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ARTICLE

# Promotion of exercise in the management of cystic fibrosis - summary of national meetings

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## Abstract

**Rationale, aims and objectives:** Physical activity (PA) and exercise are important in maintaining and improving health and wellbeing in people with cystic fibrosis (CF) and measures of exercise capacity are useful outcomes in monitoring disease progression. The roles and responsibilities of CF multi-disciplinary team (MDT) members in supporting PA and exercise have yet to be fully defined. This communication reports on national meetings of CF MDT staff whose interest is to improve and standardise person-centered exercise provision and testing as part of routine CF care. We also introduce the role of the physiotherapy technician in supporting PA interventions.
**Meetings:** The two meetings covered a range of presentations, discussions and workshops, focusing on the role of exercise and PA in CF management. Forty people from 15 NHS Hospital Trusts and 3 universities were asked to provide feedback *via* a questionnaire.
**Results:** The common roles and responsibilities of clinical staff involved in exercise testing and prescription are described, with a wide range of duties identified. In addition, physiotherapists were reported as the main MDT member responsible for exercise provision. The majority of teams reported discussing exercise at every clinical visit (57%) and felt confident in discussing exercise with patients (67%).
**Conclusions:** While this report highlights the current provision of exercise in CF MDTs, it also provides insight into the resources MDTs may require in order to enhance the profile of exercise within CF services, including enhanced training, guidelines and standardised clinical roles.

## Keywords

Activity, clinical personnel, clinical practice, exercise prescription, exercise provision, multidisciplinary clinical team, patient engagement, person-centered healthcare, physiotherapy technicians

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## Introduction

It is well established that physical activity (PA) [1] and exercise [2] are of benefit to patients with cystic fibrosis (CF). However, exercise testing and training are currently underutilised in CF clinics due to limited resources such as time, personnel, facilities and equipment [3], despite patients identifying the role of exercise as a top priority in the management of their condition [4]. This potential lack of external support can contribute to adherence issues experienced by patients with CF [5].

While all members of the CF Multi-Disciplinary Team (MDT) have a role in promoting PA, a survey of CF clinics

in the United Kingdom (UK) has shown that physiotherapists are the main MDT member responsible for exercise advice, testing and prescription [3]. There are a number of recommendations for the physiotherapy management of CF, which pertain to exercise testing and prescription. It is recommended that patients should have access to prescribed exercise programmes and should receive education and verbal and written support with exercise, as well as having the opportunity to exercise daily during hospital admissions [6]. In addition to this, patients should undergo an annual exercise test, with a cardiopulmonary exercise test (CPET) currently considered the gold standard [7], with further PA assessment using motion sensors and questionnaires being recommended [6].

Meeting such recommendations is only one component of the physiotherapy management of CF which also includes; CF clinic provision, musculo-skeletal review, incontinence assessment, nasal airway treatments, airway clearance treatments and inhalation therapies. Furthermore, it is acknowledged that the assessment of PA and exercise capacity, using motion sensors and CPET respectively, can be technical and require specific expertise [6]. In supporting the role of physiotherapists, psychologists will help motivate patients and dieticians can support the nutritional requirements of physical activity and optimal body composition, therefore highlighting the potential for an exercise professional to support duties relating to the provision of exercise.

The purpose, and use, of exercise professionals within general clinical practice, has been discussed previously [8]. However, unlike other clinical staff members [9,10], the role of such exercise-based clinical staff within the CF MDT has yet to be fully defined. Such definition will best be achieved by the sharing of good practice and the standardisation of roles and procedures.

Therefore, to further understand and enhance the role of person-centered exercise provision within the CF MDT, the current paper reports on two meetings held in August 2016 and February 2017, of healthcare professionals with an interest in the importance of exercise in CF care in the UK. This paper reports on the outcomes of these meetings, specifically in terms of current exercise provision within the CF MDT, the identification of staff members responsible for exercise promotion in the CF MDT (and their respective roles and responsibilities) and the reporting of the requirements in terms of exercise provision of all staff involved in exercise provision within the CF MDT.

## Meetings

### Meeting 1 - August 2016

Seven delegates from 5 National Health Service (NHS) CF Centres and one university from across the UK attended a one-day meeting at the Royal Devon and Exeter NHS Foundation Trust Hospital, UK, free of cost, with the purpose of exchanging best practice ideas and establishing a continuing network of non-physiotherapist professionals involved in utilising and promoting exercise and PA in CF management.

