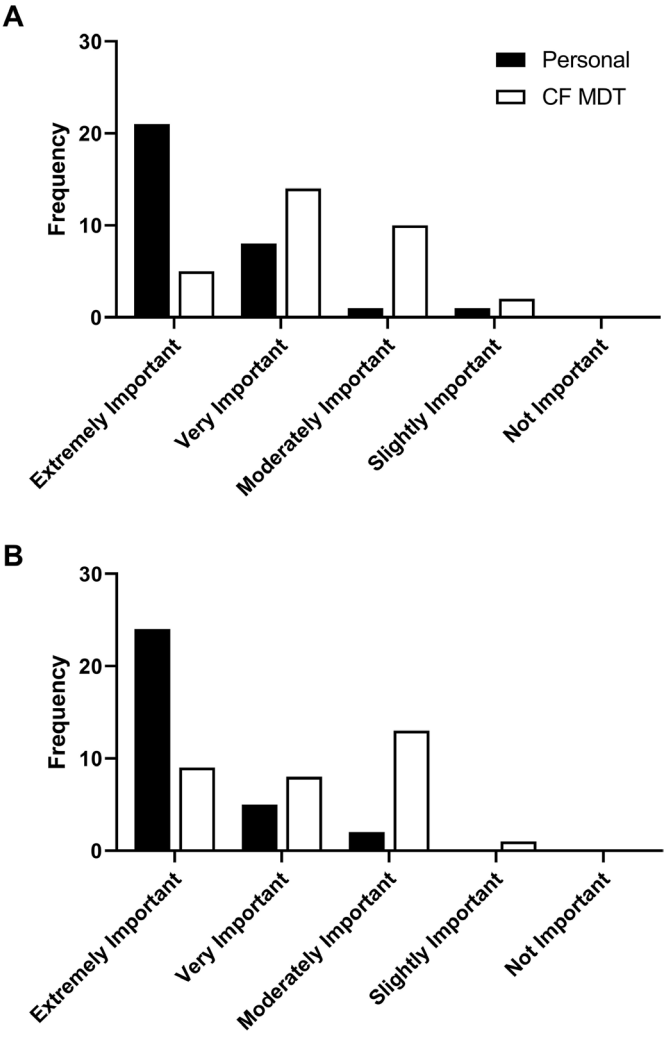

Figure 1 Relative importance of exercise testing (A) and training (B) for people with cystic fibrosis, as rated by survey respondents. 'Personal' importance is that assigned by respondent to survey in response to the question 'please indicate the importance you personally attach to the value of exercise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

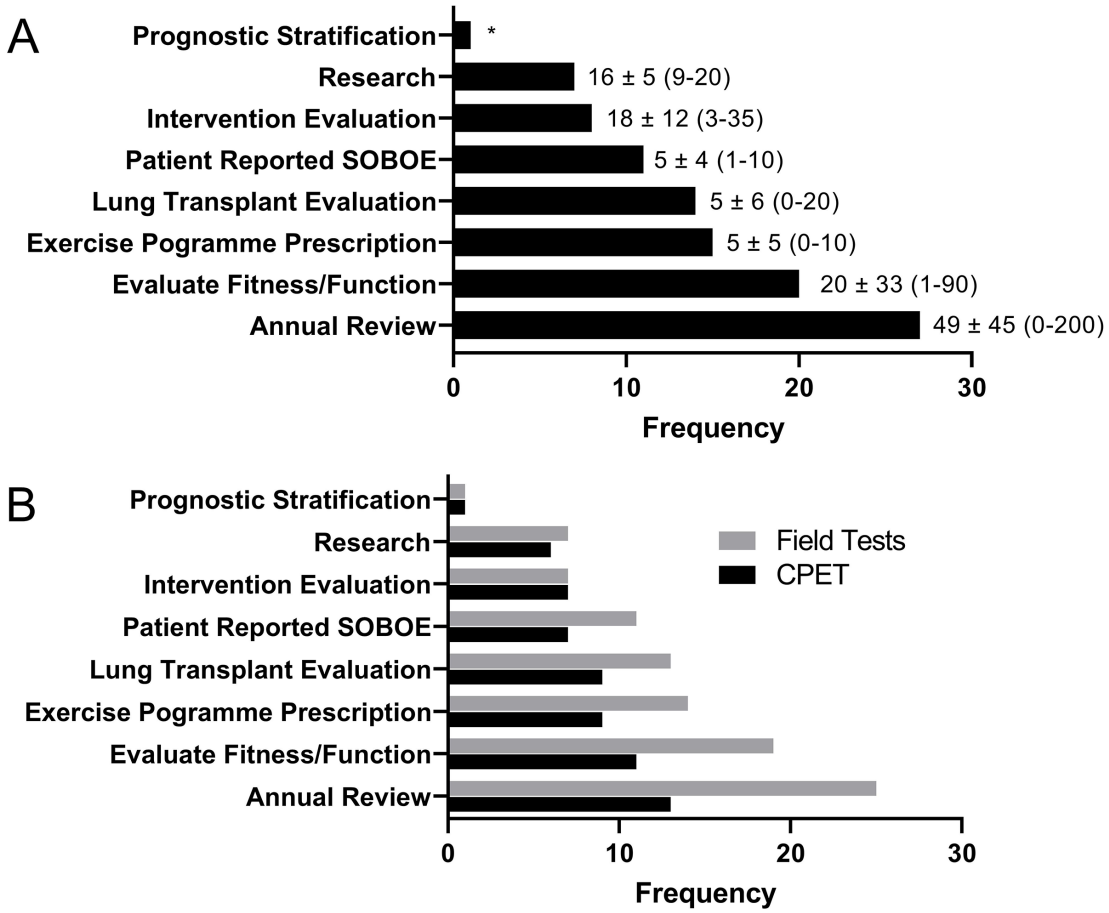

Figure 2 Reasons for, and number of, exercise tests undertaken in UK-based cystic fibrosis (CF) centres in 2019, when modality data are merged (A) and split (B). (A) Total frequency of number of CF centres using exercise testing (regardless of modality) for selected reason. The number accompanying the 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

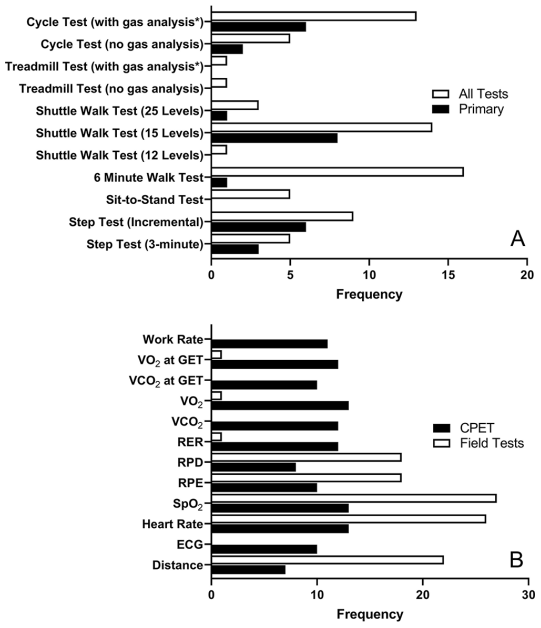

Figure 3 Frequency of exercise tests performed by cystic fibrosis (CF) centres (A) and outcome measures collected during tests (B). (A) Frequency of centres using each testing modality, displaying all tests used and the primary test used by respondent centres. (B) Frequency of outcome measures obtained 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,

