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1 **TITLE**

2 Integrating home-based exercise training with a hospital at home service for patients  
3 hospitalised with acute exacerbations of COPD: developing the model using acceler-  
4 ated experience-based co-design.

5

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## 34 **CONTRIBUTORS**

35 All authors made a significant contribution to the work reported, whether that is in the  
36 conception, study design, execution, acquisition of data, analysis and interpretation,  
37 or in all these areas; took part in drafting, revising or critically reviewing the article;  
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60

## 61 **KEY WORDS**

62 COPD; exacerbations; rehabilitation; exercise training; integrated care; co-design.

63 **ABSTRACT (322 words)**

64 **BACKGROUND**

65 Hospital at Home (HaH) schemes allow early discharge of patients hospitalised  
66 with an acute exacerbation of chronic obstructive pulmonary disease (AECOPD).  
67 Traditional outpatient pulmonary rehabilitation (PR) following an AECOPD has an  
68 established evidence-base, but there are issues with low referral, uptake and  
69 completion. One commonly cited barrier to PR post-hospitalisation relates to poor  
70 accessibility. To address this, the aim of this project was to enrol service users  
71 (patients with COPD and informal carers) and healthcare professionals to co-  
72 design a model of care that integrates home-based exercise training within a HaH  
73 scheme for patients discharged from hospital following AECOPD.

74

75 **METHODS**

76 This accelerated experience-based co-design project included three audio-rec-  
77 orded stakeholder feedback events, using key 'touchpoints' from previous quali-  
78 tative interviews and a recent systematic review. Audio-recordings were induc-  
79 tively analysed using directed content analysis. An integrated model of care was  
80 then developed and finalised through two co-design groups, with the decision-  
81 making process facilitated by the Tables of Changes approach.

82

83 **RESULTS**

84 Seven patients with COPD, two informal carers and nine healthcare professionals  
85 (from an existing outpatient PR service and HaH scheme) participated in the  
86 stakeholder feedback events. Four key themes were identified: 1) individualisa-  
87 tion, 2) progression and transition, 3) continuity between services, and 4) com-  
88 munication between stakeholders. Two patients with COPD, one informal carer  
89 and three healthcare professionals participated in the first joint co-design group,  
90 with five healthcare professionals attending a second co-design group. These  
91 achieved a consensus on the integrated model of care. The agreed model com-  
92 prised of face-to-face supervised, individually tailored home-based exercise train-  
93 ing one to three times a week, delivered during HaH scheme visits where possible  
94 by a healthcare professional competent to provide both home-based exercise  
95 training and usual HaH care.

96

## 97 **CONCLUSION**

98 An integrated model of care has been co-designed by patients with COPD, infor-  
99 mal carers and healthcare professionals to address low uptake and completion  
100 of PR following AECOPD. The co-designed model of care has now been inte-  
101 grated within a well-established HaH scheme.

102 **MAIN TEXT (6453 words)**

103 **BACKGROUND**

104 Chronic obstructive pulmonary disease (COPD) is the third leading cause of death  
105 worldwide <sup>1</sup>, with acute exacerbations of COPD (AECOPD) contributing to one in eight  
106 emergency hospital admissions and over a million bed days per year in the United  
107 Kingdom (UK) alone <sup>2</sup>. Hospital at Home (HaH) schemes allow early discharge of  
108 patients hospitalised with an AECOPD to reduce the burden on health services without  
109 increasing the risk of readmission or mortality <sup>3-5</sup>. Over 80% of acute trusts in the UK  
110 have adopted a HaH model of care for hospitalised AECOPD <sup>6</sup> and usually comprise  
111 home-based management, typically under respiratory nurse supervision as an  
112 alternative to inpatient care. The treatment commonly offered includes provision of  
113 antibiotics, steroids, nebulisers and oxygen, supported by regular home visits to  
114 monitor treatment response <sup>7</sup>.

115

116 There are other significant and deleterious consequences of acute exacerbations  
117 which are not addressed by HaH schemes. Patients report decreased ability to  
118 complete activities of daily living <sup>8,9</sup>, reduced health-related quality of life (HRQoL) and  
119 worse psychological status <sup>10,11</sup>, with significantly decreased walking time and exercise  
120 capacity <sup>12,13</sup>. Following acute exacerbations, pulmonary rehabilitation (PR: a multi-  
121 disciplinary exercise and education programme traditionally delivered in an outpatient  
122 setting) has strong evidence to support improvements in exercise capacity and HRQoL,  
123 and reduced readmission and mortality rates <sup>14,15</sup>. As such, there is a clear mandate  
124 from clinical practice guidelines to routinely offer PR following an AECOPD <sup>16,17</sup>.  
125 However, referral for, uptake and subsequent completion of PR following an acute  
126 exacerbation is low <sup>18,19</sup> despite its availability becoming increasingly widespread <sup>20</sup>.

127 An audit of a UK service showed only 30% of eligible patients were referred for PR at  
128 hospital discharge, with less than 10% completing the programme <sup>18</sup>.

129

130 Recent systematic reviews did not identify any interventions from completed trials  
131 which increased referral for, uptake or subsequent completion of post-hospitalisation  
132 PR <sup>21,22</sup>. In addition, a contemporary randomised controlled trial investigating the effect  
133 of a co-designed education video intervention shown to patients admitted to hospital  
134 with an AECOPD prior to discharge was also unable to improve post-hospitalisation  
135 PR referral, uptake or completion <sup>23</sup>. As such, improving accessibility, one commonly  
136 cited barrier to low uptake of PR following an acute exacerbation <sup>24-26</sup>, is proposed.  
137 Delivery of PR in the home setting is one potentially attractive alternative to delivery in  
138 the traditional outpatient setting given the surprising failure of other strategies to  
139 address accessibility such as provision of free door-to-door transport <sup>27</sup>. The potential  
140 of the delivery of PR in the home setting post-hospitalisation is corroborated by recent  
141 trials of home-based PR in patients with stable COPD <sup>28-30</sup> and in a small pilot study  
142 with patients hospitalised with an AECOPD <sup>31</sup>.

