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### Paper:

Denford, S., Mackintosh, K., McNarry, M., Barker, A. & Williams, C. (2019). Promotion of physical activity for adolescents with cystic fibrosis: A qualitative study of UK multi-disciplinary cystic fibrosis teams. *Physiotherapy*  
<http://dx.doi.org/10.1016/j.physio.2019.01.012>

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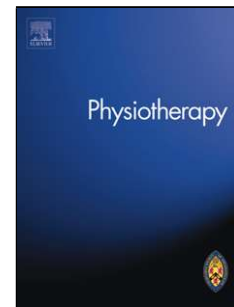
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## Accepted Manuscript

Title: Promotion of physical activity for adolescents with cystic fibrosis: A qualitative study of UK multi-disciplinary cystic fibrosis teams

Authors: S. Denford, K. Mackintosh, M. McNarry, A.R. Barker, C.A. Williams, on behalf of the Active Youth Unlimited Group



PII: S0031-9406(19)30032-X  
DOI: <https://doi.org/10.1016/j.physio.2019.01.012>  
Reference: PHYST 1091

To appear in: *Physiotherapy*

Please cite this article as: Denford S, Mackintosh K, McNarry M, Barker AR, Williams C.A. Promotion of physical activity for adolescents with cystic fibrosis: A qualitative study of UK multi-disciplinary cystic fibrosis teams. *Physiotherapy* (2019), <https://doi.org/10.1016/j.physio.2019.01.012>

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# Promotion of physical activity for adolescents with cystic fibrosis: A qualitative study of UK multi-disciplinary cystic fibrosis teams

<sup>1</sup>Denford, S., <sup>2</sup>Mackintosh, K., <sup>2</sup>McNarry, M., <sup>1</sup>Barker, A.R., <sup>1</sup>Williams, C.A.; on behalf of the Active Youth Unlimited Group

<sup>1</sup> Children's Health and Exercise Research Centre, Sport and Health Science, University of Exeter, St Lukes Campus, Exeter, Devon, UK

<sup>2</sup>Sports Science, University of Swansea, Bay Campus, Swansea, UK

Corresponding author

Dr Sarah Denford

Children's Health and Exercise Research Centre

St Luke's Campus

Baring Court

University of Exeter St Lukes Campus

Heavitree Road

Exeter EX12LU

Email: S.Denford@exeter.ac.uk

Phone: 01392 725906

Word count: 3048

## Abstract

### Background

The Cystic Fibrosis Trust recently published a standards of care document which stated that patients should be given a physical activity (PA) programme based on their motivations, fitness, and willingness to be active. However, there remains much debate regarding the roles and responsibilities for PA promotion, as well as “optimal” recommendations and advice. This study aimed to qualitatively explore cystic fibrosis (CF) multidisciplinary teams (MDTs) advice, recommendations and practices relating to PA promotion for adolescents with CF.

### Method

Semi-structured interviews were conducted with fifteen members of CF MDTs (11 physiotherapists, two dieticians and two paediatricians). Thematic analysis was used to analyse the data.

### Results

Major themes identified were: 1) structure of MDTs, 2) recommendations relating to intensities, durations and types of PA, and 3) use of exercise testing. Participants reported variation between MDTs in terms of who is responsible for promoting and supporting PA, the nature of advice given to patients, and the use of exercise testing. Participants consistently lacked confidence in their own or others’ knowledge to provide standardised recommendations to patients and highlighted that PA promotion and support was often overlooked during busy periods.

### Conclusions



Despite its importance, PA support and promotion is not always prioritised. MDTs lack confidence in their ability to promote PA. Standardised advice and training relating to optimal intensities, durations and types of PA would provide a baseline from which to individualise advice to each patient and could increase confidence in PA promotion among MDTs.

#### Contribution of the paper

- There is a significant lack of confidence among clinical team members in their ability to effectively promote physical activity for people with cystic fibrosis.
- Despite the importance of exercise testing and physical activity, its promotion is often neglected as a result of factors that could potentially be overcome.
- This study is the first to provide evidence of the urgent need for training and resources to support clinical teams promote physical activity.