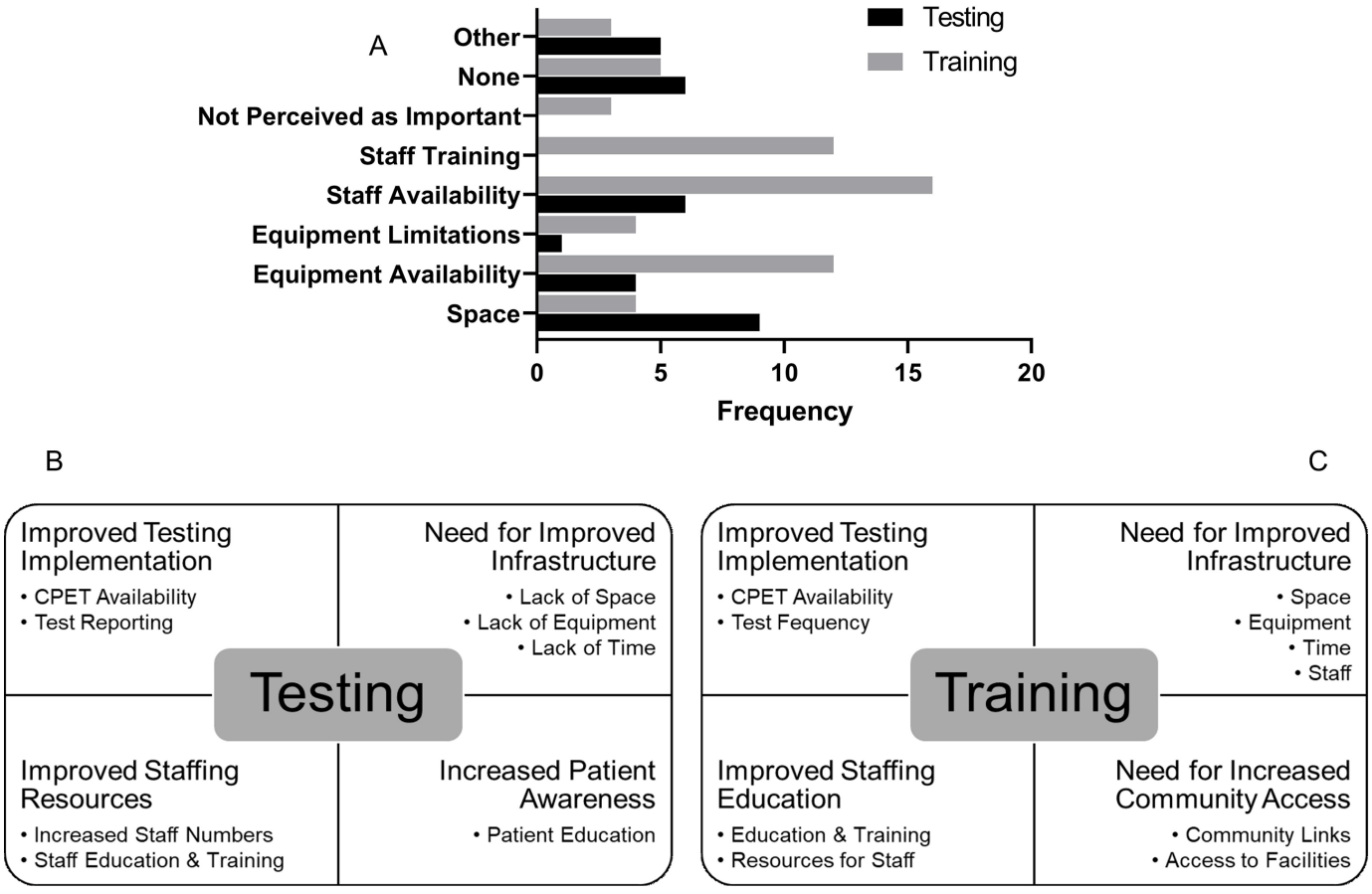

Figure 4 Predominant barriers to implementing exercise testing and training in UK-based cystic fibrosis clinics (A) and thematic analysis of factors that would enhance exercise testing (B) and training (C) provision. (A) Frequency of barriers to exercise testing and training. 'Other' responses for testing 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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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.

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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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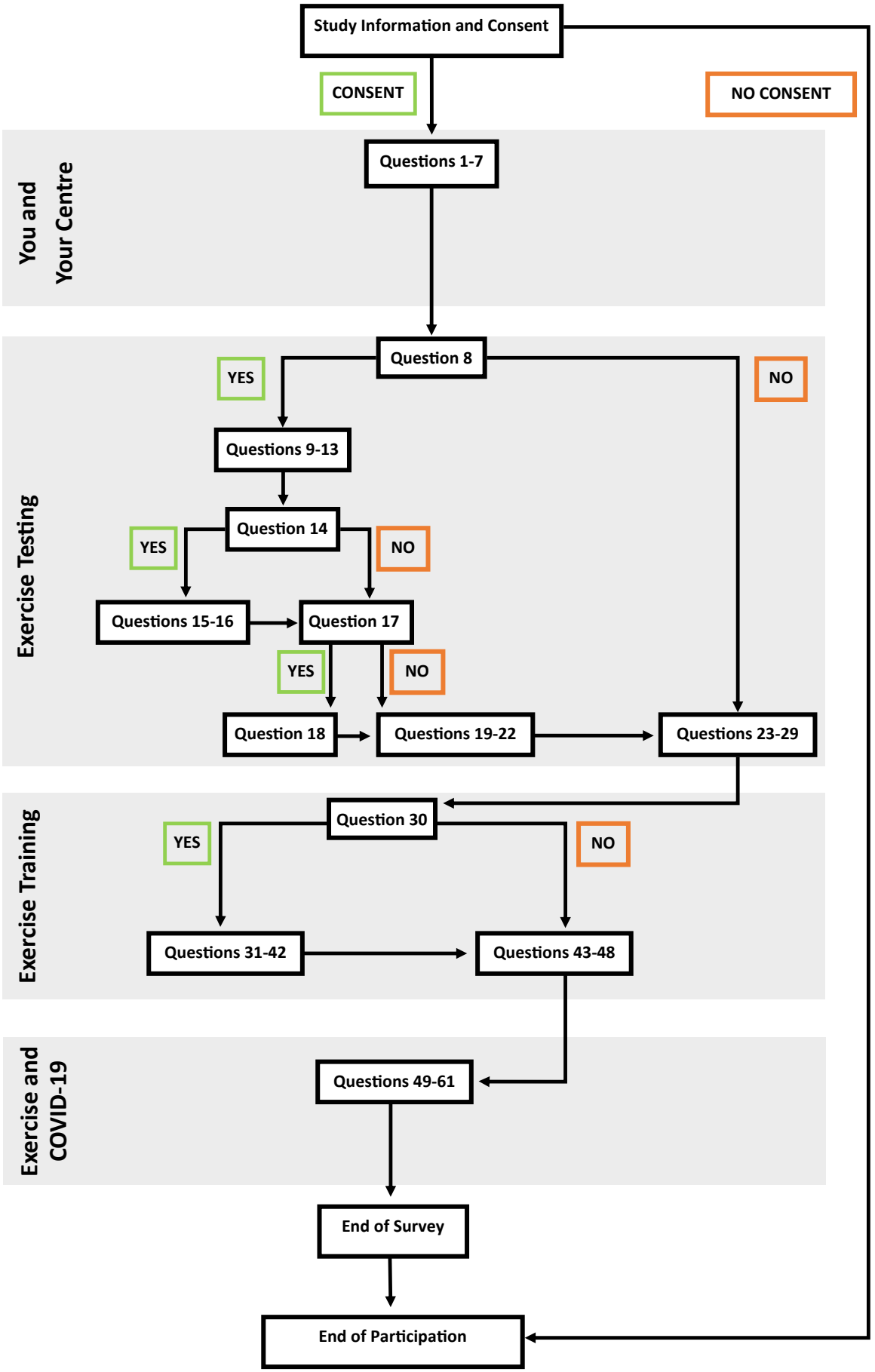

