

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

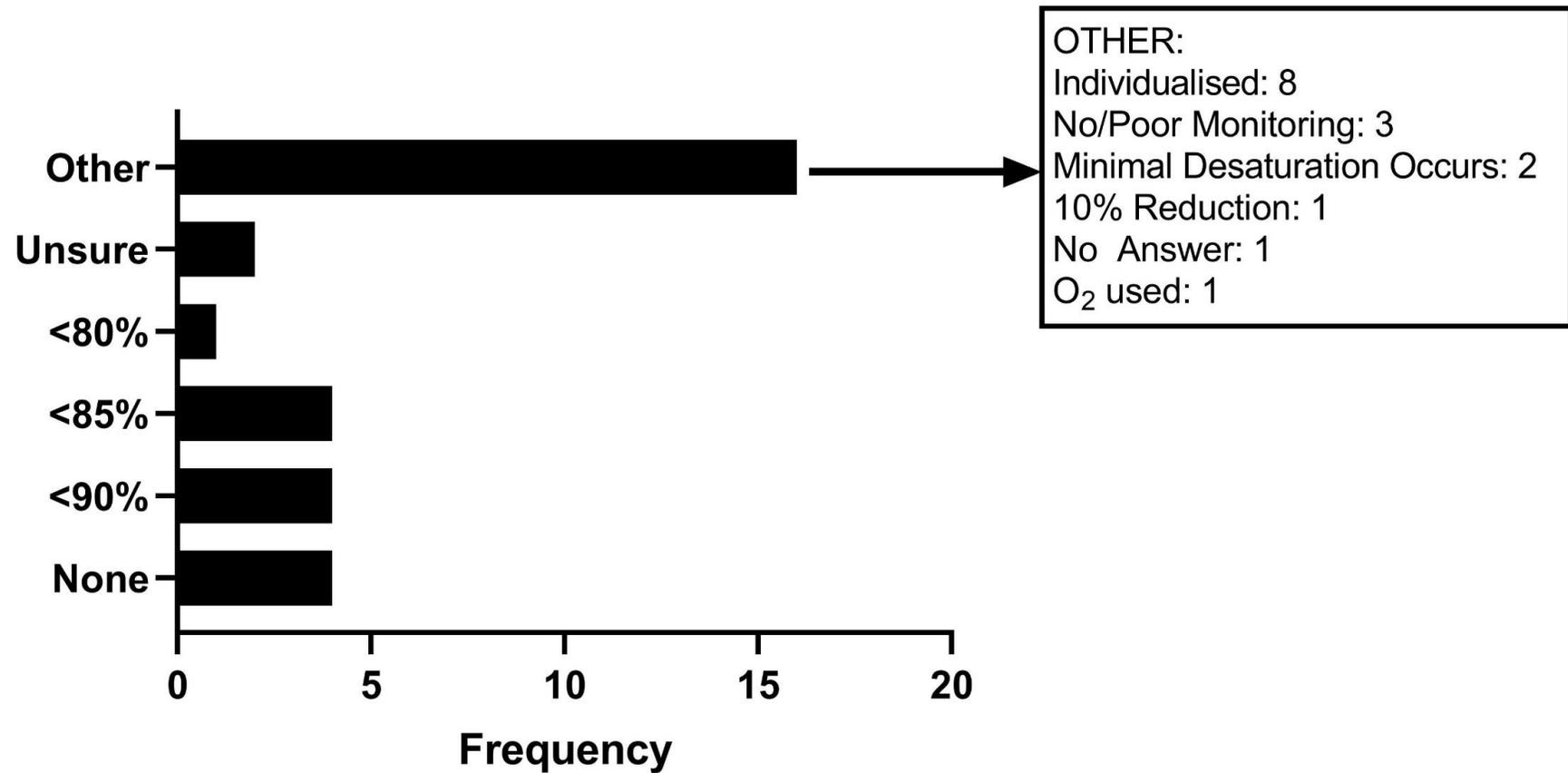


Figure S3.1. Frequency of desaturation criteria utilised by individual centres for exercise training.

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

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

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.