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1 **PROMOTION OF EXERCISE IN THE MANAGEMENT OF CYSTIC FIBROSIS –**
2 **SUMMARY OF NATIONAL MEETINGS**

3
4 **Running Title:** Exercise resources in cystic fibrosis

5
6 Owen William Tomlinson MSc ^{1, 2†}, James Shelley MSc ^{2, 3†§}, Sarah Denford PhD ⁴, Alan
7 Robert Barker PhD ⁵, Patrick John Oades MD ⁶, Craig Anthony Williams PhD ^{7*}

8
9 **Affiliations**

- 10 1. PhD Candidate; Children’s Health and Exercise Research Centre, Sport and Health
11 Science, University of Exeter, Heavitree Road, Exeter, EX1 2LU, United Kingdom.
12 2. Therapy Practitioner; Royal Devon and Exeter NHS Foundation Trust Hospital,
13 Barrack Road, Exeter, EX2 5DW, United Kingdom.
14 3. PhD Candidate; Physical Activity Exchange, Research Institute for Sport and
15 Exercise Sciences, Liverpool John Moores University, Liverpool, L3 3AF, United
16 Kingdom.
17 4. Research Fellow; Children’s Health and Exercise Research Centre, Sport and Health
18 Science, University of Exeter, Heavitree Road, Exeter, EX1 2LU, United Kingdom.
19 5. Senior Lecturer; Children’s Health and Exercise Research Centre, Sport and Health
20 Science, University of Exeter, Heavitree Road, Exeter, EX1 2LU, United Kingdom.
21 6. Consultant Paediatrician; Royal Devon and Exeter NHS Foundation Trust Hospital,
22 Barrack Road, Exeter, EX2 5DW, United Kingdom.
23 7. Professor of Paediatric Exercise Physiology and Director of Children’s Health and
24 Exercise Research Centre; Children’s Health and Exercise Research Centre, Sport and
25 Health Science, University of Exeter, Heavitree Road, Exeter, EX1 2LU, United
26 Kingdom.

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35 ***Corresponding author:**

36 Professor Craig A. Williams

37 Children's Health and Exercise Research Centre,

38 Sport and Health Sciences,

39 College of Life and Environmental Sciences,

40 University of Exeter,

41 St Luke's Campus,

42 Exeter, EX1 2LU

43 UNITED KINGDOM

44 Tel: 44 (0)1392 724890

45 Email: C.A.Williams@exeter.ac.uk

46

47 †Both authors contributed equally to first authorship

48 \$ James Shelley was a Therapy Practitioner at the Royal Devon and Exeter NHS Foundation

49 Trust Hospital when this project was undertaken. He is now a PhD Candidate at Liverpool

50 John Moore University.

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69 ABSTRACT*70 Rationale, aims and objectives*

71 Physical activity (PA) and exercise are important in maintaining and improving health and
72 wellbeing in people with cystic fibrosis (CF), and measures of exercise capacity are useful
73 outcomes in monitoring disease progression. The roles and responsibilities of CF multi-
74 disciplinary team (MDT) members in supporting PA and exercise have yet to be fully
75 defined. This communication reports on national meetings of CF MDT staff whose interest is
76 to improve and standardise exercise provision and testing as part of routine CF care. We also
77 introduce the role of the physiotherapy technician in supporting PA interventions.

78 Meetings

79 The two meetings covered a range of presentations, discussions and workshops, focusing on
80 the role of exercise and PA in CF management. Forty people from 15 NHS Hospital Trusts
81 and 3 universities were asked to provide feedback via a questionnaire.

82 Results

83 The common roles and responsibilities of clinical staff involved in exercise testing and
84 prescription are described, with a wide range of duties identified. In addition,
85 physiotherapists were reported as the main MDT member responsible for exercise provision.
86 The majority of teams reported discussing exercise at every clinical visit (57%) and felt
87 confident in discussing exercise with patients (67%).

88 Conclusions

89 Whilst this report highlights the current provision of exercise in CF MDTs, it also gives
90 insight into the resources MDTs may require in order to enhance the profile of exercise
91 within CF services, including enhanced training, guidelines and standardised clinical roles.