143

144 This accelerated experience-based co-design (EBCD) project aimed to develop a  
145 model of care which integrates home-based exercise training within a pre-existing,  
146 well-established HaH scheme for patients hospitalised with an AECOPD ready for  
147 testing within a future mixed methods feasibility trial.

148

## 149 **METHODS**

### 150 **Design**

151 The accelerated EBCD project involved three stakeholder feedback events followed



152 by two co-design groups <sup>32</sup> (Figure 1). Using a co-design method to facilitate the  
153 development of this new model of care allowed for collective ownership and greater  
154 understanding of experiences from stakeholders (service users and providers), and  
155 ensured consensus was obtained from all stakeholders regarding strategies to  
156 effectively trial the model of care <sup>33</sup>. This approach was considered vital as qualitative  
157 work has shown stakeholder acceptability and fulfilling the needs of the end-user to  
158 be key requirements for successful model of care development <sup>34</sup>.

159

160 The PR service leads and HaH scheme managers were engaged with this project from  
161 the outset and endorsed this co-design process as a strategy to develop a model of  
162 care which would integrate home-based exercise training within the HaH scheme.

163

164 Ethical approval was not required as this EBCD project was considered a service  
165 improvement project by the Health Research Authority and The Point of Care  
166 Foundation <sup>32</sup>. Nonetheless, it was conducted in accordance with the Declaration of  
167 Helsinki and good clinical practice guidelines, with written informed consent obtained  
168 from all service users and healthcare professionals involved.

169

## 170 **Topic guides**

171 The separate healthcare professional and service user stakeholder feedback events  
172 were facilitated by REB, LJB and MF using topic guides developed based on key  
173 'touchpoints' informed by the findings from a recent systematic review (PROSPERO:  
174 CRD42018104648) <sup>35</sup>. Home-based exercise training appeared to be feasible and  
175 acceptable to patients hospitalised with an AECOPD and clinicians providing  
176 healthcare to this population from this systematic review. However, no family carer

177 perspectives were available. Patients valued the individualised, accessible, and  
178 flexible nature of home-based exercise training, and models using interval training,  
179 regardless of equipment, had enhanced compliance. Evidence of clinical effectiveness  
180 of home-based exercise training regarding physical function, HRQoL and health  
181 service utilisation was mixed, and conclusions limited by heterogenous measurement.  
182 Due to the limited data currently available, as shown by the systematic review, the  
183 conclusion drawn were that development of future home-based exercise training  
184 models of care would require collaboration with stakeholders to address uncertainties  
185 around optimal delivery strategies, need to explore the experiences and role of family  
186 carers and be piloted prior to testing in a full scale trial.

187

188 The topic guides were also informed by findings which arose from previous qualitative  
189 interviews conducted as part of a different project involving patients attending PR  
190 following an AECOPD. The findings from this previous qualitative work illustrated a  
191 lack of understanding and information provision before hospital discharge regarding  
192 PR, positive perceptions of home visits to provide support after discharge from hospital,  
193 the impact hospitalisation had on a decision to attend PR as well as the elements of  
194 outpatient PR they enjoyed and disliked (including regarding the education delivered  
195 within the programme) and home-based PR as an alternative delivery option.

196

197 The topic guide for the joint service user-healthcare professional stakeholder feedback  
198 event was developed inductively, informed by responses at the previous two separate  
199 stakeholder feedback events and observational field notes.

200

201 The co-design groups were facilitated by REB using group-specific agendas to areas

202 of uncertainty following the stakeholder feedback events in order to finalise the  
203 integrated model of care.

204

## 205 **Setting and structure for project stages**

### 206 *Stage 1 – Stakeholder feedback*

207 The healthcare professional stakeholder feedback event was held at Harefield  
208 Hospital: a tertiary hospital in north west London, which hosts the PR programme. The  
209 service user and joint service user-healthcare professional stakeholder feedback  
210 events were held in a community centre local to Harefield Hospital for the convenience  
211 of service users and to take the data collection out of a healthcare setting. These  
212 stakeholder feedback events were audio-recorded and scheduled on afternoons for  
213 four hours, with catering and refreshments provided at each. The events began with  
214 introductions and were structured with 15-30 minute whole or small group discussions.  
215 Regular breaks were taken between these discussions and prior to a 'round-up' at the  
216 end. Transport provision was offered to all service users, and mileage was paid to  
217 healthcare professionals.

218

### 219 *Stage 2 – Co-design groups*

220 After the stakeholder feedback events were completed, the co-design groups took  
221 place across two sites in north west London (Harefield Hospital and Hillingdon Hospital:  
222 the local district general hospital which hosts the HaH scheme). These two-hour co-  
223 design groups were scheduled on afternoons, with catering and refreshments provided.  
224 Transport provision was offered to all service users, and mileage was paid to  
225 healthcare professionals.

226

227 **Participants**

228 Healthcare professionals from the Harefield PR service and HaH scheme (Hillingdon  
229 Integrated Respiratory Service) were invited via their line managers to attend the  
230 stakeholder feedback events and co-design groups. Healthcare professionals were  
231 purposively sampled to ensure all members of the multidisciplinary team were included:  
232 clinical nurse specialists, respiratory consultants, qualified physiotherapists and  
233 physiotherapy assistants. The healthcare professionals interested were provided with  
234 an invitation pack from their line managers. Service users were also purposively  
235 sampled to include patients with COPD who had recently been treated or experienced  
236 the delivery of the HaH scheme or outpatient PR programme, and their relatives (who  
237 could also self-identify as informal carers). They were invited by the healthcare  
238 professionals delivering their usual clinical care who provided an invitation pack. The  
239 invitation packs included a stakeholder-specific information sheet and consent form to  
240 ensure those invited had access to all necessary project documents, including ways  
241 (email, post and telephone) to contact the project team if they were interested. The  
242 project documents provided were subsequently discussed with a researcher (REB) via  
243 the telephone prior to attendance at an event or group where the consent form was  
244 signed once all question were answered. To gain fresh perspectives, additional service  
245 users and healthcare professionals were invited via the same sources to attend the  
246 joint stakeholder feedback event and subsequent joint co-design groups.