Given the small number of non-physiotherapist staff involved in exercise provision in the UK, attendees were invited to this meeting based upon ‘word of mouth’ and personal communications. Themes and topics discussed included the development of a uniform job description for those in a similar, but non-affiliated position, the potential to seek affiliation to a recognised body (to set standards and govern practice), the development of a continuing network and the exchange of clinical practices, including virtual clinics (use of *Skype*), CPET and the use of technology in engaging patients in exercise. Furthermore, it was verbally agreed to advertise the network broadly and invite additional attendees to a further meeting.

### Meeting 2 - February 2017

Following the initial meeting, it was agreed to host a second and to invite further members of the CF MDT to discuss exercise provision. Forty delegates from 15 NHS CF Centres (regional centres and networked clinics) and 3 universities, from across the UK, attended a free one-day event at the Children’s Health and Exercise Research Centre, University of Exeter, UK. This meeting was open to all healthcare professionals (30/40 attendees) and researchers (10/40 attendees) with an interest in CF and exercise and was again advertised through ‘word of mouth’ and personal contacts as well as details being circulated *via* the Association of Chartered Physiotherapists in Cystic Fibrosis group.

The content of this meeting was discussed among attendees of the previous meeting and consisted of sessions deemed important/useful by members of the network, including presentations on the clinical benefits associated with exercise, exercise testing and infection control. There were also interactive workshops on exercise testing, PA monitoring, behavioural change and patient engagement. There was also an open discussion on the roles of staff in exercise promotion and testing. Throughout, collaboration and sharing of best practice was encouraged to allow individuals to identify where their own clinical practice and resources differed from that of others.

As part of the feedback process, attendees completed 2 questionnaires. The first questionnaire (Table 1) related to current clinical practices within their own MDT. Where multiple representatives were in attendance from the same CF centre, attendees were asked to complete one survey per centre to avoid duplication. In addition, all clinical attendees were asked to complete a further questionnaire (Table 2) with a non-clinical focus, relating to the running of the meeting itself.

Questions (from Table 1) pertained to staff members responsible for exercise testing and prescription, as well as what resources would assist with exercise provision. Questions were presented on a 5-point Likert scale (with 5 as the maximum score), categorical responses produced quantitative feedback and open answers allowed for qualitative feedback. Questions from a prior survey [3] were used to provide an overview of current provision amongst CF centres represented at the meeting.