#### Keywords

Cystic fibrosis; respiratory; youth; qualitative; physical activity; exercise

## Background

Physical activity (PA) [1, 2] and exercise [3, 4] is widely advocated for adolescents with cystic fibrosis (CF). Patients and members of CF multidisciplinary teams (MDTs) consider PA to be a priority in the management of CF [5, 6], recognising both its physiological and psychosocial benefits. Whilst studies have sought to identify whether youth's PA levels differ to age- and sex-matched controls, findings remain equivocal. Indeed, research has identified those with CF to have lower [7], equivalent [8, 9] or even higher [10] PA levels than their healthy counterparts. Given this lack of consensus, it is

unsurprising that there also remains debate about optimal intensities, durations and types of PA in adolescents with CF [4].

The Cystic Fibrosis Trust recently published a standards of care document which stated that all patients should be made aware of the benefits of PA and/or exercise, and should be prescribed a programme based on their motivations, fitness, and willingness to be active [11]. Recommendations state that patients should be advised to participate in at least 150 minutes of moderate-intensity PA, or 75 minutes of vigorous-intensity PA each week, with resistance training on two or more non-consecutive days [11]. The importance of exercise testing for patients over the age of 10 years is also emphasised. Specifically, exercise testing is advocated as an invaluable assessment tool, which can be used to identify PA limitations, aid in disease prognosis, and inform and assess the efficacy of PA prescriptions [11]. The cardiopulmonary exercise test (CPET) is considered the “gold standard” exercise test. However, whilst there are specific recommendations for those with CF these are targeted at adults and there are therefore, no specific recommendations for adolescents with CF. Despite the recognition of the importance of PA, in 2010 a survey of 96 adult and paediatric clinics in the UK found that PA and exercise

assessments are currently under-utilised in clinics [5] due to limited time, staff, facilities and equipment. More recently, previous research presenting findings from a series of meetings involving healthcare professionals with an interest in PA for CF found that, even among such a motivated and interested group, over 30% of delegates did not feel confident discussing PA with patients, only 13% of centres used CPET, and 100% of delegates wanted additional resources and training relating to PA promotion [12]. Further consideration of these issues are crucial to enable clinical staff to have the skills, and confidence needed to support patients to be physically active. Aims

The aim of this study was to qualitatively explore the advice, recommendations and practices of members of CF MDTs relating to PA for adolescents with CF.

## Methods

### Design

In this exploratory study, we used in-depth interviews to explore the advice and recommendations of MDTs current practice with regard to PA promotion for adolescents with CF.

## Participant sampling and data collection

Participants were recruited via opportunity sampling; physiotherapists, paediatricians, dieticians, and nurses currently on the Cystic Fibrosis Trust email distribution list received an email inviting them to take part in a short telephone interview. Fifteen participants responded to the invitation and provided written informed consent, including eleven physiotherapists (9 female), two consultants (both male) and two dieticians (both female). Using a semi-structured topic guide, participants were asked about their practices relating to PA promotion and exercise testing for adolescents (young people between the ages of 12 and 18 years of age). Participants were asked to think specifically about their practices in relation to this age group (Supplement 1). All interviews were audio recorded and transcribed verbatim. Ethical approval was obtained from the Institutional Ethics Committee (161207/A/03).

## Data analysis

Thematic analysis was used to analyse the data [13] using the software NVivo version 12. After reading and becoming familiar with the transcripts, an initial list of codes were developed independently by two researchers (author one and two). These authors then discussed their independent coding until a consensus was reached, and combined related codes into a series of themes. These themes were then presented to a third author (author 3) who ensured that the themes accurately represent the interview data [14]. Following the six stages of thematic analysis [13], thematic charts were developed for each theme, and corresponding interview text was cut and pasted into each chart [14]. Narratives were developed utilizing these charts [15]. Potential links between the data and existing theories were sought and noted [16]. We actively looked for data that did not fit with our developing narrative, discussed potential explanations, and modified the narrative accordingly. All emerging ideas were noted in the form of a reflective diary.

To ensure the validity of our findings, codes, themes and analyses were discussed with the wider research team on multiple occasions [16]. All participants were given the opportunity to comment on the results with four participants responding. All four respondents noted that they were in agreement

with our presentation of the data. Whilst it is possible that the analysis could have been influenced by our prior training and awareness of the literature, we were conscious of our pre-existing knowledge, and every effort was made to ensure that the code and / or the theme were evident in the raw data set.

## Results

### Participants

Fifteen (11 physiotherapists, two consultants, and two dieticians) from 15 cystic fibrosis clinics in the UK took part in semi-structured interviews with the lead author. Our sample includes male and female participants from a wide range of locations in the UK and professional backgrounds. Eleven participants were from paediatric centres, and four participants worked with both adult and paediatric patients.