92

93 KEYWORDS

94 Clinical practice, prescription, activity, personnel, physiotherapy technician.

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1. INTRODUCTION

It is well established that physical activity (PA)¹ and exercise² are of benefit to individuals 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 equipment³, despite patients identifying the role of exercise as a top priority in the management of their condition⁴. This potential lack of external support can contribute to adherence issues experienced by patients with CF⁵.

Whilst 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 prescription³. 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 admissions⁶. In addition to this, patients should undergo an annual exercise test, with a cardiopulmonary exercise test (CPET) currently considered the gold standard⁷, with further PA assessment using motion sensors and questionnaires being recommended⁶.

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 expertise⁶. In supporting the role of physiotherapists, psychologists will help motivate patients, and dieticians 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 previously⁸. 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.

137

138 Therefore, to further understand and enhance the role of exercise provision within the CF
139 MDT, this document reports on two meetings held in August 2016 and February 2017, of
140 health care professionals with an interest in the importance of exercise in CF care in the UK.
141 This document aims to report on the outcomes of these meetings, specifically; current
142 exercise provision within the CF MDT, identifying staff members responsible for exercise
143 promotion in the CF MDT (and their respective roles and responsibilities), reporting the
144 requirements in terms of exercise provision of all staff involved in exercise provision within
145 the CF MDT.

146

147 **2. MEETINGS**

148 *2.1 - Meeting 1 – August 2016*

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

154

155 Given the small number of non-physiotherapist staff involved in exercise provision in the
156 UK, attendees were invited to this meeting based upon word of mouth and personal
157 communications.

158

159 Themes and topics discussed included; the development of a uniform job description for
160 those in a similar, but non-affiliated position, the potential to seek affiliation to a recognised
161 body (to set standards and govern practice), the development of a continuing network and the
162 exchange of clinical practices, including virtual clinics (use of *Skype*), CPET and the use of
163 technology in engaging patients in exercise. Furthermore, it was verbally agreed to advertise
164 the network broadly and invite additional attendees to a further meeting.

165

166 *2.2 - Meeting 2 – February 2017*

167 Following the initial meeting, it was agreed to host a second and to invite further members of
168 the CF MDT to discuss exercise provision. Forty delegates from 15 NHS CF Centres
169 (regional centres and networked clinics) and three universities, from across the UK, attended
170 a free one-day event at the Children's Health and Exercise Research Centre, University of

171 Exeter. This meeting was open to all health care professionals (30/40 attendees) and
172 researchers (10/40 attendees) with an interest in CF and exercise and was again advertised
173 through word of mouth and personal contacts as well as details being circulated via the
174 Association of Chartered Physiotherapists in Cystic Fibrosis group.

175

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

184

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

191

192 Questions (from Table 1) pertained to staff members responsible for exercise testing and
193 prescription, as well as what resources would assist with exercise provision. Questions were
194 presented on a 5-point Likert scale (with five as the maximum score), categorical responses
195 produced quantitative feedback and open answers allowed for qualitative feedback. Questions
196 from a prior survey³ were used to provide an overview of current provision amongst CF
197 centres represented at the meeting. Descriptive statistics, and thematic summaries of the free
198 text qualitative responses are presented.

199

200 **3. RESULTS**

201 *3.1 - Meeting 1*

202 The attendees of this first meeting held different job titles, and subsequently had different
203 responsibilities within their own MDTs, despite having an overall duty to cater for the
204 exercise and PA needs of patients. The titles of attendees were as follows: *Therapy*

205 *Practitioner in CF, Respiratory Technician, Physiotherapy Technical Instructor,*
206 *Physiotherapy Technician, Therapy Assistant and Exercise Practitioner.* Attending staff
207 members were from centres that were collectively responsible for 614 paediatric, and 1200
208 adult patients, representing 14% of the paediatric and 21% of the adult CF populations of the
209 UK respectively ¹¹.