247

248 **Data analysis**

249 Audio-recordings of the semi-structured discussions within the stakeholder feedback  
250 events were anonymised and transcribed by REB, then analysed alongside observa-  
251 tional logs/field notes and source documents by the researcher (REB), supported by

252 a co-analyst (MF), using inductive directed content analysis <sup>36</sup>. The separate  
253 healthcare professional and service user stakeholder feedback events were analysed  
254 prior to the joint service user-healthcare professional event and used to inform the  
255 topics of the structured discussions. Minutes were produced summarising the discus-  
256 sion in the co-design groups and subsequently approved for accuracy by attendees.  
257 These minutes were used as a record of the experiences and perspectives of the  
258 stakeholders who attended the groups. The Table of Changes approach was used  
259 throughout the data analysis process to facilitate decision-making, provide an audita-  
260 ble decision-trail and finalise the model of care <sup>37</sup>.

261

## 262 **RESULTS**

263 The separate healthcare professional and service user stakeholder feedback events  
264 were conducted in September 2018. The joint service user-healthcare professional  
265 stakeholder feedback event was conducted in October 2018. Seven patients with  
266 COPD, two informal carers and nine healthcare professionals (from an existing  
267 outpatient PR service and HaH scheme) participated in these stakeholder feedback  
268 events. Two co-design groups were conducted in February 2019. Two patients with  
269 COPD, one informal carer and three healthcare professionals participated in the first  
270 joint co-design group, with five healthcare professionals attending a second co-design  
271 group. Table 1 provides an overview of attendees at the stakeholder feedback events  
272 and co-design groups. Of interest, although perhaps unsurprisingly, all the relatives  
273 involved also classified themselves as an 'informal carer' of the patient with COPD  
274 who they attended the event with on the demographic sheet. The findings of the events  
275 and groups are presented below as a narrative summary with supporting indicative  
276 anonymised quotes.

277

278 Four themes were identified from the three stakeholder feedback events: (1)  
279 individualisation of the home-based exercise training, (2) progression and transitions  
280 during home-based exercise training and outpatient-based programme, (3) continuity  
281 between services and (4) communication between stakeholders. Table 2 provides a  
282 summary of the themes which were identified. Discussion at the first co-design group  
283 with service users and healthcare professionals focussed on integration and related  
284 to the themes of: progression and transitions during home-based exercise training and  
285 outpatient-based programme, continuity between services, and communication  
286 between stakeholders. Intentionally, discussion at the second co-design group with  
287 healthcare professionals was more focussed on home-based exercise-training  
288 delivery and related to the themes of: individualisation of the home-based exercise  
289 training, and progression and transition during home-based exercise training and  
290 outpatient-based programme.

291

### 292 *Individualisation of the home-based exercise training*

293 All participants (patients, informal carers and health care professionals) felt home-  
294 based exercise training should include individually prescribed education and exercise,  
295 tailored to achieve patient-specific goals:

296 *'I think that [the types of exercises] need to be tailored to the individual, if we*  
297 *are talking about engagement, different goals for different patients, different*  
298 *anxieties and symptoms'* [SM08, physiotherapist, PR service team member]

299 *'I think a bespoke programme, cos you're all going to be at different levels'*  
300 [SU05, patient living with COPD, previous experience of PR]

301

302 All participants also felt the home-based exercise training should include face-to-face  
303 supervision. The rationale for this supervision, which centred on adherence, was  
304 clearly stated by healthcare professionals, patients and carers:

305 *'I think a lot of people would openly say when you do offer the home programme*  
306 *is that they won't do it without anyone being there, so obviously [supervised]*  
307 *one to one, erm, yes, I think would definitely help'* [SM01, physiotherapist, PR  
308 service and HaH scheme team member]

309 *'If he [healthcare professional] says 10 minutes, you do 10 minutes'* [SU08,  
310 patient with COPD, previous experience of PR and HaH]

311 *'I also think that they haven't got enough self-discipline to actually do it'* [SU03,  
312 informal carer to SU05, previously observed PR]

313

314 It was also noted that the frequency of the supervised sessions should be similarly  
315 individually tailored:

316 *'Well at the beginning you probably want shorter but more often, and then get*  
317 *more individual'* [SM05, physiotherapist, PR service team member]

318 A minimum and maximum of one and three supervised sessions per week was  
319 suggested:

320 *'So it is [BTS guidelines] 2 supervised and one unsupervised, ... , but then*  
321 *obviously if we think healthy living advice is 30 minutes 5 times a week, so do*  
322 *we go out for 30 minutes 3 times a week'* [SM01, physiotherapist, PR service  
323 and HaH scheme team member]

324 This was to allow for individual patients to determine their own levels of motivation and  
325 confidence to complete unsupervised exercise at home, in between supervised  
326 sessions. Some patients felt more confident and motivated to exercise at home

327 unsupervised and as a result felt that a once weekly supervised session to deliver  
328 education and to support exercise progression was all that was required:

329 *'I've got a garden back and front to keep up, which means quite a bit to me, so*  
330 *I do quite a lot of exercise, I am a member to a gym, ... , I think I keep myself*  
331 *in good shape'* [SU06, patient with COPD, previous experience of PR]