Study Information and Consent
CONSENT
NO CONSENT
You and Your Centre
Questions 1-7
Exercise Testing
Question 8
YES
NO
Questions 9-13
Question 14
YES
NO
Questions 15-16
Question 17
YES
NO
Question 18
Questions 19-22
Questions 23-29
Exercise Training
Question 30
YES
NO
Questions 31-42
Questions 43-48
Exercise and COVID-19
Questions 49-61
End of Survey
End of Participation

Survey Information & Consent

Survey Information & Consent

Study Title: A survey of exercise testing and training in cystic fibrosis clinics

Participant Information Sheet (Version 1 (08/06/2020), Reviewed by The University of Exeter Sport and Health Sciences ethics committee).

Brief Introduction:

We would like to invite you to take part in a research study about exercise testing and training in cystic fibrosis clinics. Taking part in the study is entirely up to you, so before you decide, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information and to discuss it with other people to decide whether you wish to take part or not. Thank you for taking the time to read this information

What's involved?

Being more physically active has important clinical benefits for people with cystic fibrosis e.g., improved lung function, aerobic fitness, sputum clearance, as well as psychological and social benefits e.g., improved self-confidence, socialisation and self-esteem. However, many clinicians and their support teams, whilst valuing the role of exercise testing and training are unsure how to utilise and promote it within their clinics.

We are asking clinicians and their support teams (healthcare providers, physiotherapists, nurses, technicians, etc) about their current use of exercise testing and training in their clinical practice. The present survey is being conducted by the Universities of Exeter and Portsmouth (UK), the Royal Hospital for Sick Children Edinburgh (UK) and Dalhousie University (Canada). The objective of the present survey is to identify and quantify the scope of exercise testing and training used currently in Cystic Fibrosis clinics in the UK and Ireland and to determine the importance assigned by clinic staff. The survey also serves as a follow-up to a previous study [Stevens D, Oades PJ, Armstrong N, Williams CA. A survey of exercise testing and training in UK cystic fibrosis clinics. Journal of Cystic Fibrosis. 2010; 9(5):302-6.] that was conducted over a decade ago. Please note that the findings will be summarised and no individual clinics will be named in the report. We thank you in advance for your time.

What would taking part involve?

We have invited you to take part because we are looking for healthcare professionals who work in cystic fibrosis clinics. Taking part will involve completing a short survey about the use of exercise testing and training in the clinical care of CF. We anticipate that it will take approximately 20

minutes to complete the survey.

What are the possible benefits of taking part?

The main benefits of the proposed research are educational and there will be limited personal benefit to you and your team. However, the results will increase our understanding of current attitudes and behaviours surrounding exercise testing and training, and some of the barriers and facilitators that obstruct or promote its use. The information we obtain will help us develop educational materials to support clinical teams working with people with cystic fibrosis and to enable them to be physically fit and active without limitations.

What are the possible disadvantages and risks of taking part?

This is a very low risk study. We do not anticipate any risks of taking part. The main disadvantage is the time you will spend completing the survey.

Do I have to take part?

Please remember that participation in this study is entirely voluntary. It is up to you to decide whether you would like to take part or not and if you decide to take part you are free to leave the study at any time without giving a reason as to why you wish to do so. If you do decide to participate in this study you will be asked to check a box to indicate that you are happy to take part.

Are my results confidential?

Person-identifiable information will not be used in this study. All data will be stored on a password protected file within a locked office at the University of Exeter. With your permission, we may include some of the information you provide in a larger database for analysis at a later date. It will not be possible to identify you from any data we retain.

What will happen to the results of this study?

The results will increase our understanding of current attitudes and behaviours the implementation of exercise and testing in CF clinics. We will aim to publish the findings in research journals and to present them at conferences in the UK or abroad. Your data will always remain anonymous and your name will not appear on any results.

Who has reviewed this study?

All research activity at the University of Exeter is examined and approved by an ethics committee to protect your interests. This study has been approved by the Ethics Committee of Sport and Health Sciences, College of Life and Environmental Sciences, University of Exeter. This project has been reviewed by the Sport and Health Science Research Ethics Committee Exeter (ref: ……

approval date:…….)

Funder:

Cystic Fibrosis Trust (Strategic Research Centre #008)

Contacts for further information:

If you would like more information or if you have any further questions about the study please contact the investigators using the details below:

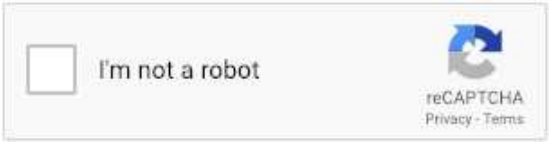
Professor Craig Williams (Chief Investigator), University of Exeter: c.a.williams@exeter.ac.uk

Dr Owen Tomlinson (Study Coordinator), University of Exeter: o.w.tomlinson@exeter.ac.uk

Ms Gail Seymour (Research Ethics and Governance Manager), University of Exeter: g.m.seymour@exeter.ac.uk

	Please Check Box
I confirm that I have read and understand the information sheet version 1 dated 08/06/2020 for the above study.	○
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.	○
I understand that any information given by me may be used in future reports, articles or presentations by the research team.	○
I understand that my name will not appear in any reports, articles or presentations.	○
I am happy for some of the information I provide to be included in a larger database for analysis at a later date.	○
I agree to take part in the above study.	○

Please check the box below to continue.



Section 1: You and Your Centre

You and Your Centre

Where is your CF centre located?

- ○ England (Midlands)
- ○ England (North)
- ○ England (South East, including London)
- ○ England (South West)
- ○ Northern Ireland
- ○ Republic of Ireland
- ○ Scotland
- ○ Wales

Is your centre adults, paediatric, or mixed?

- ○ Adult
- ○ Paediatric
- ○ Mixed (Adults & Paediatric)

Present number of patients at your centre?

Number of patients with:

Mild CF (FEV1 above 70%)	
Moderate CF (FEV1 40-69%)	
Severe CF (FEV1 below 40%)	

Number of patients on active transplant list?

Your position

- ○ CF Centre Director/Manager
- ○ Clinical Physiologist
- ○ Clinician
- ○ Nurse
- ○ Physiotherapist (Lead CF Specialist)

- ○ Physiotherapist (CF Specialist)
- ○ Physiotherapist (non-CF Specialist)
- ○ Therapy Assistant/Technician
- ○ _____ Other (please state)

Section 2: Exercise Testing

Exercise Testing

Does your clinic use exercise tests to evaluate patient health?

- ○ Yes
- ○ No

Are these tests conducted in your department (i.e. by the CF MDT) or another department in your hospital/trust (i.e. cardiology, clinical physiology)?

- ○ CF MDT
- ○ _____ Other (please state)

Which exercise tests are used in your CF centre? Please select all that apply.