210

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

218

219 3.2 - Meeting 2

220 Attending clinical staff were from five adult centres (33%), seven paediatric centres (47%),
221 and three combined centres (20%), collectively responsible for 1336 paediatric and 2153
222 adult patients, representing 31% of the paediatric and 38% of the adult CF population of the
223 UK respectively ¹¹. Attendees represented major and networked centres from across England,
224 Scotland and Wales were represented, with a variety of clinical roles attending, including:
225 *Physiotherapist, Physiotherapy Assistant, Physiotherapy Technician, Therapy Technician,*
226 *Physiotherapy Technical Instructor, Research Physiotherapist, Exercise Practitioner,*
227 *Therapy Support Practitioner, Respiratory Clinical Physiologist and Consultant*
228 *Paediatrician.*

229

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

235

236 The majority of centres stated that physiotherapists were responsible for exercise testing
237 (79%) and prescription of exercise training (75%; Figure 2). Fifty seven percent of MDTs

238 discuss exercise prescription at every clinical visit; with another 29% discussing it regularly
239 (at least alternate visits) and 14% rarely discuss it (less than alternate visits).

240

241 When asked to describe what exercise advice is given to their patients, delegates reported that
242 advice included; general discussions about exercise ($n = 7$), general education (2),
243 information about the benefits of exercise (2), information about how to exercise (types of
244 exercise, frequency and intensity) (2), information about guidelines (2) and information about
245 available applications (apps) or technology (4). Two delegates mentioned encouragement and
246 motivation, and eight delegates provided patients with written or verbal exercise programs.

247

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

255

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

261

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

270

271 **4. DISCUSSION**

272 The purpose of this report was to discuss the roles and responsibilities of exercise
273 professionals within the CF MDT; and provide quantitative and qualitative feedback from
274 meetings of interested personnel regarding the provision of exercise within the CF MDT.

275

276 *4.1 - Roles and Responsibilities*

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

291

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

302

303 Delegates at this second meeting found the day useful, citing that they would attend again. As
304 exercise is considered a key requirement of CF management ⁶, it is prudent that clinical staff

305 are given access to courses and educational resources to enhance knowledge, and improve
306 clinical care as well as contributing to their own continued professional development.

307

308 It is noted that physiotherapists are currently the key staff members responsible for exercise
309 testing and prescription, which is consistent with previous findings ³. However, whilst
310 physiotherapist have traditionally held this role, it is worthy to note that additional health care
311 professionals (exercise technicians and physiologists) appear to have an increasingly
312 important role within the MDT.

313

314 Unlike Australia ¹³ and Canada ¹⁴, two countries with similar prevalence of CF to the UK
315 ^{15,16}, there are no formal guidelines in the UK regarding ancillary exercise staff in the NHS.
316 As the role is not a protected title (like physiotherapists), there are no formal qualification
317 criteria, or professional affiliations required to attain such a position. Whilst advances have
318 been made in CF Trust Standards of Care ⁶ with definitions of Therapy Practitioners,
319 recommendations stop short of detailing fully-qualified exercise professionals. Furthermore,
320 as National CF Service Specifications ^{17,18} do not mention these roles, it is subsequently
321 desirable for there to be a clear 'top-down' (i.e. NHS) definition of roles and responsibilities
322 of CF MDT members in relation to their support of PA and exercise provision, and for this to
323 include exercise technicians. The roles and responsibilities exemplified in Figure 1 make
324 clear the independent nature of the role of the exercise technician (i.e. not being
325 physiotherapists), and their unique skill set they can provide to the CF MDT.

326

327 In addition, there would be a requirement for further support from physicians, hospital
328 management teams and policy makers to actively value, recruit and efficiently utilise such
329 exercise technicians. However, this will only be feasible if CF centres continue to value the
330 role of exercise testing and training and have adequate resources available to them.

331

332 *4.2 - Exercise Provision*

333 The results from meeting two provided updated evidence on the role exercise testing plays in
334 the CF clinic. Whilst there is an increase in the utilisation of CPET since a previous survey ³,
335 this again may be biased by the nature of the attending centres. However, it is encouraging to
336 note that all centres were adhering to recommendations ⁶ and performing some form of
337 exercise test annually. Furthermore, results of this meeting also revealed the frequency with
338 which exercise prescription is discussed with patients. Of the attending centres, 86% stated

339 that they discuss exercise prescription with patients at least every one in two visits, if not
340 every visit. This is an encouraging statistic, but may be biased by the fact that attending
341 delegates may have already had an increased interest in exercise and are therefore more likely
342 to discuss this with patients – especially if their role was that of an ‘exercise technician’ (or
343 similar non-physiotherapist allied health professional). Details of what is discussed ranged
344 from a generic “exercise is recommended”, to an increased level of detail that may involve
345 use of individualised programmes, applications, websites, diaries and even further referrals.
346 This variety in responses provides scope for further development of standardised checklists,
347 or a pro-forma, to guide practice and patient progress. Such a tool could be utilised by an
348 exercise technician to prescribe individualised CF care, and would align with recent calls for
349 ‘personalised’ medicine, but fundamentally remain affordable ¹⁹. However, the process
350 required for such development and standardisation requires further investigation and
351 collaboration.