Table 1 Questionnaire relating to clinical practice

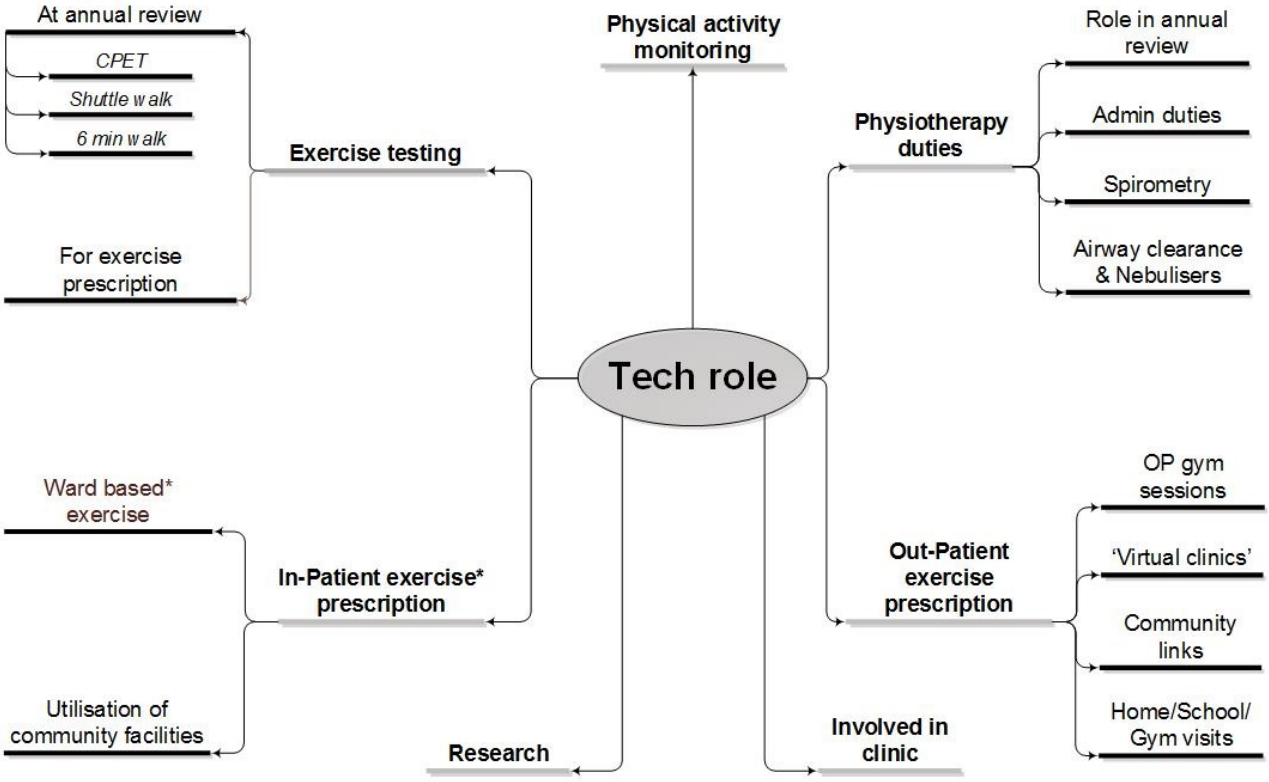
| | | | | |
|---|---|---|---|---|
| **Cystic Fibrosis and Exercise Questionnaire** | | | | |
| 1. | **Is your centre paediatric/adult/combined?** | | | |
| | ADULT | PAEDIATRIC | COMBINED | |
| 2. | **Who is primarily responsible for exercise provision in your MDT? Circle more than one if necessary.** | | | |
| | CLINICIAN/DOCTOR | NURSE | PHYSIOLOGIST | |
| | PHYSIOTHERAPIST | EXERCISE TECHNICIAN | MULTIPLE STAFF | |
| | OTHER (PLEASE SPECIFY) | | | |
| 3. | **What exercise testing (if any) is currently undertaken? And by whom?** | | | |
| | WALKING TEST (6 MIN) | WALKING TEST (12 MIN) | SHUTTLE TEST (INCREMENTAL) | |
| | STEP TEST | TREADMILL TEST (MAX) | CYCLE ERGOMETRY (MAX) | |
| | NONE | OTHER (PLEASE SPECIFY) | PERFORMED BY: | |
| 4. | **Who is primarily responsible for exercise training/prescription in your MDT?** | | | |
| | CLINICIAN/DOCTOR | NURSE | PHYSIOLOGIST | |
| | PHYSIOTHERAPIST | EXERCISE TECHNICIAN | MULTIPLE STAFF | |
| | OTHER (PLEASE SPECIFY) | | | |
| 5. | **How often do you currently discuss exercise prescription at clinics?** | | | |
| | EVERY VISIT | REGULARLY (1 IN 2 VISITS) | RARELY (MORE THAN 1 IN 2) | |
| | ANNUAL REVIEW | ONLY WHEN PATIENT REQUESTS | NEVER | |
| 6. | **What exercise advice is given? (e.g. discussions, written programmes, booklets etc.)** | | | |
| 7. | **How confident do you/your team feel in discussing exercise with your patients?** | | | |
| | NOT CONFIDENT AT ALL | | | VERY CONFIDENT |
| | 1 | 2 | 3 | 4 5 |
| 8. | **Do you feel you would benefit from additional exercise resources/training in exercise provision?** | | | |
| | YES | NO | | |
| 9. | **If yes, what would you like/find useful? (e.g. guidelines, video resources, apps, meetings, training, qualifications etc.)** | | | |

Table 2 Questionnaire relating to study day feedback

| | | | | |
|---|---|---|---|---|
| **Study Day Feedback** | | | | |
| 1. | **How useful was today at enhancing exercise knowledge for CF?** | | | |
| | NOT USEFUL AT ALL | | | VERY USEFUL |
| | 1 | 2 | 3 | 4 5 |
| 2. | **How useful was the advance information (agenda, transport, communication etc.)?** | | | |
| | NOT USEFUL AT ALL | | | VERY USEFUL |
| | 1 | 2 | 3 | 4 5 |
| 3. | **Will this help inform future practice in your own clinic?** | | | |
| | YES | | | NO |
| 4. | **If Yes – How? If No – Why not?** | | | |
| 5. | **What did you find useful today?** | | | |

