# 1 TITLE

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

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All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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### 61 KEY WORDS

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

### 63 ABSTRACT (322 words)

#### 64 **BACKGROUND**

Hospital at Home (HaH) schemes allow early discharge of patients hospitalised 65 66 with an acute exacerbation of chronic obstructive pulmonary disease (AECOPD). Traditional outpatient pulmonary rehabilitation (PR) following an AECOPD has an 67 established evidence-base, but there are issues with low referral, uptake and 68 69 completion. One commonly cited barrier to PR post-hospitalisation relates to poor accessibility. To address this, the aim of this project was to enrol service users 70 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.

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### 75 **METHODS**

This accelerated experience-based co-design project included three audio-recorded stakeholder feedback events, using key 'touchpoints' from previous qualitative interviews and a recent systematic review. Audio-recordings were inductively analysed using directed content analysis. An integrated model of care was then developed and finalised through two co-design groups, with the decisionmaking process facilitated by the Tables of Changes approach.

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#### 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, with five healthcare professionals attending a second co-design group. These 90 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 training and usual HaH care. 95

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#### 97 CONCLUSION

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

#### 102 MAIN TEXT (6453 words)

#### 103 **BACKGROUND**

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

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There are other significant and deleterious consequences of acute exacerbations 116 117 which are not addressed by HaH schemes. Patients report decreased ability to complete activities of daily living <sup>8,9</sup>, reduced health-related quality of life (HRQoL) and 118 119 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, and reduced readmission and mortality rates <sup>14,15</sup>. As such, there is a clear mandate 123 from clinical practice guidelines to routinely offer PR following an AECOPD <sup>16,17</sup>. 124 125 However, referral for, uptake and subsequent completion of PR following an acute exacerbation is low <sup>18,19</sup> despite its availability becoming increasingly widespread <sup>20</sup>. 126

An audit of a UK service showed only 30% of eligible patients were referred for PR at
 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 PR<sup>21,22</sup>. In addition, a contemporary randomised controlled trial investigating the effect 132 133 of a co-designed education video intervention shown to patients admitted to hospital with an AECOPD prior to discharge was also unable to improve post-hospitalisation 134 135 PR referral, uptake or completion <sup>23</sup>. As such, improving accessibility, one commonly cited barrier to low uptake of PR following an acute exacerbation <sup>24-26</sup>, is proposed. 136 Delivery of PR in the home setting is one potentially attractive alternative to delivery in 137 138 the traditional outpatient setting given the surprising failure of other strategies to address accessibility such as provision of free door-to-door transport <sup>27</sup>. The potential 139 of the delivery of PR in the home setting post-hospitalisation is corroborated by recent 140 trials of home-based PR in patients with stable COPD <sup>28-30</sup> and in a small pilot study 141 with patients hospitalised with an AECOPD <sup>31</sup>. 142

143

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

148

#### 149 **METHODS**

150 **Design** 

151 The accelerated EBCD project involved three stakeholder feedback events followed

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

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

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

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#### 170 **Topic guides**

The separate healthcare professional and service user stakeholder feedback events were facilitated by REB, LJB and MF using topic guides developed based on key 'touchpoints' informed by the findings from a recent systematic review (PROSPERO: CRD42018104648) <sup>35</sup>. Home-based exercise training appeared to be feasible and acceptable to patients hospitalised with an AECOPD and clinicians providing 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, regardless of equipment, had enhanced compliance. Evidence of clinical effectiveness 179 180 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

The topic guide for the joint service user-healthcare professional stakeholder feedback
event was developed inductively, informed by responses at the previous two separate
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

The healthcare professional stakeholder feedback event was held at Harefield 207 208 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. Regular breaks were taken between these discussions and prior to a 'round-up' at the 215 216 end. Transport provision was offered to all service users, and mileage was paid to 217 healthcare professionals.