- ☐ Step Test - 3 Minute
- ☐ Step Test - Incremental
- ☐ Sit-to-Stand Test
- ☐ 6 Minute Walk Test
- ☐ Shuttle Walk Test (10 Minutes)
- ☐ Shuttle Walk Test (20 Minutes)
- ☐ Shuttle Walk Test (12 Levels)
- ☐ Shuttle Walk Test (15 Levels)
- ☐ Shuttle Walk Test (25 Levels)
- ☐ Treadmill Test (no gas analysis)
- ☐ Treadmill Test (with gas analysis, i.e. CPET)
- ☐ Cycle Test (no gas analysis)
- ☐ Cycle Test (with gas analysis, i.e. CPET)
- ☐ Other (please specify) _____

If you use treadmill or cycle testing, please describe the test.

Which exercise tests is utilised **most** in your CF centre? Please select one only.

- ○ Step Test - 3 Minute
- ○ Step Test - Incremental
- ○ Sit-to-Stand Test
- ○ 6 Minute Walk Test
- ○ Shuttle Walk Test (10 Minutes)
- ○ Shuttle Walk Test (20 Minutes)
- ○ Shuttle Walk Test (12 Levels)
- ○ Shuttle Walk Test (15 Levels)
- ○ Shuttle Walk Test (25 Levels)
- ○ Treadmill Test (no gas analysis)
- ○ Treadmill Test (with gas analysis, i.e. CPET)
- ○ Cycle Test (no gas analysis)
- ○ Cycle Test (with gas analysis, i.e. CPET)
- ○ Other (please specify)

What equipment does your clinic have to facilitate exercise testing? Please select all that apply.

- ☐ Cycle Ergometer
- ☐ Electrocardiogram (ECG)
- ☐ Metabolic Cart
- ☐ Pulse Oximeter
- ☐ Treadmill
- ☐ None
- ☐ Other (please specify)

Does your centre undertake cardiopulmonary exercise testing (CPET)?

- ○ Yes
- ○ No

Please state which measurements are recorded during CPET. Please select all that apply.

- ☐ Distance
- ☐ Electrocardiogram (ECG)
- ☐ Heart Rate
- ☐ Oxygen Saturation (SpO2)
- ☐ Rating of Perceived Effort (RPE)
- ☐ Rating of Perceived Dyspnoea (RPD)
- ☐ Respiratory Exchange Ratio (RER)
- ☐ VCO2
- ☐ VO2
- ☐ VCO2 at Gas Exchange Threshold
- ☐ VO2 at Gas Exchange Threshold
- ☐ Work Rate
- ☐ Other (please specify)

Please state which exercise protocols are used for CPET. Please select all that apply.

- ☐ Incremental Ramp
- ☐ Step Test
- ☐ Other (please state)

Does your centre undertake field tests (e.g. shuttle walks, step tests)?

- ○ Yes
- ○ No

What measurements are recorded using field tests? Please select all that apply.

- ☐ Distance
- ☐ Electrocardiogram (ECG)
- ☐ Heart Rate
- ☐ Oxygen Saturation (SpO2)
- ☐ Rating of Perceived Effort (RPE)
- ☐ Rating of Perceived Dyspnoea (RPD)
- ☐ Respiratory Exchange Ratio (RER)
- ☐ VCO2
- ☐ VO2
- ☐ VCO2 at Gas Exchange Threshold
- ☐ VO2 at Gas Exchange Threshold
- ☐ Work Rate
- ☐ Other (please specify)

Do you use reference values to evaluate the exercise test(s)?

- ○ Yes (please state which values)
- ○ No

When, and how often, are exercise tests carried out? Please select all that apply.

	Yes, exercise testing is undertaken at this point (Please check box if 'yes')	If Yes... On how many patients in the last 12 months?

	Yes, exercise testing is undertaken at this point (Please check box if 'yes')	If Yes... On how many patients in the last 12 months?
At annual review	☐	
On an individual basis when patient reports breathlessness on exertion	☐	
On an individual basis as part of lung transplant evaluation	☐	
To determine impact following therapeutic intervention (e.g. antibiotics, modulators, nutritional changes)	☐	
To evaluate fitness/function	☐	
To prognostically stratify patients	☐	
To prescribe individualised exercise programmes	☐	
For research purposes	☐	
Never	☐	

Which member of the MDT normally supervises the exercise test and records the results?

- ○ Clinical Physiologist
- ○ Clinician
- ○ Nurse
- ○ Physiotherapist
- ○ Therapy Assistant/Technician
- ○ _____ Other (please state)

Does your centre have a limit regarding the level of oxygen desaturation permitted during exercise testing?

- ○ No limit
- ○ Yes - when SpO2 is less than 90%
- ○ Yes - when SpO2 is less than 85%
- ○ Yes - when SpO2 is less than 80%
- ○ Unsure
- ○ _____ Other (please specify)

If you do not currently utilise exercise testing, is your centre currently considering incorporating exercise testing into its standard of care?

- ○ Yes
- ○ No

Does the availability of the following limit your ability to undertake exercise testing?

	Always	Usually	Sometimes	Sporadically	Rarely	Never
Equipment	○	○	○	○	○	○
Personnel	○	○	○	○	○	○
Space	○	○	○	○	○	○
Time	○	○	○	○	○	○

What is the **main** barrier to conducting exercise testing in your centre? Please select one only.

- ○ Equipment Availability
- ○ Equipment Limitations
- ○ Staff Availability
- ○ Staff Training
- ○ Not viewed as important in our centre
- ○ No limits
- ○ [ ] Other (please specify)

Using the scale below, please indicate the importance **you personally attach** to the value of exercise testing in the healthcare of people with CF.

Extremely important	Very important	Moderately important	Slightly important	Not at all important
○	○	○	○	○

Using the scale below, please indicate the importance **your team** attaches to the value of exercise testing in the healthcare of people with CF.

Extremely important	Very important	Moderately important	Slightly important	Not at all important
○	○	○	○	○

Please state what, if anything, would enhance the role of exercise testing in your clinic (e.g. personnel, equipment, space).

Do you have any final comments on exercise testing in your centre?

Section 3: Exercise Training

Exercise Training

Does your clinic discuss exercise training and/or physical activity with patients?

- ○ Yes
- ○ No

How often is exercise training and/or physical activity discussed with patients in your clinic? Select all that apply.

- ☐ Every Appointment
- ☐ Only if mentioned by the patient
- ☐ When a patient begins to experience exercise difficulties
- ☐ Once a year (i.e. annual review)
- ☐ Never

Which member of the MDT normally **discusses** exercise training and/or physical activity with patients?

- ○ Clinical Physiologist
- ○ Clinician
- ○ Nurse
- ○ Physiotherapist
- ○ Therapy Assistant/Technician
- ○ Other (please state)

Which member of the MDT normally **delivers** exercise training and/or physical activity with patients?

- ○ Clinical Physiologist
- ○ Clinician
- ○ Nurse
- ○ Physiotherapist
- ○ Therapy Assistant/Technician
- ○ _____ Other (please state)

What advice is given to patients on the topic of exercise training/physical activity? Please select all that apply.

- ☐ None
- ☐ General encouragement regarding exercise
- ☐ Exercise training recommendations that weigh up benefits and risks
- ☐ Individualised exercise programme based on exercise testing
- ☐ Specific activity encouraged (please state)

Are any specific guidelines followed regarding exercise prescription? (e.g. national physical activity guidelines)

- ○ Yes (please specify)
- ○ No

Does your clinic offer exercise training programmes for patients?

- ○ Yes (please specify)
- ○ No

How are patients referred for exercise training? Please select all that apply.

- ☐ Patient/Self Referral
- ☐ Referral from Clinician
- ☐ Referral from another healthcare professional
- ☐ Not applicable
- ☐ Other (please state)

How does your centre triage/prioritise patients for exercise referrals? Please select all that apply.