| | | | | | |
|---|---|---|---|---|---|
| 6. | **What could be improved?** | | | | |
| 7. | **Which afternoon session did you attend?** | | | | |
| | CARDIOPULMONARY EXERCISE TESTING | | PHYSICAL ACTIVITY | | BEHAVIOUR CHANGE |
| 8. | **How useful was this?** | | | | |
| | NOT USEFUL AT ALL | | | | VERY USEFUL |
| | 1 | 2 | 3 | 4 | 5 |
| 9. | **What was useful?** | | | | |
| 10. | **What could be improved?** | | | | |
| 11. | **Would you attend a future meeting?** | | | | |
| | YES | | | | NO |
| 12. | **If Yes – How frequently? If No – Why not?** | | | | |

Figure 1 Schematic representation of the technician role within a multi-disciplinary cystic fibrosis team across multiple NHS trusts. *Common duties included in the job description of all technicians attending first meeting



Descriptive statistics and thematic summaries of the free text qualitative responses are presented.

## Results

### Meeting 1

The attendees of this first meeting held different job titles and subsequently had different responsibilities within their own MDTs, despite having an overall duty to cater for the exercise and PA needs of patients. The titles of attendees were as follows: *Therapy Practitioner in CF, Respiratory Technician, Physiotherapy Technical Instructor, Physiotherapy Technician, Therapy Assistant* and *Exercise Practitioner*. Attending staff members were from centres that were collectively responsible for 614 paediatric and 1200 adult patients, representing 14% of the paediatric and 21% of the adult CF populations of the UK respectively [11].

The common and differing roles and responsibilities of these staff members in terms of exercise provision are provided in Figure 1. Further discussion led to consensus among attendees that an established network of such professionals, with appropriate schemes for accreditation, training and affiliation, was required. Several organisations, such as the Health and Care Professions Council, Chartered Society of Physiotherapists, the Registration Council for Clinical Physiologists and the British Association of Sport and Exercise Scientists were suggested to provide a basis for such demands.

### Meeting 2

Attending clinical staff were from 5 adult centres (33%), 7 paediatric centres (47%) and 3 combined centres (20%), collectively responsible for 1336 paediatric and 2153 adult patients, representing 31% of the paediatric and 38% of the adult CF population of the UK respectively [11]. Attendees represented major and networked centres from across England, Scotland and Wales, with a variety of clinical roles attending, including: *Physiotherapist, Physiotherapy Assistant, Physiotherapy Technician, Therapy Technician, Physiotherapy Technical Instructor, Research Physiotherapist, Exercise Practitioner, Therapy Support Practitioner, Respiratory Clinical Physiologist* and *Consultant Paediatrician*.

Questionnaires (from Table 1) were returned from attendees from all 15 CF centres. Furthermore, 23/30 clinical attendees completed the questionnaire presented in Table 2. Ninety one percent of respondents rated the day as useful (4/5 or 5/5). Furthermore, all respondents stated that the meeting would inform future practice in their own clinics, as well as stating that they would attend a similar day in the future.

The majority of centres stated that physiotherapists were responsible for exercise testing (79%) and prescription of exercise training (75%; Figure 2). Fifty seven percent of MDTs discuss exercise prescription at every clinical visit; with another 29% discussing it regularly (at least alternate visits) and 14% rarely discuss it (less than alternate visits).

Figure 2 Responses to question surrounding staff members responsible for exercise within the CF MDT (Table 1, Q3 and Q4). More than one response was permitted if applicable

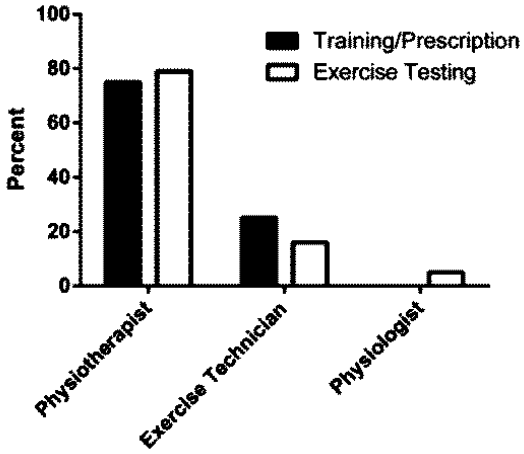
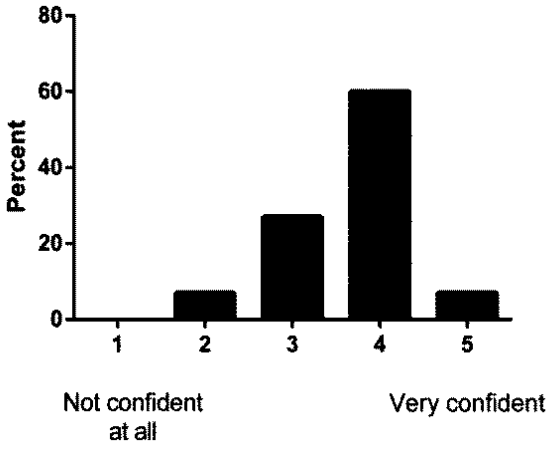