352

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

364

365 These results provide a unique insight into the current provision of exercise within CF MDTs
366 in the UK. However, they represent an opportunistic, cross-sectional view of a limited
367 number of NHS Trusts, and may be biased by answering questions following the study day as
368 opposed to prior to it, and the nature of attendees themselves – already being interested in the
369 role of exercise management of CF. A further challenge will be to engage clinicians and CF
370 MDTs that do not place an emphasis on exercise provision; whether by choice, or necessity
371 (i.e. funding, infrastructure).

372

373 However, the views and requests of CF MDT staff clearly suggest that more work is required
374 to increase resources and knowledge, to ensure an increased level of confidence and ability in
375 prescribing and discussing exercise with patients. Furthermore, it identifies the need to define
376 and standardise roles, including new, and complementary ones.

377

378 **5. CONCLUSION**

379 The meetings discussed here have highlighted the roles and responsibilities that allied health
380 professionals have in using exercise to manage CF in UK MDTs. Furthermore, the role
381 exercise plays in managing CF appears to be growing, successfully heeding the advice
382 national and international recommendations.

383

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385 Funding for the initial meeting was provided to JS by the Royal Devon & Exeter NHS
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387 University of Exeter Open Innovation Link Fund.

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474 **FIGURE LEGENDS**

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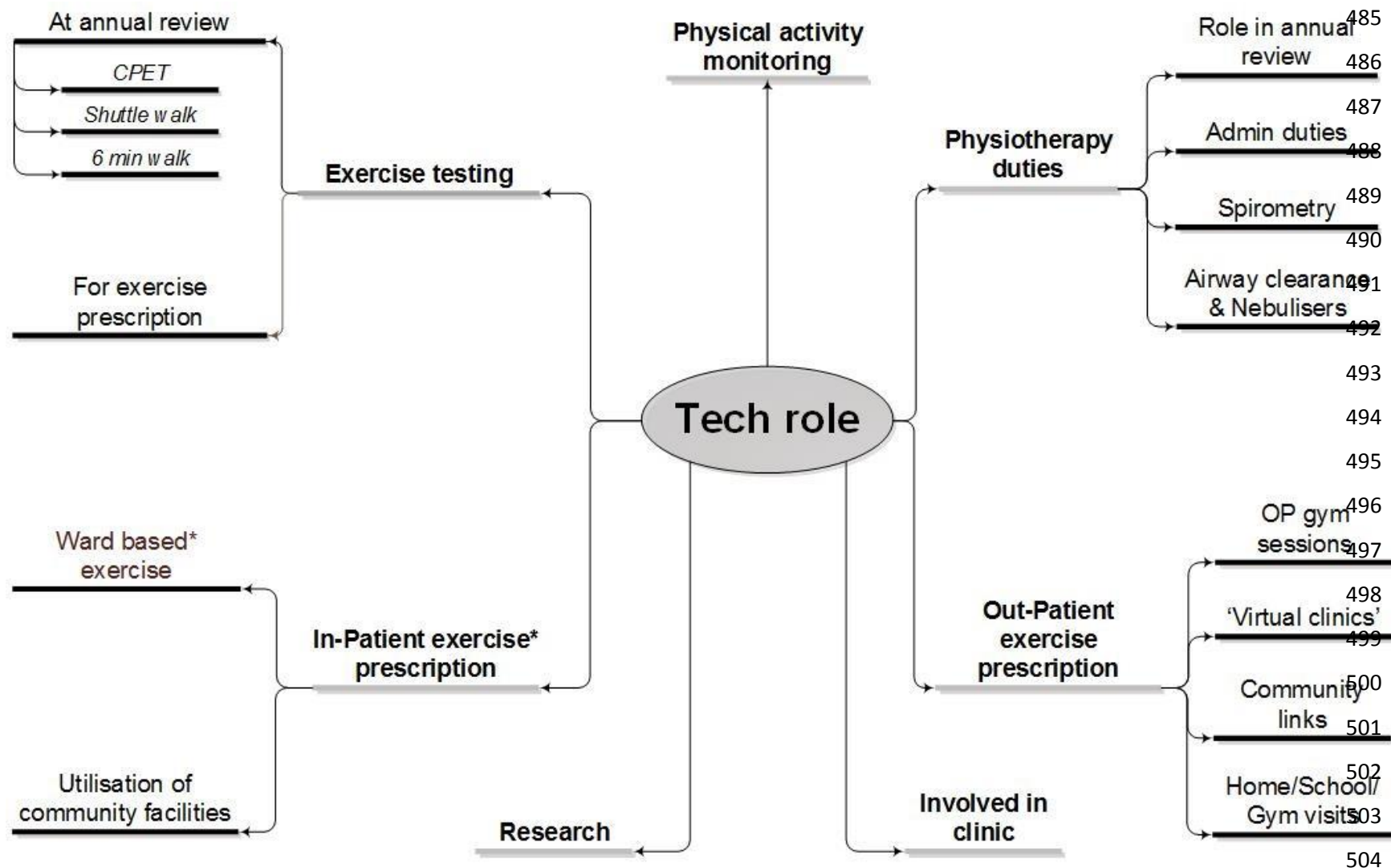
476 **Figure 1.** Schematic representation of the technician role within a multi-disciplinary cystic
477 fibrosis team across multiple NHS trusts. *Common duties included in the job description of
478 all technicians attending first meeting.