218

219 Stage 2 – Co-design groups

After the stakeholder feedback events were completed, the co-design groups took place across two sites in north west London (Harefield Hospital and Hillingdon Hospital: the local district general hospital which hosts the HaH scheme). These two-hour codesign groups were scheduled on afternoons, with catering and refreshments provided. Transport provision was offered to all service users, and mileage was paid to 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 purposively sampled to ensure all members of the multidisciplinary team were included: 231 232 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 ensure those invited had access to all necessary project documents, including ways 240 241 (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 signed once all question were answered. To gain fresh perspectives, additional service 244 245 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

Audio-recordings of the semi-structured discussions within the stakeholder feedback events were anonymised and transcribed by REB, then analysed alongside observational 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 discussion in the co-design groups and subsequently approved for accuracy by attendees. 256 257 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 stakeholder feedback event was conducted in October 2018. Seven patients with 265 266 COPD, two informal carers and nine healthcare professionals (from an existing outpatient PR service and HaH scheme) participated in these stakeholder feedback 267 events. Two co-design groups were conducted in February 2019. Two patients with 268 COPD, one informal carer and three healthcare professionals participated in the first 269 270 joint co-design group, with five healthcare professionals attending a second co-design 271 group. Table 1 provides and 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.

278 Four themes were identified from the three stakeholder feedback events: (1) individualisation of the home-based exercise training, (2) progression and transitions 279 280 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 to the themes of: progression and transitions during home-based exercise training and 284 285 outpatient-based programme, continuity between services, and communication 286 between stakeholders. Intentionally, discussion at the second co-design group with healthcare professionals was more focussed on home-based exercise-training 287 288 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

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

'I think that [the types of exercises] need to be tailored to the individual, if we
 are talking about engagement, different goals for different patients, different
 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:

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

and HaH scheme team member]

This was to allow for individual patients to determine their own levels of motivation and confidence to complete unsupervised exercise at home, in between supervised sessions. Some patients felt more confident and motivated to exercise at home unsupervised and as a result felt that a once weekly supervised session to deliver
 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

*in good shape'* [SU06, patient with COPD, previous experience of PR]

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

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

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

340

Including a minimum and maximum contact number in the individually tailored frequency also allowed healthcare professionals to feel reassured that at least some face-to-face supervision was provided to ensure patient safety and effective exercise progression, without resulting in an unfeasible frequency (e.g. five days a week 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

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]

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

359

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

A key finding was that some of the patients with COPD remained keen to attend traditional outpatient PR when they felt well enough post-exacerbation. The reason for this was that they liked the social content and contact of an outpatient programme, 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

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]

Nonetheless, the viewpoint of co-offering outpatient PR was also held by some of the
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 pathway, and strategies to allow seamless transition between home-based and 398 399 outpatient PR, were co-designed (see Figure 2 for the final co-designed model of care).

400

#### 401 *Continuity between services*

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

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

so I think it needs to be timed right when we are offering this at home rather
than straight away' [SM07, nurse, HaH scheme team member]
Nonetheless, the more widely held view of healthcare professionals was that
beginning exercise training as soon as possible (as soon as the day after discharge)

431 was key from their experience:

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

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

This again reinforces the idea that programmes should be individually tailored to meet patients' needs. A solution was to compromise and agree the most acceptable time point to begin delivering exercise training within the programme. To enable this the 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

There was greater agreement on who should deliver the home-based exercise training. All participants felt those who delivered it should be competent to undertake a comprehensive respiratory assessment which would usually be completed as part of 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]

This was considered imperative as patients and informal carers preferred the prospect that one person, regardless of professional background (physiotherapist or nurse), could deliver all elements of their management (exercise training at home and exacerbation management). To this end, both patients and carers felt comfortable as 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

Healthcare professionals felt that only a limited number of team members across the
two existing services (HaH scheme and outpatient PR) currently held this skill set and
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]

It was therefore agreed that the delivery of home-based exercise training, whilst it was
tested within a trial, would be restricted to delivery by those who already held this skill
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 important by all participants. It was acknowledged that this could be a challenge where 487 488 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. Nonetheless, patients and their informal carers felt being selective with the 490 491 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]

Healthcare professionals felt a combination of formal face-to-face groups (weekly multidisciplinary team meeting) and daily handovers (either face-to-face, by telephone or email) was important for effective and regular communication between all the healthcare professionals involved. Face-to-face communication was preferred to telephone or email by healthcare professionals, however they felt this may not always 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]

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

532

In terms of the communication between healthcare professionals and service users, all patients reported they would prefer to verbally communicate with healthcare professionals face-to-face where possible (for example during sessions), or via 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 email540 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 replicate the local eight-week outpatient-based PR programme provided, with the 565 focus upon similar outcomes to traditional outpatient-based PR (exercise capacity / 566 health-related quality of life / dyspnoea) <sup>14,38</sup>. All eight weeks of the home-based 567 568 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 transitioning into traditional outpatient-based PR, the home-based exercise training 573 574 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 been shown to be non-inferior to PR delivered using specialist equipment <sup>39</sup>. 579 580 Prescription of the exercises training provided within the home-based exercise training programme is intended to be completed using the same standard operating 581 582 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 peri-exacerbation, however the exercises would be progressed, and the intensity 584 585 increased, as symptom burden reduces.