### Results of the analysis

Results are presented under three headings: i) structure of MDTs; ii) recommendations relating to intensities, durations and types of PA; and iii) use of exercise testing.

### Structure of MDTs

Multidisciplinary teams varied in size and structure, knowledge and passion for the promotion of PA, and the roles and responsibilities of each team member with regard to PA promotion (Table 1). Whilst the majority of participants reported that the main responsibility for PA promotion lay with the physiotherapists, it was considered to be a task for all members of the team. Physiotherapists were viewed as having the time and knowledge to accommodate specific PA issues – but everyone should be promoting it (Quote 1). However, even physiotherapist's struggle to fit PA promotion into their day, and during busy periods, certain clinical activities (e.g., those focusing on PA promotion) would have to be cancelled (Quote 2-5).

All participants highlighted the need for additional support with at least one person whose time and energy could be dedicated to PA promotion. Three of the 15 centres currently had a member of staff who was employed specifically to support PA among patients. Such a role was considered to be invaluable and a huge benefit to the team and the patients (Quote 6), and the centres without such a role described how this would be beneficial (Quote 7).

Whilst all participants in the current study spoke of their passion for PA, it was recognised that not all team members were as knowledgeable or as passionate. This was considered critical for successful PA promotion, and it was suggested that those with an exercise background, or personal interest in PA, were better placed to promote PA than those who did not have such a background (Quote 8-9).

### Recommendations relating to intensities, durations and types of PA

Participants described how they are required to make recommendations in relation to various aspects of PA, including type, intensity, frequency and duration, and dealing with infection control (Table 2). In making such recommendations, some physiotherapists referred to guidelines written for people without chronic conditions, such as physiotherapy guidelines (Quote 1). None of our participants were aware of existing guidelines that are specific to people with CF (Quote 2-3).

As a result, participants' specific recommendations (i.e., intensity, frequency and duration) of PA varied – both between participants, and within participants for different patients. Although the difference between PA and exercise was not always explicitly mentioned, there was recognition that for some patients, PA was more appropriate than exercise. However, most importantly, recommendations were always individualised to the patient taking into consideration their needs and preferences.

Participants' recommendations relating to the intensity and duration of PA sessions were based on maximum heart rate (Quote 4); levels of intensity (Quote 5); and degrees of breathlessness (Quote 6). Recommendations relating to duration of PA sessions included a minimum duration (Quote 7), specific

targets (Quote 8); and upper and lower limits (Quote 9). However, participants noted that any recommendations should be dependent on baseline PA levels (Quote 10).

In terms of types of PA, a combination of cardiovascular, strength and flexibility training was considered optimal (Quote 11). Specific activities, such as running, yoga, Pilates, Zumba, trampolining and walking the dog were all mentioned (Quote 12) as examples of activities that could be performed by young people with CF. Such examples were intended to highlight the range of activities available to young people rather than being an exhaustive list of all activities endorsed by the team. The majority of the participants (13 of 15) did not feel that there were any limitations to what participants could do. Only two participants mentioned any caution and these related to high-intensity interval training (HIIT) and plyometric training (Quote 13-14). These cautions were based on clinical experience rather than formal recommendations.

It was noted that recommendations should be individualised on the basis of PA goals or simply in terms of what the patient enjoys doing. Very few participants explicitly mentioned the difference between PA and exercise, however, those who were aware of the distinction suggested that, for some patients, PA may be a more realistic option. Other participants alluded to this without explicitly referring to PA rather than exercise, and just promoted moving more (Quote 15). Ultimately, it was noted that the needs and preferences of the patient are crucial – even if they are not considered to be optimal (Quote 16).

### Use of exercise testing

Exercise testing was viewed as positive, but the type of test used, the interpretation of the results, and the way in which the results were used to inform treatment varied between clinics (Table 3). Participants referred to the importance of exercise testing for informing exercise plans and for prognostic purposes (Quote 1). Three or six minute step tests were commonly used (Quote 2), though these were considered to be sub-optimal in comparison with cardiopulmonary exercise testing (CPET), which was considered to be gold standard (Quote 3).



Common barriers and limitations to exercise testing included patient refusal (Quote 4), the test not assessing maximal capacity (Quote 5), and space and time limitations (Quote 6). Interpretation of test results was often confusing, with many participants unsure what a specific result meant (Quote 7).