479

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

482

483 **Figure 3.** Responses to question “How confident do you/your team feel in discussing
484 exercise with your patients?”



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

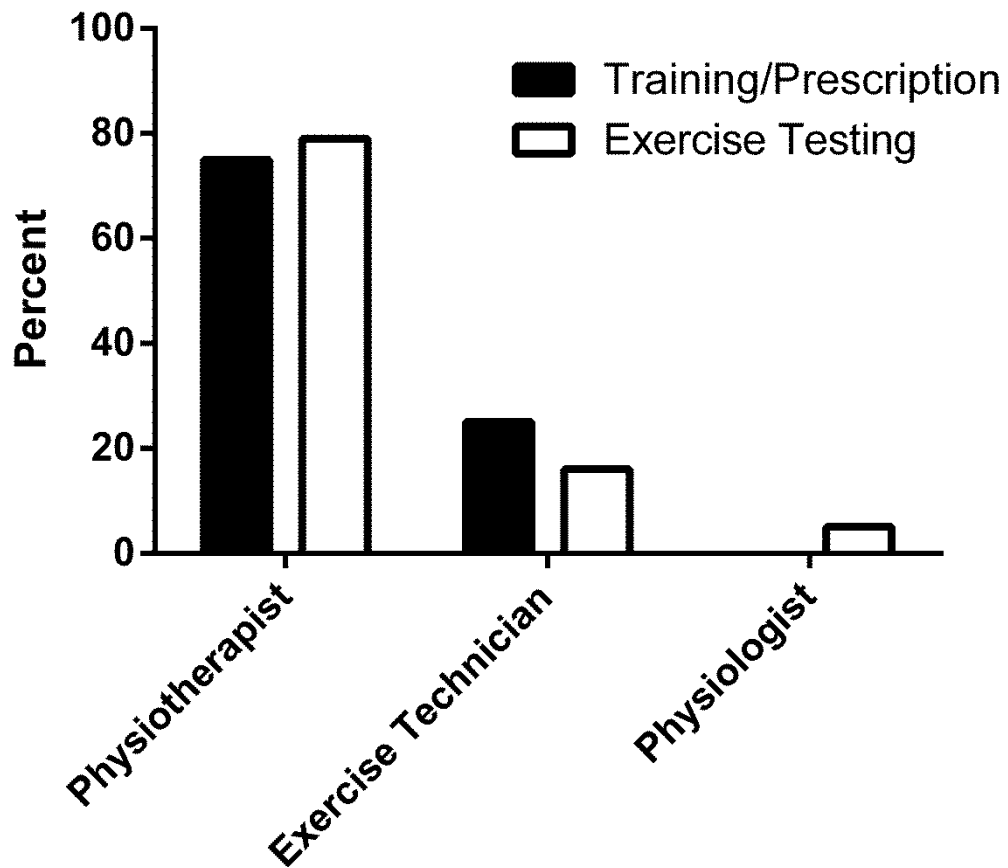
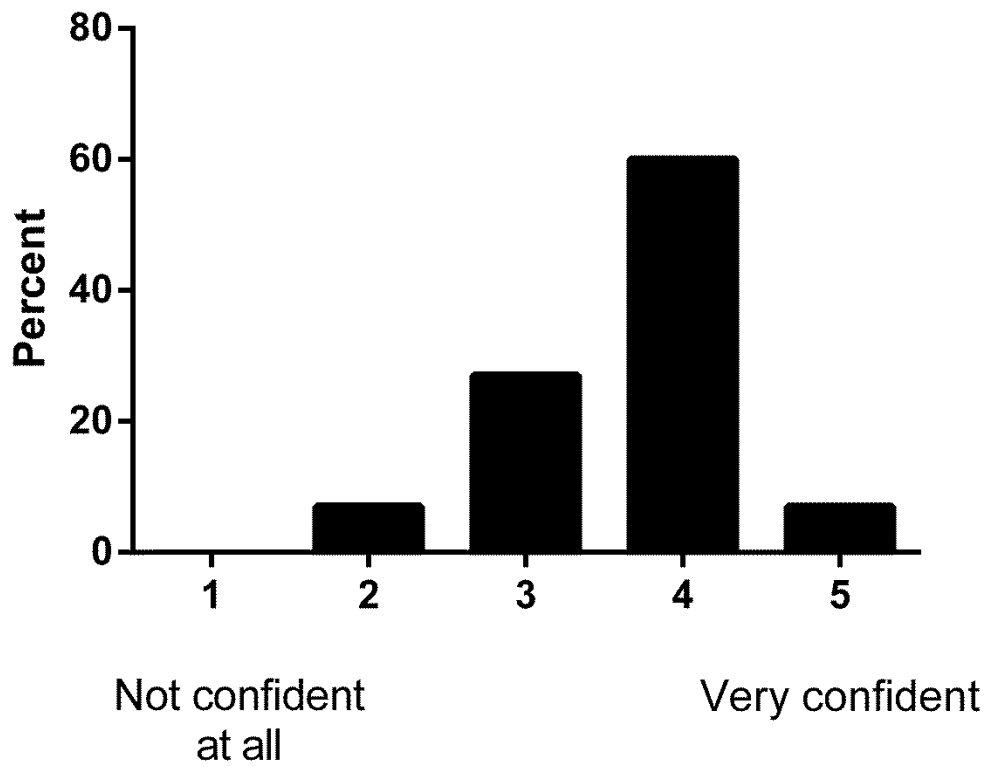


Figure 2. Responses to question surrounding staff members responsible for exercise within the CF MDT (Table 1, Q3 and Q4). More than one response was permitted if applicable.



557 **Figure 3.** Responses to question “How confident do you/your team feel in discussing
558 exercise with your patients?”

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575 **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.) | | |
| <hr/> | | |
| 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.) | | |
| <hr/> | | |

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581 **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 |
| 2. | How useful was the advance information (agenda, transport, communication etc.)? | | | |
| | NOT USEFUL AT ALL | | | VERY USEFUL |
| | 1 | 2 | 3 | 4 |
| 3. | Will this help inform future practice in your own clinic? | | | |
| | YES | | NO | |
| 4. | If Yes – How? If No – Why not? | | | |
| <hr/> | | | | |
| 5. | What did you find useful today? | | | |
| <hr/> | | | | |
| 6. | What could be improved? | | | |
| <hr/> | | | | |
| 7. | Which afternoon session did you attend? | | | |
| | CARDIOPULMONARY | PHYSICAL ACTIVITY | BEHAVIOUR CHANGE | |
| | EXERCISE TESTING | | | |
| 8. | How useful was this? | | | |
| | NOT USEFUL AT ALL | | | VERY USEFUL |
| | 1 | 2 | 3 | 4 |
| 9. | What was useful? | | | |
| <hr/> | | | | |
| 10. | What could be improved? | | | |
| <hr/> | | | | |
| 11. | Would you attend a future meeting? | | | |
| | YES | | NO | |
| 12. | If Yes – How frequently? If No – Why not? | | | |
| <hr/> | | | | |