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# Exploring the perceptions and experiences of community rehabilitation for long COVID from the perspectives of Scottish General Practitioners and people living with long COVID: a qualitative study.

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1 **TITLE PAGE**

2 **TITLE:** Exploring the perceptions and experiences of community rehabilitation for Long  
3 COVID from the perspectives of Scottish General Practitioners' and people living with  
4 Long COVID: a qualitative study.

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24 **ABSTRACT**

25 **Objectives:** To explore the experience of accessing Long COVID community  
26 rehabilitation from the perspectives of people with Long COVID and General Practitioners  
27 (GPs).

**NOTE:** This preprint reports new research that has not been certified by peer review and should not be used to guide clinical practice.

28 **Design:** Qualitative descriptive study employing one-to-one semi-structured virtual  
29 interviews analysed using the framework method.

30 **Setting:** Four NHS Scotland territorial health boards.

31 **Participants:** Eleven people with Long COVID (1 male, 10 female; aged 40-65 [mean  
32 53], and 13 GPs (5 male, 8 female).

33 **Results:** Four key themes were identified: i) The lived experience of Long COVID; ii) The  
34 challenges of an emergent and complex chronic condition; iii) Systemic challenges for  
35 Long COVID service delivery, and iv) Perceptions and experiences of Long COVID and its  
36 management, including rehabilitation.

37 **Conclusions:** There are several patient, GP, and service-level barriers to accessing  
38 community rehabilitation for Long COVID. There is a need for greater understanding by  
39 the public, GPs, and other potential referrers of the role of community rehabilitation  
40 professionals in the management of Long COVID. There is also a need for community  
41 rehabilitation services to be well promoted and accessible to the people with Long COVID  
42 for whom they may be appropriate. Service providers need to consider availability and  
43 accessibility of Long COVID rehabilitation and ensure adequate interprofessional  
44 communication and collaboration to enhance the experience for people with Long COVID.

45 **Strengths and limitations of this study:**

- 46 • This is the first study to explore the issue of accessing Long COVID community  
47 rehabilitation from the perspectives of potential service users and referrers in the  
48 Scottish context.
- 49 • One researcher conducted all interviews, ensuring consistency in their conduct
- 50 • Data were analysed and interpreted by multiple researchers, including people with  
51 Long COVID
- 52 • The small sample size, largely drawn from health boards with a similar approach to  
53 Long COVID rehabilitation, limits generalisability

54 **Keywords**

55 Long COVID; Allied Health Personnel, Rehabilitation, General Practice: Primary Health  
56 Care; Health Services Research; Qualitative

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61 **MANUSCRIPT**

62 **INTRODUCTION**

63 Long COVID in adults is a multisystemic condition described as signs and symptoms that  
64 develop during or after an infection consistent with COVID-19, and continue for more  
65 than 12-weeks, which cannot be explained by an alternative diagnosis [1]. While global  
66 prevalence remains unclear, the World Health Organisation estimated that as many as 34  
67 million people may have experienced Long COVID by 2022. [2] In the UK, the Office for  
68 National Statistics estimated that 1.9 million people (2.9% of the UK population) had  
69 self-reported Long COVID as of March 2023 [3]. The effect of Long COVID on individuals  
70 varies. More than 200 symptoms have been identified affecting multiple organ systems  
71 including thrombotic and cerebrovascular disease, chronic fatigue, and dysautonomia,  
72 resulting in significant reduction in quality of life [4].

73 Healthcare professionals, and general practitioners (GPs) in particular, are faced with  
74 complex challenges associated with the diagnosis and management of people with Long  
75 COVID (PwLC) as they attempt to disentangle nonspecific symptomology associated with  
76 the virus from those related to other conditions [5]. The National Institute for Health and  
77 Care Excellence (NICE) rapid guideline on Long-term effects of COVID-19 recommends  
78 that individuals have access to rehabilitation that is personalised and multi-disciplinary in  
79 nature [1]. Subsequent studies have emphasised the importance of this approach [6-8].  
80 However, uncertainty remains around the effectiveness of rehabilitation, with research  
81 ongoing [9 10]. In England, service provision for Long COVID has centred around the  
82 development of specialised clinics, usually comprising multidisciplinary teams that  
83 include medical, allied health and psychology professionals[11]. In Scotland, Long  
84 COVID rehabilitation is delivered in community (non-hospital) settings by generalist  
85 allied health professionals, with local variation in models of service delivery [12].