Figure 3 Responses to question "How confident do you/your team feel in discussing exercise with your patients?"




When asked to describe what exercise advice is given to their patients, delegates reported that advice included general discussions about exercise ($n$ = 7), general education (2), information about the benefits of exercise (2), information about how to exercise (types of exercise, frequency and intensity) (2), information about guidelines (2) and information about available applications (apps) or technology (4). Two delegates mentioned encouragement

and motivation and 8 delegates provided patients with written or verbal exercise programs.

Clinics performed a range of exercise tests at annual review, including gold-standard CPET [7], with 4 centres (27%) using cycle ergometery and 2 centres (13%) using a treadmill. Additionally, 73% of centres performed an incremental shuttle test, 53% performed the 6 minute walk test (6MWT) and 40% performed a step test. Tests are performed by various members of staff, including physiotherapists, physiotherapy technicians (exercise technicians) and physiologists which are external to the CF MDT (i.e., respiratory clinical physiologists).

When rating confidence in discussing exercise ("How confident do you/your team feel in discussing exercise with your patients?"), 67% of respondents felt confident in discussing exercise (rating 4 or 5 out of 5; Figure 3). Of respondents, 100% answered 'yes' to the question "Do you feel you would benefit from additional exercise resources/training in exercise provision?".

To elaborate on the previous question, delegates were then asked to discuss what resources would be useful with regard to exercise prescription. Six delegates noted that training courses and practical sessions would be beneficial. Videos, resources and applications were also mentioned (5). Delegates stated that the following would be useful: more meetings and other opportunities for collaborations (3), CF specific exercise guidelines (3), training on the interpretation of CPET results (1), information on how to engage patients (1) and 4 delegates highlighted the need for accreditation, qualifications, or standardisation of technicians' roles.

## Discussion

The purpose of the present paper was to discuss the roles and responsibilities of exercise professionals within the CF MDT and to provide quantitative and qualitative feedback from meetings of interested personnel in the provision of exercise within the CF MDT.

A number of NHS CF Centres in the UK now employ additional healthcare professionals to complement MDTs, relieve the workload of physiotherapists and assist with exercise provision. The roles of these professionals vary in title (personal trainers, physiotherapy technicians and physiology technicians among others) and responsibility, with specific duties differing depending on individual skills, the patient cohort, funding, capital infrastructure or equipment available. The first meeting of such professionals not only provided impetus for establishment of a network, but also provided the first categorical description of the different roles within the CF MDT that are responsible for exercise delivery, detailing key responsibilities, with results displayed in Figure 1. The only common duty among attending staff was the provision of in-patient and ward-based exercise. In contrast, there were a number of tasks that were not mutually undertaken by all - involvement in clinics, research, physical activity monitoring, exercise testing, outpatient exercise and physiotherapy duties. This represents a wide array of skills that can require specialised education and training.

Given the advent of international guidance on exercise prescription [12], refinement and implementation of defined roles within the CF MDT require further work. The physiotherapy technician/physiologist/exercise technician is potentially an important additional team member who could enable this. However, given the lack of uniformity in job descriptions, necessary qualifications, accreditation, roles, responsibilities and expectations, further discussions are warranted at both the local and national level. The practicalities of standardised service development and provision could be recognised by organisational impetus from national or international bodies (e.g., European Cystic Fibrosis Society), or by peer liaison and support - which was subsequently enabled by the secondary meeting of interested healthcare professionals.

Delegates at this second meeting found the day useful, citing that they would attend again. As exercise is considered a key requirement of CF management [6], it is prudent that clinical staff are given access to courses and educational resources to enhance knowledge and improve clinical care as well as contributing to their own continued professional development.