- ☐ No system in place for prioritising patients
- ☐ Patients who are post-discharge for exacerbations are prioritised
- ☐ Patients with more sever respiratory disease are prioritised
- ☐ All patients are offered an outpatient exercise programme
- ☐ All patients treated equally
- ☐ Unsure
- ☐ Not applicable
- ☐ Other (please state)

How are aerobic exercise programmes **prescribed** at your centre? Please select all that apply.

- ☐ Results from CPET
- ☐ Results from field-based testing
- ☐ Target heart rates
- ☐ SpO2 measures
- ☐ Symptom scores
- ☐ Unsure
- ☐ Not applicable

☐ Other (please specify)

How are aerobic exercise programmes **progressed** at your centre? Please select all that apply.

- ☐ Results from CPET
- ☐ Results from field-based testing
- ☐ Target heart rates
- ☐ SpO2 measures
- ☐ Symptom scores
- ☐ Unsure
- ☐ Not applicable
- ☐ Other (please specify)

Does your centre have a limit regarding the level of oxygen desaturation permitted during exercise training?

- ○ No limit
- ○ Yes - when SpO2 is less than 90%
- ○ Yes - when SpO2 is less than 85%
- ○ Yes - when SpO2 is less than 80%
- ○ Unsure
- ○ Other (please specify)

What level of supervision do you have for outpatient exercise training?

- ○ Fully Supervised (face to face)
- ○ Fully Supervised (telehealth, video calls etc.)
- ○ Partially Supervised
- ○ Unsupervised
- ○ Unsure
- ○ Not Applicable

If you do not currently discuss exercise training, is your centre currently considering incorporating exercise training into its standard of care?

- ○ Yes

- ○ No

Do any of the following limit exercise prescription in your clinic? Please select all that apply.

- ☐ Equipment Availability
- ☐ Equipment Limitations
- ☐ Staff Availability
- ☐ Staff Training
- ☐ Not viewed as important in our centre
- ☐ No limits
- ☐ _____ Other (please specify)

Using the scale below, please indicate the importance **you personally attach** to the value of exercise training in the healthcare of people with CF.

Extremely important	Very important	Moderately important	Slightly important	Not at all important
○	○	○	○	○

Using the scale below, please indicate the importance **you personally attach** to the value of exercise training in the healthcare of people with CF.

Extremely important	Very important	Moderately important	Slightly important	Not at all important
○	○	○	○	○

Please state what, if anything, would enhance the role of exercise training in your clinic (e.g. personnel, equipment, space).

Do you have any final comments on exercise training in your centre?

Section 4: COVID-19

Exercise & COVID-19

Has the COVID-19 pandemic affected your ability to deliver exercise **testing**?

- Yes
- No

How often are you able to undertake exercise **testing** due to the pandemic?

Always	Most of the time	About half the time	Sometimes	Never
○	○	○	○	○

How has you centre adapted exercise **testing** in light of the pandemic (e.g. video tests, home visits, stopped altogether, no change)

Has the COVID-19 pandemic affected your ability to deliver exercise **training**?

- Yes
- No

How often are you able to undertake exercise **training** due to the pandemic?

Always	Most of the time	About half the time	Sometimes	Never
○	○	○	○	○

How has you centre adapted exercise **training** in light of the pandemic (e.g. video tests, home visits, stopped altogether, no change)

What have been the major barriers to delivering exercise services (testing and training) during the pandemic?

What resources have you found to benefit your team in during the pandemic?

Are there any changes you have made due to the pandemic that you **intend to keep and/or maintain?**

What questions have **your patients** been asking you in relation to exercise and COVID-19?

Have you been able to confidently answer your patients questions?

- Yes
- No

Do **you** have any questions with regards to exercise and COVID-19 for cystic fibrosis that you would like answering/addressing?

Do you have any final comments on exercise and COVID-19 in your centre?

Supplemental File 2. Additional details on exercise testing from respondent centres.

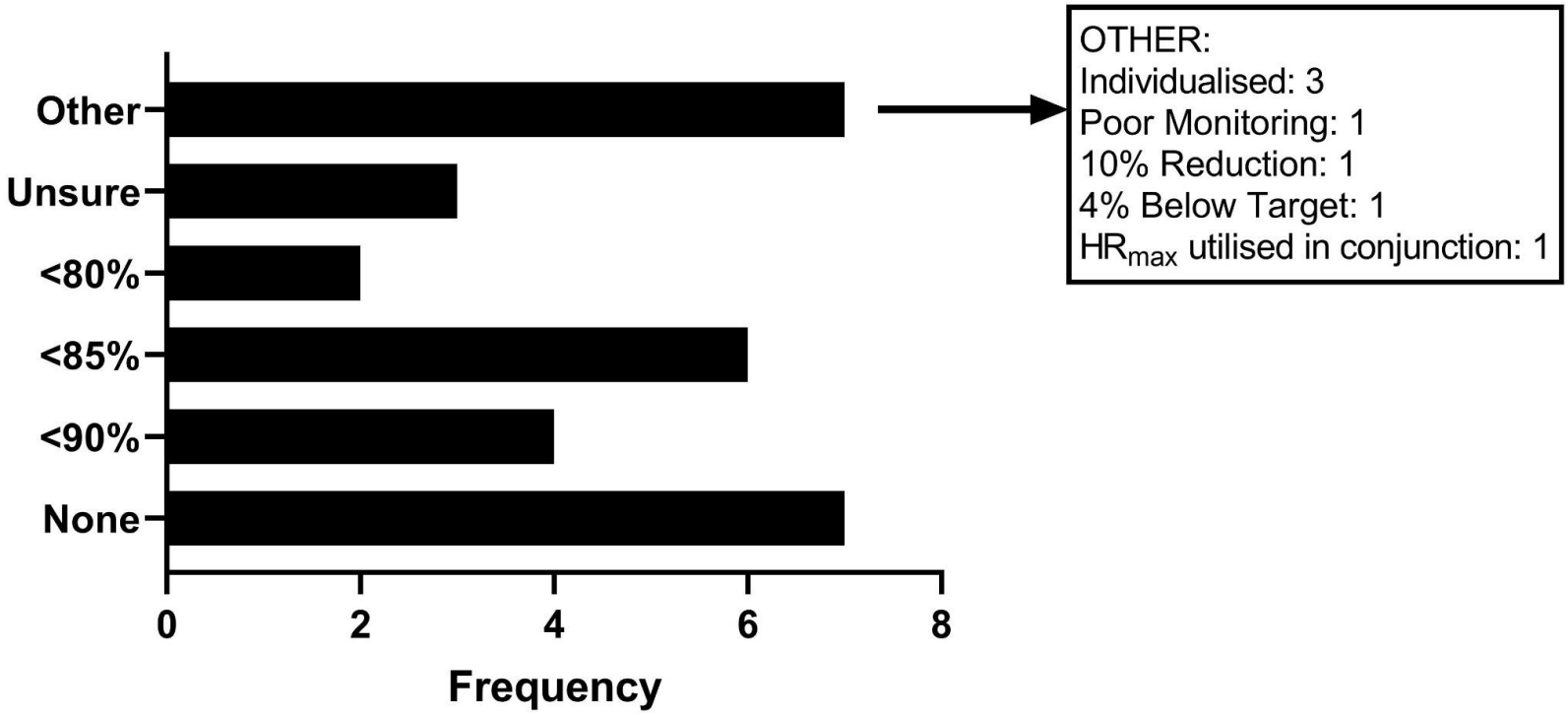


Figure S2.1. Frequency of desaturation criteria utilised by individual centres for exercise testing.