332 However, other patients felt either less confident or reported they might lack motivation  
333 to exercise regularly unsupervised at home and so felt they would prefer more frequent  
334 supervised sessions for their home-based exercise training:

335 *'When you live on your own it's very difficult, you don't have another person to*  
336 *push you, telling you to do it, ... , it's hard'* [SU07, patient with COPD, previous  
337 experience of PR]

338 The need for individualised programmes, to meet patients' individual needs, was  
339 therefore clear.

340

341 Including a minimum and maximum contact number in the individually tailored  
342 frequency also allowed healthcare professionals to feel reassured that at least some  
343 face-to-face supervision was provided to ensure patient safety and effective exercise  
344 progression, without resulting in an unfeasible frequency (e.g. five days a week  
345 supervised exercise training) of supervised sessions being requested:

346 *'If you had it five days a week, I'd want to go'* [SU08, patient with COPD,  
347 previous experience of PR and HaH]

348

349 Informal carers felt their role was to support the needs of the patient with COPD who  
350 had been hospitalised and having access to the patients' session would enable this:

351 *'If someone's not on their own, like we're not, could I go to those [education*



352 *sessions] so I know what they're talking about? ... Because you hear things,*  
353 *but they can hear other things'* [SU01, informal carer to SU02, previously  
354 observed both PR and HaH]

355 They also considered that it should be a collaborative process between themselves,  
356 healthcare professionals and the patient with COPD to identify the goals of the patient  
357 with COPD, which could then determine the individually tailored education programme  
358 content and frequency of exercise sessions.

359

360 *Progression and transition during home-based exercise training and outpatient-based*  
361 *programme*

362 A key finding was that some of the patients with COPD remained keen to attend  
363 traditional outpatient PR when they felt well enough post-exacerbation. The reason for  
364 this was that they liked the social content and contact of an outpatient programme,  
365 and the access it gave them to specialist gym equipment with one patient saying:

366 *'Prefer to go to the gym [outpatient PR] myself, ... and see how you progress*  
367 *over the eight weeks, I don't think I would get that progress at home, with a one*  
368 *to one even'* [SU06, patient with COPD, previous experience of PR]

369 *'I think it is a bit of both [doing rehab with others as well motivation from*  
370 *therapist], because you've got the other people literally in the same boat as you,*  
371 *and you can see people that have literally worked up the ladder from square*  
372 *one'* [SU08, patient with COPD, previous experience of PR and HaH]

373 However, this was disparate from other patients who felt entirely home-based exercise  
374 training was more suited to them given the difficulties they had previously leaving their  
375 house after being hospitalised with an acute exacerbation and that they would not  
376 attend traditional outpatient PR even if it was offered. This further supports the idea

377 that programmes should be individually tailored to meet patients' needs.

378

379 Contrasting views were also found between healthcare professionals. Some  
380 healthcare professionals felt there would be some patients with COPD who would  
381 prefer entirely home-based exercise training:

382 *'There is that whole cohort that you [outreach] probably more touch base with*  
383 *at Hillingdon that you can't convince to come [to PR]'* [SM08, physiotherapist,  
384 PR service team member]

385 Nonetheless, the viewpoint of co-offering outpatient PR was also held by some of the  
386 healthcare professionals, with one healthcare professional stating:

387 *'For those that can get here but don't want to, you can use it [home-based PR]*  
388 *as a way to gradually convincing them, and erm obviously show exercise is*  
389 *beneficial and enjoyable, and those ones might go on to do it [outpatient PR]'*  
390 [SM01, physiotherapist, PR service and HaH scheme team member]

391 This was because some healthcare professionals perceived traditional outpatient PR  
392 to be the gold standard of care post-exacerbation. As such, they felt not offering  
393 traditional outpatient PR to those allocated to receive a home-based exercise training  
394 whilst the home-based exercise training was being tested as part of a trial and not part  
395 of clinical practice guidelines could result in patients missing out on a cornerstone of  
396 the management of COPD. As a result, offering traditional outpatient PR to all patients  
397 was included as a requirement in the model of care developed. Therefore, a referral  
398 pathway, and strategies to allow seamless transition between home-based and  
399 outpatient PR, were co-designed (see Figure 2 for the final co-designed model of care).

400

401 *Continuity between services*

402 Sub-themes for continuity between services included content delivered, timing of  
403 delivery, skill set of the healthcare professionals and types of assessments required.  
404 With regards to the content delivered, all participants felt it was important for the  
405 different healthcare professionals (for example a nurse and a physiotherapist) and  
406 services involved in the delivery of the co-designed model of care (for example within  
407 HaH, home-based exercise training and outpatient PR) to provide consistent  
408 information and education:

409 *'[post-exacerbation PR] reinforcing messages and education provided in the*  
410 *hospital'* [SM08, physiotherapist, PR service team member]

411 *'And that knowledge checking as well, you know, ... , if the outreach team are*  
412 *doing at the beginning, you know, 6 weeks later, then you can check and see*  
413 *whether it has been retained'* [SM03, physiotherapist, PR service team member]

414 In order to deliver this desired consistency, a series of resources which would be used  
415 by all the services was agreed upon during this co-design project (for example a HaH  
416 scheme leaflet on self-management and PR service presentation slides).