It is noted that physiotherapists are currently the key staff members responsible for exercise testing and prescription, which is consistent with previous findings [3]. However, while physiotherapists have traditionally held this role, it is worthy to note that other healthcare professionals (exercise technicians and physiologists) appear to have an increasingly important role within the MDT.

Unlike Australia [13] and Canada [14], two countries with similar prevalence of CF to the UK [15,16], there are no formal guidelines in the UK regarding ancillary exercise staff in the NHS. As the role is not a protected title (such as physiotherapists), there are no formal qualification criteria, or professional affiliations required to attain such a position. While advances have been made in CF Trust Standards of Care [6] with definitions of Therapy Practitioners, recommendations stop short of detailing fully-qualified exercise professionals. Furthermore, as National CF Service Specifications [17,18] do not mention these roles, it is subsequently desirable for there to be a clear 'top-down' (i.e., NHS) definition of roles and responsibilities of CF MDT members in relation to their support of PA and exercise provision and for this to include exercise technicians. The roles and responsibilities exemplified in Figure 1 make clear the independent nature of the role of the exercise technician (i.e., not being physiotherapists) and their unique skill set they can provide to the CF MDT. In addition, there would be a requirement for further support from physicians, hospital management teams and policymakers to actively value, recruit and efficiently utilise such exercise technicians. However, this will only be feasible if CF centres continue to value the role of exercise testing and training and have adequate resources available to them.

The results from meeting two provided updated evidence on the role exercise testing plays in the CF clinic.

While there is an increase in the utilisation of CPET since a previous survey [3], this again may be biased by the nature of the attending centres. However, it is encouraging to note that all centres were adhering to recommendations [6] and performing some form of exercise test annually. Furthermore, the results of this meeting also revealed the frequency with which exercise prescription is discussed with patients. Of the attending centres, 86% stated that they discuss exercise prescription with patients at least at every one in two visits, if not *every* visit. This is an encouraging statistic, but may be biased by the fact that attending delegates may have already had an increased interest in exercise and are therefore more likely to discuss this with patients - especially if their role was that of an 'exercise technician' (or similar non-physiotherapist allied healthcare professional). Details of what is discussed ranged from a generic "exercise is recommended", to an increased level of detail that may involve use of individualised programmes, applications, websites, diaries and even further referrals. This variety in responses provides scope for further development of standardised checklists, or a pro-forma, to guide practice and patient progress. Such a tool could be utilised by an exercise technician to prescribe individualised CF care and would align with recent calls for 'personalised' medicine, but fundamentally remain affordable [19]. However, the process required for such development and standardisation requires further investigation and collaboration.

Furthermore, it is worthy to highlight the confidence with which MDT members have in discussing exercise with patients. Of the respondents, 67% reported feeling confident in discussing exercise with patients, which is a positive finding. Contrastingly, a considerable number of respondents (33%) were either neutral, or not fully confident in discussing exercise with patients - a statistic that may in turn contribute towards the fact that exercise is not always discussed with patients, as previously discussed. This results in a number of individuals that are not confident in discussing exercise, with this number potentially being higher for individuals/MDTs that did not attend and may not place as a high a priority on exercise. Consequently, this is reflected in the fact that 100% of respondents felt they would benefit from additional, specific, training, resources and accreditation. This is a similar response to a previous survey in German CF centres [20].

These results provide a unique insight into the current provision of exercise within CF MDTs in the UK. However, they represent an opportunistic, cross-sectional view of a limited number of NHS Trusts and may be biased by answering questions following the study day as opposed to prior to it and the nature of attendees themselves - already being interested in the role of exercise management of CF. A further challenge will be to engage clinicians and CF MDTs that do not place an emphasis on exercise provision, whether by choice or necessity (i.e., funding, infrastructure). However, the views and requests of CF MDT staff clearly suggest that more work is required to increase resources and knowledge, to ensure an increased level of confidence and ability in person-centered prescribing and for discussing exercise with patients. Furthermore, it identifies the need to define and standardise roles, including new and complementary ones.

## Conclusion

The meetings discussed here have highlighted the roles and responsibilities that allied healthcare professionals have in using exercise to manage CF in UK MDTs as part of person-centered approaches to care. Furthermore, the role exercise plays in managing CF appears to be growing, successfully heeding the advice of national and international recommendations.

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