Table S2.1. Direct qualitative quotes referring to reference equations used.

Quotes
"MSWT: (15L) Pred distance -Probost VO_2 Peak - Cooper and Storer VO_2 Peak – Neves"
"All values used to evaluate test. HR, VO_2, Max Watt, SpO_2, Perceived effort. We are working with [Redacted] University to formulate a %predicted for the VO_2 to help evaluate the test with our patients and MDT"
"Compared to previous years predicted 6MWT averages"
"Wasserman"
"If child is unable to do CPET, i.e., too small, equipment not available we would do MSWT"
"Werkman et al (2013) Non gas tests Values provided by equipment for gas tests"
"We look at minimal clinical important difference for walk and shuttle testing. Norms."
"These are done by our respiratory physiologist - different values for different parameters."

N.B. 9/29 (31%) of centres stated they used reference equations, but only 8/9 (89%) provided details as above.

Table S2.2. Additional details on protocols used to perform CPET in respondent centres.

CPET protocol used	Ramp-Incremental, *n* = 11 Step-Incremental, *n* = 2 Other (respondent was unsure), *n* = 1
Qualitative descriptions of protocols	"We have a clinic room with a bike. The tests have been carried out for us by a PhD student until exercise testing stopped with COVID. Equipment is a sats [SpO_2] and HR monitor, gas exchange mask." "Incremental ramp test. Starting at 50W and 10W increments every minute." "All conducted by Exercise Physiologists using their own protocol and equipment." "Based on the Godfrey test, using our exercise bike (now condemned as broken) increasing resistance increments every minute until failure. Now reliant on step test when able to do within clinic setting in clinic room with physio doing testing and Borg assessment of breathlessness as well as sats [SpO_2] monitoring." "CPET as add on to end of surgical list. 1 slot per week at set time. Small, poorly ventilated room, crowded, inconsistent test report summaries. Godfrey protocol currently but aiming to work to incremental protocol with smax [supramaximal] verification when services resume post COVID and to be physiologist and CF physio led. Mouth piece currently but will be moving to face masks. Ear lobe oximetry. Visual cadence screen. BORG/RPE Scores. ECG, spiro, BP. Physio discusses results in clinic in order to guide exercise but interpretation of results needs guidance-further support to maximise this." "CPET test, specific allocated space with treadmill, protocol and physiologists." "Cortex Metalyzer 3B-R3 with Lode ergometer Incremental Ramp protocol + Supramax test 1 small gym 1 staff member completing CPET's." "Consultant and respiratory physiology complete the CPET testing,"

	"Use of [Redacted] University facilities to carry out the CPET testing for patients. Use of [Redacted] University staff i.e., student physiologists previously."
	"Godfrey Protocol, respiratory physiology staff CPET full gas analysis Small well ventilated room."
	"Godfrey protocol 1 member of staff BP, HR, SaO_2 and Borg scores."

BP: blood pressure; CPET: cardiopulmonary exercise test; ECG: electrocardiogram; HR: heart rate; RPE: rating of perceived exertion.

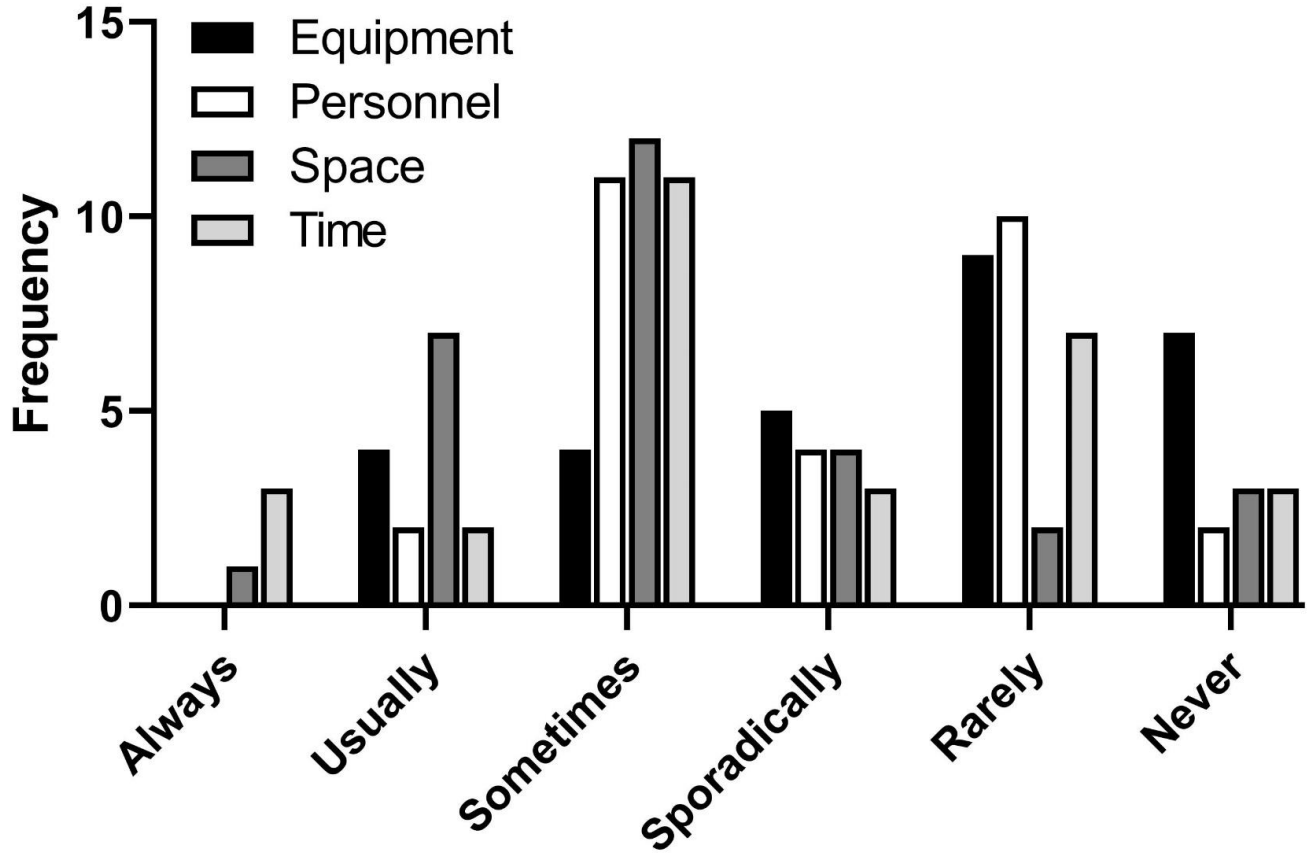


Figure S2.2. Frequency with which predominant barriers to exercise testing occur in respondent CF centres.

Table S2.3. Open comments on exercise testing in respondent cystic fibrosis centres.