417

418 In terms of timing of delivery, there were multiple views on when the home-based  
419 exercise training should commence. Most patients and informal carers felt a period of  
420 readjustment of up to two weeks was needed after returning home from hospital before  
421 exercise training could commence. This same perspective was held by some of the  
422 healthcare professionals from the HaH scheme based on their experience – they felt  
423 that commencing exercise training too early could be detrimental to longer term patient  
424 adherence:

425 *'I don't think starting it too early would be beneficial, often they're fighting for*  
426 *breath still, and, and I think they would decline it cos they are feeling like that, ...*

427           *so I think it needs to be timed right when we are offering this at home rather*  
428           *than straight away'* [SM07, nurse, HaH scheme team member]

429 Nonetheless, the more widely held view of healthcare professionals was that  
430 beginning exercise training as soon as possible (as soon as the day after discharge)  
431 was key from their experience:

432           *'For patients whose breathlessness is very severe and limiting what they feel*  
433           *able to do, erm, it might be an option for something to start with to try and get*  
434           *those muscles working to erm, reduce the deficits that develop in that initial*  
435           *acute post-exacerbation period'* [SM05, physiotherapist, PR service team  
436           member]

437 Some patients also supported this, as this was the period when they were most limited  
438 by breathlessness to complete their daily activities. As such, beginning exercise  
439 training during the peri-exacerbation phase of their recovery was vital to some patients  
440 so that they could be guided by healthcare professionals on how hard to push  
441 themselves:

442           *'That's why I went down so low, cos I wasn't doing anything, well not a lot, you*  
443           *know, I did try, I mean, I wasn't really, I was just kind of walking around, and I*  
444           *have to go upstairs the loo, I have to go upstairs to bed, that was basically my*  
445           *exercise, just being honest, ... , I think this is, would be, excellent for that initial*  
446           *period to get you started again'* [SU05, patient with COPD, previous experience  
447           of PR]

448 This again reinforces the idea that programmes should be individually tailored to meet  
449 patients' needs. A solution was to compromise and agree the most acceptable time  
450 point to begin delivering exercise training within the programme. To enable this the  
451 initial session post-discharge would be focussed around goal setting, with the early

452 sessions including more time devoted to deliver education. The proportion of time  
453 spent exercising would then gradually be built up based upon individual need whilst  
454 reducing the proportion of time delivering education over the first few weeks post-  
455 discharge to allow for a period of readjustment.

456

457 There was greater agreement on who should deliver the home-based exercise training.  
458 All participants felt those who delivered it should be competent to undertake a  
459 comprehensive respiratory assessment which would usually be completed as part of  
460 the HaH scheme visits as well as prescribe exercise:

461 *‘One person, both skills, also whether they are physio or nurse doesn’t matter’*

462 [SM06, physiotherapy assistant, PR service team member]

463 This was considered imperative as patients and informal carers preferred the prospect  
464 that one person, regardless of professional background (physiotherapist or nurse),  
465 could deliver all elements of their management (exercise training at home and  
466 exacerbation management). To this end, both patients and carers felt comfortable as  
467 long as appropriate training had been provided:

468 *‘Someone trained in that kind of rehabilitation, doesn’t necessarily have to be*

469 *someone trained and been through university’* [SU05, patient with COPD,

470 previous experience of PR]

471 *‘We wouldn’t mind if someone came out with someone who had to learn’* [SU01,

472 informal carer to SU02, previous experience of PR and HaH]

473

474 Healthcare professionals felt that only a limited number of team members across the  
475 two existing services (HaH scheme and outpatient PR) currently held this skill set and  
476 additional training was beyond the scope of the trial this model of care would be tested

477 in:

478 *'Yes, it's [training required] not going to happen in a week, it's going to happen*  
479 *over several years, realistically I think, but ultimately, yes, long term'* [SM01,  
480 physiotherapist, PR service and HaH scheme team member]

481 It was therefore agreed that the delivery of home-based exercise training, whilst it was  
482 tested within a trial, would be restricted to delivery by those who already held this skill  
483 set as opposed to providing training to up-skill all healthcare professionals.

484

485 Finally, continuity in the assessments undertaken between outpatient PR assessments  
486 and those undertaken as part of home-based exercise training was highlighted to be  
487 important by all participants. It was acknowledged that this could be a challenge where  
488 there was transition of patients into outpatient PR within this co-designed model of  
489 care at time points which differed to when the trial assessments would be conducted.  
490 Nonetheless, patients and their informal carers felt being selective with the  
491 assessments undertaken to avoid duplication, and not being required to repeat  
492 assessments unnecessarily would be preferable. They also felt that this would make  
493 them more likely to consider taking part in the trial if their clinical care and research  
494 assessments were closely aligned. Healthcare professionals also highlighted that  
495 carefully considering the assessments undertaken within the trial itself to mirror the  
496 data collected in the clinical assessments wherever possible to be practicable. As such,  
497 the healthcare professionals felt streamlined assessments could also be beneficial:

498 *'And that's the key thing, an assessment of some sort, as they would not be*  
499 *able to do all of the assessment that we do, but some of it'* [SM05,  
500 physiotherapist, PR service team member]

501 This could, in turn, relieve some of the burden on patients and their informal carers as

502 the appointments would be shorter, and potentially less frequent in number.

503

#### 504 *Communication between stakeholders*

505 Two sub-themes were identified within communication between stakeholders:  
506 communication between healthcare professionals and communication between  
507 healthcare professionals and service users. All participants felt that communication  
508 was an integral part of developing a model of care:

509 *'You don't want to have to keep repeating yourself do you'* [SU07, patient with  
510 COPD, previous experience of PR service]

511 *'Suppose it would be nice [for the healthcare professionals to meet face to face],*  
512 *as you could have been in the hospital with one crowd, and it would be nice for*  
513 *the two of them to get together'* [SU08, patient with COPD, previous experience  
514 of PR service and HaH scheme]

515 Healthcare professionals felt a combination of formal face-to-face groups (weekly  
516 multidisciplinary team meeting) and daily handovers (either face-to-face, by telephone  
517 or email) was important for effective and regular communication between all the  
518 healthcare professionals involved. Face-to-face communication was preferred to  
519 telephone or email by healthcare professionals, however they felt this may not always  
520 achievable and therefore having alternative strategies as a backup was required:

521 *'If different people are going in, erm, obviously different people going in on*  
522 *different days, there needs to be communication at end, or during every single*  
523 *day ... obviously it would be nice to have that face to face contact, erm, but*  
524 *realistically it is not going to happen'* [SM01, physiotherapist, PR service and  
525 HaH scheme team member]

526

527 Informal carers had no preferences regarding the channels of communication between  
528 healthcare professionals as long as two criteria could be met. First, the healthcare  
529 professionals were able to discuss the care of a patient proficiently to ensure safe care  
530 could be provided. Second, that personal information was not shared beyond those  
531 who should have access to it.