There was considerable variation in the way in which the test results were used. In one centre, exercise test results formed the basis of exercise programs (Quote 8), other centres used the results to provide achievable goals (Quote 9), and other centres would simply keep test scores on record (Quote 10). One participant verbalised this variance, highlighting that better knowledge of how to use results of an exercise test is necessary (Quote 11).

## Discussion

This is the first study to explore, in-depth, the practices, advice and recommendations of members of MDTs relating to PA and exercise testing for youth with CF. Our findings complement and extend previous work that has explored the use of exercise testing [5] and PA promotion [12] by presenting detailed information on challenges faced by MDTs, as well as highlighting areas in which additional training and support is urgently needed. This study provides urgently needed evidence that action must to be taken to ensure physical activity recommendations are informed by evidence and guidelines, and that staff feel confident in the recommendations they provide.

### Multi-disciplinary teams

Whilst the majority of participants acknowledged that PA promotion was considered to be a whole team role, in accord with previous research [5, 12] there was recognition that it was largely undertaken by the physiotherapists. However, participants described that their time-constraints and work-load often leave them at full capacity, and PA sessions are consequently sacrificed. Tomlinson et al. [12] highlighted a range of highly-skilled tasks undertaken by MDTs in relation to PA promotion - above and beyond physiotherapy duties. Not only does this take considerable time, it also requires significant knowledge and training. The current study concurs with Tomlinson et al. [12] suggesting that

physiotherapists do not feel confident to promote PA. Within the current study, it was suggested that those with an exercise background, or personal interest in PA were better placed to promote PA than those who did not have such a background. Participants suggested that patients would benefit if MDTs incorporated an exercise specialist tasked solely with the promotion and prescription of PA for patients. Nonetheless, funding restrictions and limited budgets mean that developing such a role may not be possible; however, at the very least, protected time and adequate training is required for such a role to be carried out efficiently.

## Recommendations

The Cystic Fibrosis Trust Standards of Care and Good Clinical Practice for the Management of CF [11] state that, for individuals with CF, recommendations should include 150 minutes of moderate-intensity PA, or 75 minutes of vigorous-intensity PA per week. Those who are inactive and/or are limited in their physical capacity to exercise should be encouraged to accumulate 10-minute bouts of PA throughout the day [11]. It should be noted that this generic guideline is based on adult PA recommendations with no differences for paediatric patients. However, healthy children and adolescents have different guideline compare to adults. This distinction should be recognised by the CF community.

Whilst participants in the current study did not specifically mention the Cystic Fibrosis Trust standards of care, their advice and recommendations given were complimentary, although variation between centres exists. This may suggest that certain members of MDTs are not aware of the advice relating to PA in the standards of care, particularly members of the team who are not physiotherapists. Therefore, informing or educating members of MDTs of this advice may be beneficial.

Participants' suggested intensities for physical activity were significantly varied. In line with the standards of care recommendations, participants highlighted the relationship between intensity and duration, noting that higher-intensity PA should be of a shorter duration. However, recommendations for an "optimal" duration of PA ranged from thirty minutes per day to one hour per day, and from

three sessions per week to two and a half to five hours per week. Whilst specific advice relating to the type, intensity, and duration of PA were slightly different between clinics, in line with the Trust's Standards of Care [11], all participants described the need to consider patients' motivations and goals, circumstances, fitness, and willingness to be active when prescribing PA. Consideration of enjoyment is essential for long-term, sustainable PA behaviour change [17], as well as having an impact on patient's quality of life. Indeed, pleasurable PA with family members or peers is likely to lead to greater satisfaction and feelings of normalcy [18].

Participants recommended a range of strength, cardiovascular and flexibility work. In line with the Cystic Fibrosis Trust Standard of Care [11], Yoga and Pilates was also considered to be useful. Participants were cautious about the use of HIIT, suggesting that this should only be recommended for those with a certain level of fitness. Plyometric training was also avoided. As some studies have demonstrated positive effects of HIIT in CF [19, 20], further research into the relative benefits of such training for certain patients may be beneficial.