Quotes
"We have struggled to complete any during COVID but are keen to use STS virtually and get back to CPET as soon as able."
"We have an access to exercise lab run by respiratory physiologists. We do not use this resource however as it's deemed too expensive of a test sadly which is why Physio team have settled for second best test in our opinion - Modified Shuttle Walk Test. The pandemic required us to be more inventive and we implemented Chester Step Test as an interim monitoring tool. It appears that the uptake of patients performing the test have been much better when compared to maximal exercise test (CPET or MSWT)."
"The work we are doing to establish a percent predicted for VO_2 and fitness should allow for patients fitness to be more objectively understood within our centre."
"Have previously tried to access exercise test at specialist centre but their resources limited."
"Not specific and difficult to decide where on the scale each child should as no reference data."
"Currently trying to implement 6MWT on admission and discharge from ward for IV antibiotics."
"I think it is of limited value in paediatrics. It is very useful in adults."
"We completed around 100 exercise tests in 2019 - not able to easily determine why each test was done from the data available. Majority would be for exercise prescription, evaluation of fitness and determine impact of intervention."
"It is our aim to do better in this area but we are limited by equipment and step test does not often trigger any response in our very well children. We were previously very motivated following the Nuffield rollout in our area and other local gym involvement but COVID among other things have reduced our ability to do this at all now."
"Even more essential with the advent of modulators to establish lung limitations vs de conditioning to maximise benefits of exercise."
"Currently in discussions with a nearby university to see if we can use CPET with them as a joint project (they already have CPET)."
"I think our centre works well with CPETs but that's largely due to a particular consultant being very passionate about it and helping the team to

understand results in a meaningful way to be able to devise exercise plans."
"CPET equipment issue for most of 2019 cause centre to only complete approx. 20% of patient tests, this was then followed by the pandemic which caused us to pause the CPET service."
"Certain tests are completed by different teams, e.g., CPET by physiology and Field tests by physiotherapy."
"New CPET service starting in 2020-2021."
"We feel exercise testing is very important but don't feel the incremental step test is a sufficient test within paediatrics and is sub optimal."
"Would like more guidance/advice on exercise prescription."
"This has been more difficult over the past 12 months which has been frustrating and I view this will continue to be an issue in 2021."
"Aim for 2020 was to introduce CPET, had started stakeholder engagement work with Anaesthetists which was going well. Unfortunately had to put on hold due to COVID."

CPET: cardiopulmonary exercise testing; MSWT: modified shuttle walk test; STS: sit to stand; VO_2, volume of oxygen consumption.

Supplemental File 3. Additional details on exercise training from respondent centres.

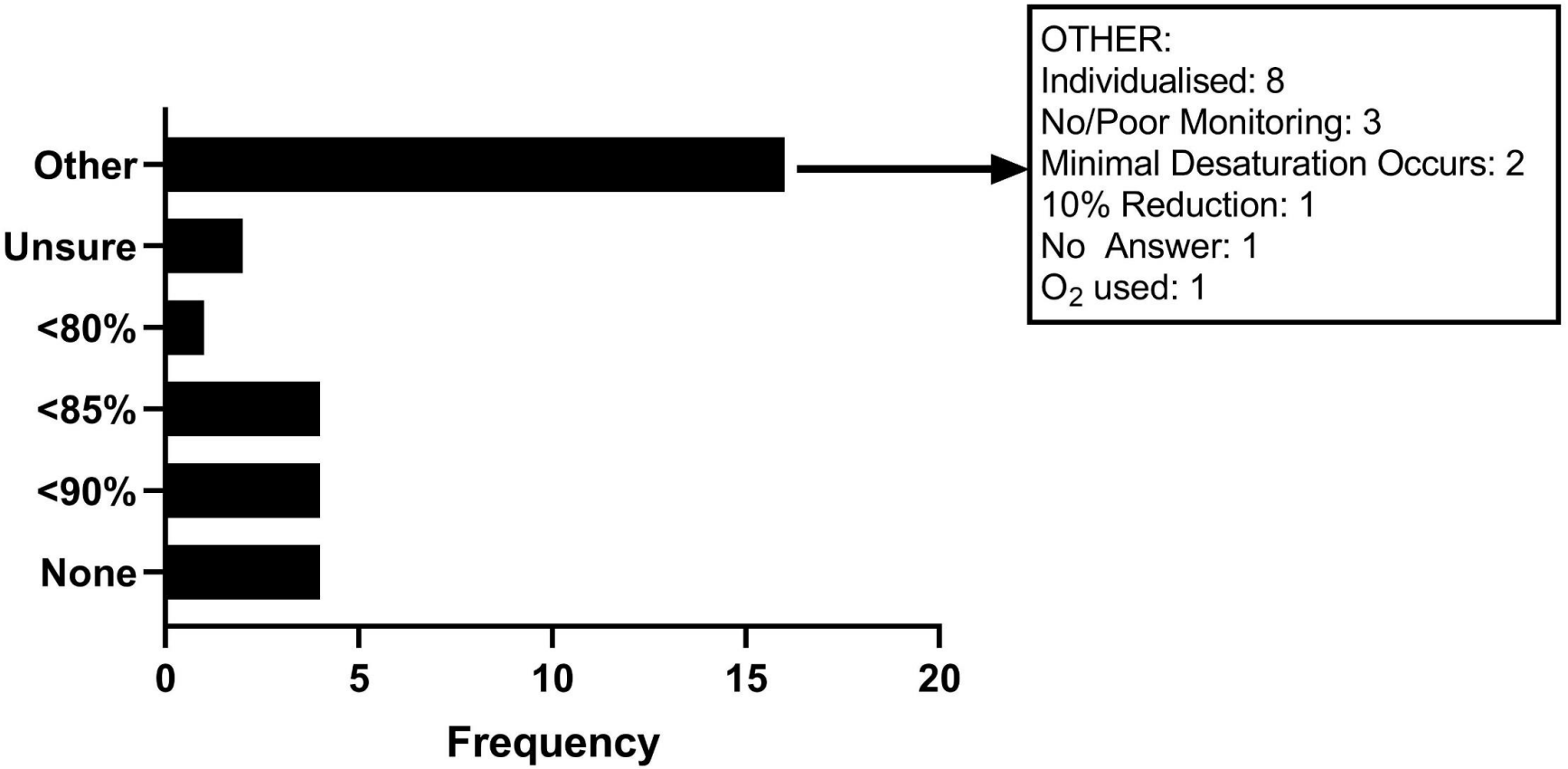


Figure S3.1. Frequency of desaturation criteria utilised by individual centres for exercise training.

Table S3.1. Specific types of training programmes offered by cystic fibrosis centres.

Quotes
"Make up individualised programmes for patients. Joint discussions with patients and physio staff."
"Yes but not very often, independence in choosing favourable activities is proffered. If patient experiences issues (i.e.. due to physiological limitations brought on by disease progression) we would be more involved in modifying regular exercise routines. There is an exception for Pre-transplant patients when we try to offer 1:1 exercise sessions if required."
"Yes, individualised exercise prescriptions."
"At the moment only written or verbal advice rather than face to face delivery."
"Using polar heart rate monitors. We use polar coach to create and monitor our exercise programmes."
"If patient identifies specific need/goal then we can produce a training plan for them. Often direct them to more general resources."
"New video links with physiotherapist."
"We advise on specific activities and amount to do plus heart rate expectations also refer for personal training at local gym, where a supported programme is developed if the child takes up the offer."
"These are rare due to workload and space. Most kids are not keen on this."
"Exercise prescription and follow up either virtually or face to face."
"We write them individually for patients when needed. We did run an exercise programme over 5 weeks in the first lockdown for all our children 2 and above."
"Individualised programmes following physio assessment."
"Dependent on the patient and their need for further engagement."
"Yes, supervised training programmes and repeat CPET. "
"Training programmes designed by exercise therapist."