532

533 In terms of the communication between healthcare professionals and service users,  
534 all patients reported they would prefer to verbally communicate with healthcare  
535 professionals face-to-face where possible (for example during sessions), or via  
536 telephone between sessions:

537 *'I think most people prefer a human body in front of them'* [SU08, patient with  
538 COPD, previous experience of PR and HaH]

539 Patients reported they did not feel confident, or have access, to communicate via email  
540 or other online platforms such as a patient portal or app:

541 *'My kids do [have access to the internet or smart phone], but I don't use that'*  
542 [SU08, patient with COPD, previous experience of PR and HaH]

543 Healthcare professionals from the HaH scheme felt it was important to discourage use  
544 of their direct telephone number for calls regarding home-based exercise training as  
545 the workload would potentially become too overwhelming for them to manage, and  
546 this was true across services (PR service and HaH scheme):

547 *'To be honest, it [hotline] is a job on its own... it can take up a large proportion*  
548 *of the day whilst trying to see other patients on the wards'* [SM01,  
549 physiotherapist, PR service and HaH scheme team member]

550 *'It is a nightmare, it is a nightmare, you can have 20 to 30 calls a day'* [SM07,  
551 nurse, HaH scheme team member]



552 They also felt it could be misleading for patients who would then not receive the  
553 support they anticipated for their home-based exercise queries between sessions. All  
554 patients and informal carers felt that provision of a separate telephone number was  
555 satisfactory as long as calls were returned in a timely manner should an issue arise.

556

#### 557 *Model of care developed*

558 Following the three stakeholder feedback events and two co-design groups, delivery  
559 strategies for home-based exercise training were finalised and a pathway for  
560 integration within a HaH scheme developed based on the findings reported. Figure 2  
561 shows a schematic of the final co-designed model of care which is currently being  
562 piloted within a single-centre mixed method feasibility trial.

563

564 The home-based exercise training programme is intended to last up to eight weeks to  
565 replicate the local eight-week outpatient-based PR programme provided, with the  
566 focus upon similar outcomes to traditional outpatient-based PR (exercise capacity /  
567 health-related quality of life / dyspnoea) <sup>14,38</sup>. All eight weeks of the home-based  
568 exercise training programme would be delivered at home for patients who decline  
569 referral to traditional outpatient-based PR. The home-based exercise training  
570 programme would continue to be delivered until the patient has completed their pre-  
571 PR assessment and the outpatient-based PR programme begins for patients who are  
572 referred to the traditional outpatient-based PR programme. For the patients  
573 transitioning into traditional outpatient-based PR, the home-based exercise training  
574 programme will serve as a bridging programme.

575

576 The intention is replicate the types of exercises offered in traditional outpatient-based

577 PR programmes delivered in community settings which uses minimal, low cost and  
578 portable equipment. This 'minimal equipment' strategy for delivering PR has recently  
579 been shown to be non-inferior to PR delivered using specialist equipment <sup>39</sup>.  
580 Prescription of the exercises training provided within the home-based exercise training  
581 programme is intended to be completed using the same standard operating  
582 procedures as the traditional outpatient-based PR programme. The intensity of the  
583 home-based exercise training programme may initially differ whilst patients are early  
584 peri-exacerbation, however the exercises would be progressed, and the intensity  
585 increased, as symptom burden reduces.

586

## 587 **DISCUSSION**

588 In this accelerated EBCD project, an integrated model of care, including home-based  
589 exercise training and HaH scheme, was co-designed by service users and healthcare  
590 professionals to address low uptake, referral and subsequent completion of PR  
591 following hospitalisation for an AECOPD.

592

593 Previous studies have shown barriers to post-hospitalisation PR to be complex and  
594 multifactorial. Commonly cited barriers to a traditional outpatient PR programme after  
595 an acute exacerbation include access to transport and travel <sup>26,40,41</sup>, with a previous  
596 trial having shown a more fundamental adaptation to PR delivery was required beyond  
597 transport provision <sup>27</sup>. As such, the primary intention of this project was to develop a  
598 co-designed model of care to allow the integration of home-based PR and a HaH  
599 scheme which could be seamlessly delivered together. Delivery in the home setting  
600 was also considered given the outcomes of recent trials of home-based PR in patients  
601 with stable COPD <sup>28-30</sup>. However, the post-exacerbation population differs from those

602 with stable COPD given their recent, acute worsening of symptoms. As such, it was  
603 felt that simply mimicking home-based programmes delivered to those with stable  
604 COPD may render them infeasible in the post-exacerbation population. We also felt  
605 that by looking for ways to embed home-based exercise training within an already  
606 established scheme (HaH) may result in the home-based programme being  
607 considered more feasible and acceptable post-hospitalisation to all stakeholders. This  
608 would allow for this intervention to be delivered at the point in the care post-  
609 hospitalisation pathway when it has the potential to achieve clinically meaningful  
610 outcomes <sup>42</sup>.

611

612 As this was an accelerated EBCD project, it ensured the key stakeholders (patients  
613 with COPD, informal carers and healthcare professionals) who participated were the  
614 drivers behind the model of care's design <sup>32</sup>. To do this we ascertained a wide range  
615 of stakeholder priorities <sup>34</sup> but ensured a consensus was reached prior to investigation  
616 within a feasibility trial.