586

#### 587 **DISCUSSION**

In this accelerated EBCD project, an integrated model of care, including home-based exercise training and HaH scheme, was co-designed by service users and healthcare professionals to address low uptake, referral and subsequent completion of PR 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 an acute exacerbation include access to transport and travel <sup>26,40,41</sup>, with a previous 595 596 trial having shown a more fundamental adaptation to PR delivery was required beyond transport provision <sup>27</sup>. As such, the primary intention of this project was to develop a 597 598 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 was also considered given the outcomes of recent trials of home-based PR in patients 600 601 with stable COPD <sup>28-30</sup>. However, the post-exacerbation population differs from those

with stable COPD given their recent, acute worsening of symptoms. As such, it was 602 603 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 established scheme (HaH) may result in the home-based programme being 606 607 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 outcomes <sup>42</sup>. 610

611

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

617

618 There was agreement that home-based exercise training should be individualised, supervised and be sufficiently flexible to enable it to be tailored to meet the need of 619 620 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 from this project could have resonance for other services considering a redesign or for 622 the development of other interventions specifically for this patient population. 623 624 Nonetheless, face-to-face supervised exercise training has temporarily become impracticable due to the current Coronavirus Disease 2019 (COVID-19) pandemic, 625 626 with alternative ways of delivering exercise training emerging due to the suspension

of face-to-face supervised clinical encounters. As such, application of this finding may
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 postexacerbation, with an established evidence-base <sup>14</sup> and is mandated by clinical 636 practice guidelines <sup>16,17</sup>. The healthcare professionals felt withholding this PR 637 638 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 importance of ensuring evidence-based care continues was highlighted in a recent 640 641 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 the programme <sup>15</sup>. Therefore, to address this, progression and transition during the 643 home-based exercise training and outpatient-based programme was explored in detail 644 645 during the stakeholder feedback events to ensure all patients would be provided the 646 opportunity to attend traditional outpatient-based PR.

647

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

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

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

675

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

<sup>658</sup> 

677 additional learning was gained about what is important from key stakeholders' 678 perspectives regarding home-based exercise training and integration of care following an acute exacerbation of COPD. This additional learning could be more widely applied 679 680 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 given the paucity of effective interventions that address this area currently <sup>45</sup>. 684

685

This project had both strengths and weaknesses. The accelerated EBCD process, a 686 quality improvement approach that enables stakeholders to co-design services in 687 partnership <sup>32</sup>, used to develop the model of care was informed by the findings of a 688 mixed methods systematic review (PROSPERO: CRD42018104648)<sup>35</sup> and gualitative 689 work. Consequently, the initial discussions at the stakeholder feedback events, which 690 691 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 of Information Power <sup>46</sup>), was achieved; previous work by Hennink and colleagues <sup>47</sup> 693 694 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

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

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

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

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for participating in this study. We would also like to thank the staff of the Harefield
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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

Stakeholder feedback events				
Healthcare professional event				
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)			
Service user event				
Patients with COPD n=5	Previously underwent pulmonary rehabilitation and received hospital at home care (n=2; male: n=1; fe- male: 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)			
Joint service user-healthcare professio	nal event			
Patients with COPD n=6	Previously underwent pulmonary rehabilitation and received hospital at home care (n=3; male: n=2; fe- male: n=1) Previously underwent pulmonary rehabilitation only (n=3; male: n=1; female: n=2) Did not attend did not attend separate service user			
Pulmonary rehabilitation team members n-3	Oualified 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			
Co-desian aroups				
Service user and healthcare profession	al co-design group			
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			
Healthcare professional co-design group				
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; EBCD: experience-based co-design.

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

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## 883 **FIGURE LEGENDS**

- **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

Abbreviations: COPD: Chronic obstructive pulmonary disease; HaH: Hospital at home; HIRS: Hillingdon Integrated
 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.

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

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

903