Our study is the first to show that participants have individual understanding of what "optimal" PA recommendations comprise; however, all participants acknowledge the need to tailor PA programs to the individual patient. However, participants were aware of the futility of recommending "optimal" PA programmes, particularly for participants not at all interested in PA. This is often an obstacle to progress; too much emphasis is often placed on the "best" training program and is likely to hinder the patient who is aiming simply to be more active. Whilst identifying the best way to optimise health from PA is important, this is not useful for patients who are not willing or able to achieve the level of PA needed. It is arguably more important to prescribe PA that patients can and will achieve over what is optimal.

Our findings show that there is an element of uncertainty surrounding the recommended intensity and duration of PA for people with CF. Whilst standards do exist [11], the quality of evidence is rated low-to-moderate, indicating that further research is needed to standardise PA advice and

recommendations [2, 4]. Additional training for members of the MDTs is clearly required to enhance confidence in prescribing and discussing PA with patients, as well as combining “optimal” recommendations with patients’ individual motivations and circumstances. Initiatives such as “Exercise is Medicine”, and the growing enthusiasm for broadening medical curriculum have made substantial progress in addressing some of these issues and building necessary skills [21].

### Exercise testing

Previous research found that, whilst MDTs valued the use of exercise testing, it was often under-utilised, with less than 40% and 30% of paediatric and adult patients, respectively, having had an exercise test in the past 12 months [5, 12]. Whilst the majority of participants in the current study reported using exercise testing with their patients, the type of test, interpretation and use of the results differed between centres. The three and six-minute step test and the modified shuttle test were reported by participants as standard practice, but the CPET was considered to be gold-standard despite only being used by a small number of MDTs. Participants stated time, space, and patient refusal were the biggest barriers to exercise testing, thereby highlighting the need for specific time to be allocated to this annual test. Moreover, MDTs often lacked a comprehensive understanding of the results of the exercise tests and were therefore limited in how they utilised them to inform patient-specific treatment, likely exacerbating patient refusals as the merit of the tests was not evident. In the majority of cases, test results were stored and used as a comparator for future test results. Indeed, participants highlighted the need for normative data in both healthy and CF peers to facilitate comparisons and goal-setting strategies for their younger participants. These findings not only indicate that further training is required for MDTs in relation to how data from all exercise tests are interpreted and used within clinics, but also for the need for further research to provide reference data. This is crucial if the use of exercise testing within clinics is to be maximised [12].

## Implications for policy and practice

Our study has a number of implications for policy and practice. First, our study highlights the need for the development of standardised recommendations relating to PA promotion for young people with CF. This would include evidence-based advice relating to the type, intensity, and frequency of PA for young people with CF, as well as recommendations for supporting PA behaviour change in this population. Second, training is required to ensure clinical teams are familiar with, and confident in their ability to adhere to, the recommendations. Third, considerable investment will be needed to ensure clinical teams have the time and funding to dedicate to the promotion of this critical aspect of treatment. Finally, additional training and support is required to ensure consistency in the conduct, interpretation, and use of exercise testing.

## Strengths and limitations

A key strength of the study is the use of qualitative methods to provide a rich account of MDTs current practices with regard to PA promotion, and the challenge they face. To enhance the trustworthiness of our study, we used multiple coders and asked respondents to validate our findings. During analysis, we triangulated our emerging results and the existing literature. However, our findings must be interpreted with a number of limitations in mind. First, our study was based on a small sample of 15 participants (11 physios, 2 doctors and 2 dieticians). As this is not fully representative of a UK cystic fibrosis clinic, relevant voices (e.g., nurses, exercise specialists etc) may have been missed. Secondly, all participants were from UK hospitals, thus may reduce the transferability of the results beyond this area. Furthermore, our use of opportunity sampling may have led to a biased sample of people who were interested in PA. Whilst there was still considerable variation in the practices, advice and recommendations given by our participants, we suggest that the richness of the data could have been improved with the inclusion of additional teams members; including those less enthusiastic about PA promotion. Potentially important information about the barriers to PA promotion could have been missed from those who chose not to participate; thus additional research and training is needed.

## Conclusion

Despite the known importance of PA and exercise testing, both are often under-utilised in CF clinics. The present study shows that MDTs vary greatly in terms of who is responsible for PA promotion, the advice and recommendations that are given to patients, and how exercise tests are used and interpreted. Although physiotherapy standards exist [11], their relevance to adolescents is unclear. Our findings highlight the need for changes to both policy and practice, with further training required for those responsible for PA promotion in individuals with CF, in order to develop standards of care that are widely accepted for this specific population.