617

618 There was agreement that home-based exercise training should be individualised,  
619 supervised and be sufficiently flexible to enable it to be tailored to meet the need of  
620 each patient. These findings reflect the results from a recent mixed methods  
621 systematic review which reported similar conclusions <sup>35</sup>. This suggests the findings  
622 from this project could have resonance for other services considering a redesign or for  
623 the development of other interventions specifically for this patient population.  
624 Nonetheless, face-to-face supervised exercise training has temporarily become  
625 impracticable due to the current Coronavirus Disease 2019 (COVID-19) pandemic,  
626 with alternative ways of delivering exercise training emerging due to the suspension

627 of face-to-face supervised clinical encounters. As such, application of this finding may  
628 be limited until face-to-face supervised exercise training is permitted again.

629

630 There was a strongly held desire among some patients to attend traditional outpatient-  
631 based PR when they felt well enough. However, other patients felt home-based  
632 exercise training was more suited to them and, even if offered, they would not attend  
633 traditional outpatient-based PR. The idea of offering outpatient-based PR was also  
634 welcomed by some of the healthcare professionals. The underlying reasons for their  
635 beliefs was that traditional outpatient-based PR was the gold standard of care post-  
636 exacerbation, with an established evidence-base <sup>14</sup> and is mandated by clinical  
637 practice guidelines <sup>16,17</sup>. The healthcare professionals felt withholding this PR  
638 programme from those receiving home-based exercise training could result in patients  
639 missing out on a programme which is a cornerstone in the management of COPD. The  
640 importance of ensuring evidence-based care continues was highlighted in a recent  
641 study which found people who received post-hospitalisation PR within 3 months of  
642 discharge to have lower mortality at one year compared to those who did not receive  
643 the programme <sup>15</sup>. Therefore, to address this, progression and transition during the  
644 home-based exercise training and outpatient-based programme was explored in detail  
645 during the stakeholder feedback events to ensure all patients would be provided the  
646 opportunity to attend traditional outpatient-based PR.

647

648 Views on the timing of initiation of exercise training post-hospitalisation varied between,  
649 as well as within, the different stakeholder groups. This was unsurprising given a  
650 recent systematic review found disparities as to when the optimal time to commence  
651 exercise training post-acute exacerbation was <sup>35</sup>. Moreover, our work has previously

652 shown that delivering an intervention at sub-optimal timing during an AECOPD to be  
653 an important factor that can result in an intervention being rendered ineffective <sup>23</sup>. As  
654 such, in order to address these differences in perspectives of optimal timing for  
655 initiation, the decision was made to design a highly individualised model of care that  
656 could be sufficiently flexible and adaptable to be tailored to meet the needs of each  
657 patient.

658

659 In addition to timing of initiation, the skill set required by the healthcare professional  
660 delivering home-based exercise training was considered important. All the  
661 stakeholders involved felt those who delivered home-based exercise training to  
662 patients' post-exacerbation should be competent to undertake a comprehensive  
663 respiratory assessment as well as prescribe exercise. This led to discussions  
664 regarding the training requirements of the current healthcare professionals employed  
665 within the HaH scheme and PR service. However, given that there were already  
666 healthcare professionals employed, albeit a limited number, who had the skill set to  
667 deliver the comprehensive co-designed model of care, for the purpose of this project  
668 it was decided that up-skilling other staff at the current time was unnecessary.  
669 Nonetheless, a training intervention which provides formal teaching and competency  
670 assessments surrounding exercise prescription and progression as well as respiratory  
671 assessment skills may be required in other localities. Moreover, as role of the referrer  
672 <sup>43</sup> and referrer knowledge <sup>44</sup> are other barrier to PR referral and participation, this type  
673 of formal training intervention could be beneficial and in itself have a knock-on effect  
674 and potentially address this other barrier to post-hospitalisation PR.

675

676 During this co-design process, along with developing an integrated model of care,

677 additional learning was gained about what is important from key stakeholders'  
678 perspectives regarding home-based exercise training and integration of care following  
679 an acute exacerbation of COPD. This additional learning could be more widely applied  
680 beyond this project should other services be considering implementing more closely  
681 integrated services, home-based exercise training programmes, or be attempting to  
682 enhance the delivery of traditional outpatient-based PR services for patients following  
683 hospitalisation for an AECOPD. As such, these insights could be particularly important  
684 given the paucity of effective interventions that address this area currently <sup>45</sup>.

685

686 This project had both strengths and weaknesses. The accelerated EBCD process, a  
687 quality improvement approach that enables stakeholders to co-design services in  
688 partnership <sup>32</sup>, used to develop the model of care was informed by the findings of a  
689 mixed methods systematic review (PROSPERO: CRD42018104648) <sup>35</sup> and qualitative  
690 work. Consequently, the initial discussions at the stakeholder feedback events, which  
691 were semi-structured in nature, were facilitated by seminal 'touchpoints' and evidence-  
692 based topics. We can also be assured that data saturation, based upon the concept  
693 of Information Power <sup>46</sup>), was achieved; previous work by Hennink and colleagues <sup>47</sup>  
694 estimated the number of focus groups required to ensure at least 90% saturation to  
695 be a minimum of three, and up to six groups.

696

697 In addition, the previous review found no data on relative or informal carer  
698 perspectives of home-based exercise training following hospitalisation for an AECOPD  
699 <sup>35</sup>. Therefore, this project provided new insights into the experiences and perspectives  
700 from these key stakeholders. In so doing, this project provides some assurances that  
701 an integrated model of care which embeds home-based exercise training into a HaH

702 scheme is not perceived by informal carers as likely to increase their burden. This was  
703 important to ascertain given AECOPD already significantly and negatively impact  
704 relatives and informal carers <sup>48</sup>, and unknowingly adding to this burden could have  
705 resulted in this model of care being determined to be impracticable and unfeasible in  
706 the longer term.