"Via the Nuffield gym scheme."
"Yes - individualised sessions 1:1, offered patients to cycle during clinic appointment or come in for an outpatient gym use./session during a clinic visit."
"We do occasionally but would like to be able to offer more and to be able to support virtually and regularly and provide joint sessions and follow up when our TI is fully trained. Where possible we try to offer individualised exercise programmes but these are loosely based on the exercise test and more aligned to the patients goals and interests."
"We have access to an online library where we can set up and share exercise programmes with patients."
"Variety of cardio and strengthening programs."
"Available but as a developing service with a predominantly well young cohort not had to complete a formalised programme as of yet."

Answers are in response to the question: "Does your clinic offer exercise training programmes for patients? If 'Yes', please describe".

Table S3.2. Specific activities discussed by CF MDTs with patients.

Quotes
"Yoga, couch to 5k 30 day challenges."
"Patient led/specific but often encouragement to explore Yoga in addition to other activities."
"We often reference online sites and videos such as Beam, The Body Coach etc. The above tends to depend on the individual and what they are likely to respond best to."
"We currently use our individual patient heart rate monitors to prescribe our exercise programmes. This will fit into our new exercise test and allow for more targeted heart rate programmes."
"Core training if problems identified, pelvic floor if issues with continence."
"Posture and correct breathing patterns, pelvic floor with exercise."
"Any high intensity sport, activity for cardiovascular and pulmonary function. In keeping with patients own interests to maintain motivation and compliance. Postural/core based exercises for postural control; physiotherapy individual tailored programme."
"Utilise the skills of team member with exercise training experience."
"Can be very variable dependent on the patient and Physiotherapist delivering the care."
"Patient specific exercises are discussed based on hobbies and engagement."
"Working towards programmes based on outcomes of exercise testing with more focus on improved reporting to enable this."
"Local activities to their address encouraged. Nuffield Gym programme. Exercise related to apps e.g., couch to 5km."
"Ambulatory exercises e.g., running programmes, walk to jog programmes."
"Encourage a mix of cardio, strength building, stretches and most importantly exercise they enjoy. We also encourage a lot of swimming, especially with the babies and we encourage family based exercise to encourage the family to have fun exercising together."

"Personalised programmes are given on request from patients and exercise tests will be looked at in these cases but it is not adopted generally. In children this can take the fun out of exercise for them."
"What patient enjoys, different sports or exercise classes."
"Have a predominantly well young cohort therefore can adopt a supportive general principle of engaging with exercise as part of daily life rather than individualised prescriptive programmes."

Answers are in response to the question: "What advice is given to patients on the topic of exercise training/physical activity?" whereby the answer of "Specific activities encouraged (please state)" was checked by respondents.

Table S3.3. Guidelines utilised by CF centres for exercise prescription.

Quotes
"Government guidelines e.g., 30 mins moderate exercise x 5 per week."
"National physical activity guidelines."
"To at least meet National physical activity guidelines. Poor performance in exercise test warrants extra interventions. ACSM guidelines for exercise prescription and progression."
"Scottish government recommendations for daily/weekly exercise."
"We reference physical activity guidelines and define moderate and vigorous intensity."
"Often use WHO but will often take smaller steps and move from say 1 session a week to 2."
"WHO guidelines, National physical activity guidelines."
"National and CF Trust guidelines."
"National physical activity guidance based on WHO guidelines."
"National guidelines and CF Nuffield health/GOSH scheme guidance."
"Government guidelines."
"ACSM guidelines. National guidance."
"Exercise and Habitual Physical Activity for People with Cystic Fibrosis: Expert Consensus, Evidence-Based Guide for Advising Patients CF Trust consensus document Physiotherapy management 2017."
"We encourage 60 mins activity/exercise a day as advised in national guidelines. We also discuss intensity of exercise - mild, moderate, and vigorous and examples of these."
"CF physio guidelines working papers on exercise in CF."
"National physical activity guidelines Benefits in regards to support airway clearance. Benefits in regards to bone health."

"National physical activity guidelines for children."
"National Physical activity guidelines, WHO guidelines, CF Trust guidelines, ACSM guidance."
"National physical activity guidance."
"National guidance."
"Discuss exercise in context of National Guidance via Public Health England etc."

ACSM: American College of Sports Medicine; CF: cystic fibrosis; GOSH: Great Ormond Street Hospital; WHO: World Health Organisation.

Table S3.4. 'Other' reasons for referring, prescribing, progressing, and supervising exercise training programmes in respondent CF centres.

How are patients referred for exercise training?	"From discussions between physio staff and patients."
	"Post exercise test - if outcomes are below predicted values we would offer input."
	"Every CF patient on our list gets exercise training as in-patient and out-patient."
	"We issue heart rate monitors to all patients over 6 and will look to establish all of these with a training programme."
	"No pathway."
	"Discussions in clinic with MDT."
	"Physiotherapists will decide based on clinic review whether or not they should have follow-up for this."
	"When we have assessed exercise in clinic or via an exercise test. This is usually highlighted by the physio team."
How are aerobic exercise programmes prescribed at your centre?	"Not formally prescribed."
	"Encouraged to pursue exercise that kids enjoy to improve adherence"
	"No requirements or information, just general advice written for specific interests, considering disease severity."
	"Aiming for all of the above but not yet in progress."
	"We don't 'prescribe' programmes. Just give general exercise advice based on their current levels and their annual exercise test."
	"Patient goals."
	"Not completed to date."

How are aerobic exercise programmes progressed at your centre?	"Functional goals."
	"Patient dependent goals short term/long term and review of progress/exacerbations/social etc."
	"Done on patient feedback and reporting. Many don't have them as they are very well and in normal times doing our gym scheme or in sports clubs."
	"Discussion, nil objective currently."
	"Via discussion re: progress and generally how they are getting on with their current levels."
	"Patient dependent."
	"Subjective measures from speaking with patient."
	"Patient feedback helps drive progression."
	"Patient goals."
	"Not completed to date."
What level of supervision do you have for outpatient exercise training?	"Not completed to date."
	"This is what we want to do more of."
	"Supervised if they come for an outpatient step-test. Other than this we don't offer outpatient exercise sessions."
	"Patients carry out at home."
	"It varies depending on the patients' needs and preferences."
	"We offer 2 x week virtual sessions but most sessions we expect patients to complete independently."

Entries that were reported as 'n/a' have been excluded from this table. CF: cystic fibrosis; MDT: multi-disciplinary team.

Table S3.5. Open comments on exercise training in respondent cystic fibrosis centres.

Quotes
“It’s a fast progressing area.”
“Not carried out on site. Depends on parents taking children and accessing the programme which very few do.”
“Need for support with exercise identified.”
“Exercise training in our centre is only a last ditch measure when the child is struggling to find an exercise strategy that suits them. Then it is carried out as a scoping exercise to find strategies that suit.”
“We are not meeting the exercise testing recommendation and we are very keen to do better but are limited in the pandemic and with staff, space and equipment but will continue to push and drive our service forward when possible.”
“Exercise consensus on protocol clarification -smax or not. Godfrey or not. Need to be all doing the same thing and so disseminating ‘how to’ guides for physiologists completing the tests who may not be familiar with CF would be beneficial and limit disparity and inconsistencies.”
Physiotherapists are often relied upon to provide the exercise advice and education to patients. Therefore, it is hard to 'prescribe' exercise without the full knowledge that a CPET can give you. Realistically we are not getting CPET any time soon so we need to think of what training we could utilise to help us advise our CF patients better.”
“Find it very difficult to do due to only having access to a static bike and gym room/area or other equipment.”
“It's not really needed for our patient population. we encourage exercise but they don't need a set programme.”

CF, cystic fibrosis; CPET, cardiopulmonary exercise testing.