Ethical approval was provided by the University of Exeter Sport and Health Science Ethics Committee (161207/A/03).

### Funding

This work was funded by the Cystic Fibrosis Trust. Grant number SRC 008.

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### Conflict of interest statement

The authors declare no conflict of interest

## Acknowledgements

We would like to thank the Cystic Fibrosis Trust for funding this study. We would also like to thank all the practitioners who volunteered their valuable time to participate in this study.

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Table 1: Structure of MDTs

Quote 1	<i>"I think all of us should be, in the CF team. I think the Physio's are the main ones with their experience and the time to hopefully to be seeing these patients for exercise but I think all of the team have a role to play to discuss activity with their patients" (Female Physiotherapist).</i>
Quote 2	<i>"We try and do three exercise sessions a week, but we've got a hundred and fifty children so it's not enough. It works out that we're doing an exercise session once every three or four months with someone"(Female physiotherapist)</i>
Quote 3	<i>"It's not just the initial promotion, it's the continuing support for that. And we just don't have the time"(Male Consultant)</i>
Quote 4	<i>"Our activity levels are very much dictated by our in-patient service. So if we have lots of in-patients then we'll have to cancel community visits for our out-patients" (Female Physiotherapist).</i>
Quote 5	<i>"We're struggling to manage to do lots of exercise sessions especially in the winter as well we have got a very restricted gym at the hospital...We are restricted with not enough bodies and not enough space (Male Physiotherapist)</i>
Quote 6	<i>"[The role] is invaluable. I think really having the time and the expertise and, you know, being able to work individually with each patient – as an individual to work out a really tailored exercise plan. Yeah it's crucial" (Female Dietician)</i>
Quote 7	<i>"I think it is in an ideal world, if we could have a qualified person who is there to promote exercise so whether they've got a Physio or physiology, or PT [personal trainer], or coaching background. I think, I've been to European conferences, and they have in Wales a person whose job is to just to teach and do exercise with the adolescents" (Female Physiotherapist)</i>

Quote 8	<p><i>"I don't think there's a huge understanding from I mean one of the reasons I got my job was because I had the exercise experience and so I work in a team of Physio's and I was shocked that they didn't know what I would call basic gym weight exercises" (Male Physiotherapist)</i></p>
Quote 9	<p><i>"A wee bit harsh what I'm going to say, but I think that it's all very well to advocate it, but I think you have to participate in an activity yourself, because I don't think it's a good thing for me to say 'you need to be doing all this exercise' if I'm sat on my bum and not doing anything. And I think if you're an inactive person to be advocating activity I think the patients will see right through you. So it's a hard one I think everybody's responsible but I would rather it would be somebody that can actually enthuse a patient than somebody that says well you know you're meant to be exercising with someone less than enthusiastic about it" (Female Physiotherapist)</i></p>

Table 2: Recommendations relating to intensity, duration and types of physical activity

Quote 1	<i>"Well to fit in with the Association of Physiotherapist Guidelines, we say thirty minutes of out of breath exercises five times a week" (Female Physiotherapist)</i>
Quote 2	<i>"Yeah I don't think we have any sort of sets of protocols or advice. We will often do it dependent on...what their endurance is like with exercise, what they can tolerate at the time" (Female Physiotherapist)</i>
Quote 3	<i>"I'm not aware that there are CF Trust directions for exercise within CF I guess if we had some sort of consensus around what would be the recommended levels of activity for someone with CF" (Female Physiotherapist)</i>
Quote 4	<i>"So we would say between 60 and 80 percent of their max heart rate" (Male Physiotherapist)</i>
Quote 5	<i>"It needs to be at half an hour at least and be high-intensity for it to be classed as a Physio session" (Female Physiotherapist)</i>
Quote 6	<i>"I do sort of explain that ideally they need to be getting out of breath you know increasing their respiratory rate and the heart rate" (Female Physiotherapist)</i>
Quote 7	<i>"I would suggest that they try and be active... at least 5 or 10 minutes a day" (Female Physiotherapist)</i>
Quote 8	<i>"If you're over five, an hour of activity a day and with a lot of that being exercise to a more moderate or intense level" (Female Physiotherapist)</i>
Quote 9	<i>"I would say we would suggest two and a half hours to five hours a week but then that's additive so that they can say well I actually go for a walk with the dog on a Monday" (Female Physiotherapist)</i>
Quote 10	<i>"If they're starting at a baseline of zero they are not expected to go out and play football three times a week at a really high level but just trying to set more realistic goals for</i>