707

708 This project engaged a nationally accredited PR programme in the UK and a well-  
709 established respiratory-specific HaH scheme which has received recognition from the  
710 national clinical director for respiratory services at NHS England. Therefore, we are  
711 reassured that the perspectives of the healthcare professionals involved in this project  
712 included those with the expertise to provide valuable insights to aid decision-making,  
713 and as a result can be an exemplar for other services. Nonetheless, this project only  
714 represents the perspectives of the stakeholders involved and from just one locality. In  
715 particular, we cannot guarantee the transferability of our results to those service users  
716 who have experienced HaH care but not PR. Therefore, we acknowledge that although  
717 these insights may be useful for other services, the transferability of the specific model  
718 of care developed in this project may require some adaptation and service-specific  
719 exploration before wider implementation is possible.

720

## 721 **CONCLUSION**

722 A model of care integrating home-based exercise training within a well-established  
723 HaH scheme has been co-designed by service users and healthcare professionals to  
724 address the low referral, uptake and subsequent completion of PR following AECOPD.

725

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728 for participating in this study. We would also like to thank the staff of the Harefield  
729 Pulmonary Rehabilitation Unit and Hillingdon Integrated Respiratory Service for their  
730 participation in this project.



731 **TABLES**

732 Table 1. Accelerated experience-based co-design project attendees at each  
 733 stakeholder feedback event and co-design group

<b>Stakeholder feedback events</b>	
<b>Healthcare professional event</b>	
Pulmonary rehabilitation team members n=5	Qualified physiotherapists (n=4; female: n=4) Physiotherapy assistant (n=1; female: n=1)
Hospital at home service members n=2	Specialist nurse (n=1; female: n=1) Specialist physiotherapist (n=1; male: n=1)
<b>Service user event</b>	
Patients with COPD n=5	Previously underwent pulmonary rehabilitation and received hospital at home care (n=2; male: n=1; female: n=1) Previously underwent pulmonary rehabilitation only (n=3; male: n=1; female: n=2)
Relatives or carer of person with COPD n=2	Observed pulmonary rehabilitation (n=1; female: n=1) Observed hospital at home care (n=1; female: n=1)
<b>Joint service user-healthcare professional event</b>	
Patients with COPD n=6	Previously underwent pulmonary rehabilitation and received hospital at home care (n=3; male: n=2; female: n=1) Previously underwent pulmonary rehabilitation only (n=3; male: n=1; female: n=2)  Did not attend did not attend separate service user feedback event: 2/6
Pulmonary rehabilitation team members n=3	Qualified physiotherapists (n=2; female: n=2) Physiotherapy assistant (n=1; male: n=1) Did not attend separate healthcare professional feedback event: physiotherapy assistant
Hospital at home service members n=2	Consultant respiratory physician (n=1; female: n=1) Specialist physiotherapist (n=1; male: n=1) Did not attend separate healthcare professional feedback event: consultant respiratory physician
<b>Co-design groups</b>	
<b>Service user and healthcare professional co-design group</b>	
Patients with COPD n=2	Previously underwent pulmonary rehabilitation and received hospital at home care (n=2; female: n=2) Did not attend the stakeholder feedback events:2/2
Relative or carer of person with COPD n=1	Observed pulmonary rehabilitation and hospital at home care (n=1; female: n=1) Did not attend stakeholder feedback events: 1/1
Pulmonary rehabilitation team members n=1	Qualified physiotherapist (n=1; male: n=1) Did not attend stakeholder feedback events: 0/1
Hospital at home service members n=2	Specialist nurses (n=2; female: n=2) Did not attend the stakeholder feedback events: 2/2
<b>Healthcare professional co-design group</b>	
Pulmonary rehabilitation team members n=5	Qualified physiotherapists (n=4; female: n=4) Physiotherapy assistant (n=1; male: n=1) Did not attend stakeholder feedback events:2/4 qualified physiotherapists

734 Abbreviations: COPD: Chronic obstructive pulmonary disease; EBDCD: experience-based co-design.

735 Table 2. Summary of the findings: four key themes and their related sub-themes

Theme	Sub-themes
1. Individualisation of the home-based exercise training	-
2. Progression and transitions during home-based exercise training and outpatient-based programme	-
3. Continuity between services	a) Content delivered b) Timing of delivery c) Skill set of the healthcare professionals d) Types of assessments required
4. Communication between stakeholders	a) Communication between healthcare professionals b) Communication between healthcare professionals and service user

736

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- 882

883 **FIGURE LEGENDS**

884 **Figure 1.** Schematic of the stages of this accelerated experience-based co-design  
885 project

886

887 **Figure 2.** Schematic of the final co-deigned model of care

888 *Abbreviations: COPD: Chronic obstructive pulmonary disease; HaH: Hospital at home; HIRS: Hillingdon Integrated*  
889 *Respiratory Service; PR: pulmonary rehabilitation.*

890 *\* Research Physiotherapist to ask participant re: preference for outpatient PR location, and when referral to*  
891 *outpatient PR may be acceptable to participant; Research Physiotherapist to identify availability for the preferred*  
892 *class at proposed start date.*

893 *+ Deliver education topics alongside home-based exercise training using PR education pack/presentations and*  
894 *HIRS self-management plan; begin education with pacing, breathing control, positions of ease, anxiety manage-*  
895 *ment, self-management plan, smoking cessation, inhaler technique and airway clearance.*

896 *^ Research Physiotherapist to refer participant into outpatient PR if / when the participant consents to the refer-*  
897 *ral; the same referral and triaging process to be followed when refereeing participants into an outpatient PR*  
898 *programme as usual care; continue the home-based exercise training programme until the outpatient PR class*  
899 *begins.*

900 *~ Research Physiotherapist to provide copy of home-based exercise training programme to outpatient PR; PR*  
901 *Physiotherapist to complete short pre-PR assessment; PR Physiotherapist to complete a short post-PR assessment*  
902 *at the end of the after 8 weeks of outpatient PR programme.*

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