86 PwLC have previously reported barriers to accessing healthcare and difficulties in  
87 navigating interactions with disjointed healthcare services [12-15]. Kingstone et al. [16]

88 highlighted the importance of “finding the right GP” for PwLC accessing primary care.  
89 GPs are the first point of contact for PwLC and have an important role in ensuring that  
90 people receive appropriate treatment and are referred to specialist services, including  
91 community rehabilitation, when needed. GPs, however, continue to face uncertainty  
92 around providing a Long COVID diagnosis and ongoing management and, furthermore,  
93 experience challenges referring PwLC onto appropriate diagnostic and interventional  
94 services [15 17].

95 There is a growing body of research on the lived experience of PwLC [18 19] including  
96 their self-reported barriers to accessing healthcare [13 14]. Until recently, however [15],  
97 none have focussed on community rehabilitation. There is also a growing body of  
98 research on the role of the GP in providing care to PwLC, including the challenges of  
99 diagnosis and medical management [17 20]. Brennan et al’s scoping review [17]  
100 included 19 studies on the management of Long COVID by GPs. They reported five  
101 articles that described difficulties with accessing services, particularly those in the  
102 community such as follow-up services and Long COVID clinics [17]. Bachmeier et al’s  
103 qualitative study found that German GPs rarely referred their Long COVID patients to  
104 specialist care or rehabilitation [20]. This was partly due to referral restrictions in the  
105 German healthcare system and lengthy waiting times for rehabilitation services or post-  
106 COVID clinics.

107 The current study explored PwLC and GPs’ perspectives of accessing Long COVID  
108 community rehabilitation in the context of four Scottish regional health boards.  
109 Rehabilitation in this study is defined as intervention/s aimed at optimising function and  
110 reducing disability [21], delivered by any appropriate healthcare professional in a  
111 community setting. Community rehabilitation typically takes place in clinics and people’s  
112 homes. This work was embedded within a larger realist evaluation study called LOCO-  
113 RISE, investigating models of service delivery for Long COVID community rehabilitation  
114 in Scotland. The initial phase of the realist evaluation (November 2021 – April 2022)  
115 focussed on PwLC and service providers’ perspectives, experiences, and outcomes of

116 Long COVID rehabilitation [15]. During this time period, we observed that in some  
117 areas, there were low numbers of PwLC receiving community rehabilitation services [15].  
118 We sought approval for an amendment to the study (Ref: 21/WA/0118 A03) to  
119 understand potential reasons for these low numbers, in the context of the increasing  
120 number of PwLC, recommendations for providing community rehabilitation to PwLC [6 8  
121 22] and knowledge that services existed across Scotland [12]. The study reported here  
122 aimed to address two questions: i) what are the perceptions and experiences of PwLC on  
123 accessing rehabilitation for Long COVID? and ii) what are GPs' perceptions and  
124 experiences of managing PwLC presenting with symptoms of Long COVID that may be  
125 suitable for rehabilitation? PwLC were defined as adults (aged 18+) with Long COVID  
126 (with or without a positive COVID test) living in the community (i.e., not hospitalised).

## 127 **METHODS**

### 128 **Study Design**

129 This was a qualitative descriptive study employing semi-structured virtual interviews  
130 with a convenience sample of PwLC and GPs in four Scottish health boards. The study  
131 followed an a priori protocol (Supplementary File 1) and is reported in keeping with the  
132 consolidated criteria for reporting qualitative research (COREQ) [Supplementary File 2]  
133 [23].

### 134 **Participants**

135 The four Scottish health boards were chosen for the larger realist evaluation study based  
136 on variation in population and accessibility (using the Scottish Government Urban Rural  
137 Classification 2020) [24], Long COVID prevalence, and Long COVID rehabilitation service  
138 delivery models. We recruited from these same health boards for this study. At the time  
139 of conducting this study, two health boards were offering an integrated Long COVID  
140 rehabilitation service (i.e., integrated within existing community rehabilitation  
141 pathways), one had recently launched a dedicated Long COVID community rehabilitation  
142 service, and one pre-existing dedicated Long COVID service was closed to new referrals

143 due to an increased referral rate combined with reduction in funding and therefore  
144 inability to staff the service.