	<i>them that's anything more than what they are doing already so that it's achievable"</i> <i>(Male Consultant)</i>
Quote 11	<i>"We try and do a bit of cardio, a bit of strength work and some core or postural stuff so a bit of everything really" (Female Physiotherapist)</i>
Quote 12	<i>"We do a muscular skeletal assessment as part of the annual assessment which checks for pain, back pain and core stability as well. And with it, you know girls and mums if that's an issue we'll try and sort of promote Pilates and Yoga" (Female Physiotherapist)</i>
Quote 13	<i>"I just have to be careful promoting HIIT sessions because if they're kind of not very fit I don't want them to get injured really and that's the best way to do it in a HIIT session with no warm up and straight in. Full on high impact kind of stuff it does get you fit but you've got to have a certain level of fitness to begin with" (Female physiotherapist)</i>
Quote 14	<i>"The only ones I would refuse to do with patients are plyometrics and heavy high-intensity because plyometrics, unless I know the patient and I've worked with them for a while, I don't think their joints can cope because they are very prone to arthropathy and the impact, because of malnutrition, on the bones, well, I just wouldn't want to risk it with them" (Male Physiotherapist)</i>
Quote 15	<i>"We might focus slightly less on the exercise corner of our triangle and look at more physical activity and trying to maintain a base of activity so they're not taking the car everywhere, they're not getting a lift to every opportunity they are doing walking the dog, the lower level activities and still getting them some cardio benefits" (Male Physiotherapist)</i>
Quote 16	<i>"[The patient's choice of activity] might not be optimal, but it is a start. And it is better than not being able to do anything. It gives us something to work with. So it might not have the health benefits that we know comes with being active, but if they enjoy it, if</i>

	<i>they are still moving and being active and interacting with peers, then yes they are getting benefit from it. And it is a starting point” (Female Physiotherapist)</i>
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Table 3: Use of exercise testing

Quote 1	<i>Exercise is an important component of the patient's overall health and prognosis... and when we do the exercise tests, it is the actual standard, but it's not just the adherence to standards that we're looking to achieve... it's a really useful outcome for looking at prognostics for health" (Male Physiotherapist)</i>
Quote 2	<i>"At the moment with the, well it's the three-minute step test, which I don't think is a brilliant exercise test" (Female Physiotherapist)</i>
Quote 3	<i>"We don't do sort of the formal CPETs or exercise testing, but that would probably give us some better results" (Female Physiotherapist)</i>
Quote 4	<i>"A lot of people refuse to do [the modified shuttle], so it's not a good uptake" (Female Physiotherapist)</i>
Quote 5	<i>"We used to do the shuttle walk, modified shuttle walk, but we often found that they'd get to the end of it and they'll be able to keep going it wasn't like an accurate test" (Female Physiotherapist)</i>
Quote 6	<i>"I've just started doing some exercise tests. We've had trouble doing things because of space and time" (Female Physiotherapist)</i>
Quote 7	<i>"We've not got any direct comparisons for the younger age range. So that kind of limits what we can deduce. We obviously know the lower the value the less well they've done, but I think perhaps those things would be useful for trying to help us guide and inform patients on what they should be doing and where they dip compared to sort of the relative population. That's what the family want to know after we've done any exercise or any tests or any sort of intervention they and rightly so they want to be informed they want to know where that, what that actually means" (Male Physiotherapist)</i>
Quote 8	<i>"So we get a summary from control, and the person that runs the test, so whether they were limited by ventilation or deconditioning, and what their metabolic equivalents were</i>

	<i>at each level, and heart rate, and prescribed sort of exercise based on that” (Female Physiotherapist)</i>
Quote 9	<i>We will do a yearly as a minimum exercise test so we will always try and encourage them to do better than their last test or use that as a goal” (Female Physiotherapist)</i>
Quote 10	<i>“We keep that data and it will all go on their, it will be their annually for all the team to look at” (Female Physiotherapist)</i>
Quote 11	<i>“I think you’ll find quite a large variance as to what different people are using and if they, if they’re then what are they doing with that information because as I said it’s all very good collecting data for data’s sake but we need to know what the practical applications of what people are doing with that information when they collect, when they get the information back from an exercise test what do they then actually do with that?” (Male Consultant)</i>