145 A convenience sample of PwLC were recruited via social media accounts of the research  
146 team and their institutions and by Long COVID Scotland, a volunteer-led charity run by  
147 PwLC. Inclusion criteria for PwLC were the following: community-dwelling (i.e., not  
148 currently hospitalised); aged 18 or over; experiencing symptoms of Long COVID (with or  
149 without a positive COVID-19 test; and experience of accessing or attempting to access  
150 healthcare services for possible rehabilitation. Those interested in the study contacted  
151 the research team, were sent detailed study information, and provided informed consent  
152 (audio recorded) prior to taking part. A second convenience sample of GPs were  
153 recruited by email invitation circulated on behalf of the research team by the NHS  
154 Research Scotland Primary Care Network. The network coordinator provided eligible GP  
155 practices in the four health boards with an electronic letter of invitation and participant  
156 information sheet to be shared with GPs. Those interested in taking part contacted the  
157 research team and provided informed consent as described above. Inclusion criteria for  
158 GPs were the following: GP in a practice within one of the four health boards taking part  
159 in the study; and experience of patients with probable Long COVID who may be suitable  
160 for rehabilitation. Several recruitment reminders were issued, and we aimed to recruit  
161 12-20 PwLC and 8-20 GPs in total.

## 162 **Data collection**

163 Interview topic guides [Supplementary File 3] were developed. While not formally pilot  
164 tested, the topic guides were refined by the research team, in consultation with people  
165 with lived experience of Long COVID and informed by initial findings from our realist  
166 evaluation study [15] and the wider literature in the field. During the period June 2022  
167 to January 2023 semi-structured online interviews (Microsoft Teams) and one telephone  
168 interview were conducted by one research assistant [EHW], who received training and  
169 supervision from KC and ED. No repeat interviews were undertaken. GP participants  
170 were either in their workplace or homes when interviewed, while PwLC participants were

171 all at home while interviewed. The research assistant, a female, was a qualified nurse  
172 and had worked in critical care from the start of the coronavirus pandemic (March 2020)  
173 until December 2021. She had no prior relationship with the GP practices or participants  
174 who all understood that EHW was employed as a study research assistant. The  
175 interviews lasted 17 to 47 minutes (mean  $23 \pm 7.8$  minutes) and were audio recorded.  
176 No other individuals were present during the interviews. No field notes for analysis were  
177 taken. Interviews with PwLC were transcribed by an external transcription service. Due  
178 to the homogeneity of the GP interviews, these were not transcribed but instead were  
179 listened to on multiple occasions by two researchers [25 26]. Neither transcripts nor  
180 audio files were returned to participants for comment or correction.

### 181 **Data analysis**

182 Data were analysed using the framework method (Gale et al. 2013) [27], which  
183 proposes a matrix-based format to facilitate the sharing and management of data as a  
184 team. This approach is widely used in applied health research and recognised as  
185 appropriate for multidisciplinary research teams as it provides a structure to consider  
186 data within and across interviews. Familiarisation with the data began by reading and re-  
187 reading the transcripts (PwLC) and listening/re-listening to the recordings (GPs), making  
188 analytical notes that informed the 'working analytical framework' for each participant  
189 group [27]. Although line-by-line coding is common in qualitative research, it is also  
190 possible to develop a framework without engaging in explicit coding [28]; due to the  
191 small scale and nature of the data we adopted the latter approach. The framework  
192 method was used to construct matrices in Microsoft Excel, enabling the data to initially  
193 be summarised into broad categories. This was led by EHW, in close consultation with  
194 two experienced qualitative researchers (KC, ED). The charted data were then analysed  
195 by interpreting within and between participants to identify concepts, which were  
196 subsequently grouped into themes, and finally overarching themes consisting of data  
197 from both participant groups. This was an iterative process involving multiple  
198 researchers (KC, ED, JC, TT, JS, ES), the study team, and subsequent refinement until

199 there was consensus that the data had been comprehensively analysed. As with our  
200 previous study we did not seek participant feedback directly on the findings. We did,  
201 however, present the findings in a webinar attended by health professionals and PwLC.  
202 Webinar attendees endorsed this study's findings and reflected that the analysis reflected  
203 their personal experiences.

#### 204 **Patient and public involvement**

205 Two members of the public with lived experience of Long COVID were core members of  
206 the study team (AL, JO). Both contributed throughout the study and were integral to its  
207 success, helping with design and identification of important issues to explore. They co-  
208 developed study materials and interview topic guides and contributed to analysis and  
209 interpretation of study findings.

### 210 **RESULTS**

#### 211 **Participant characteristics**

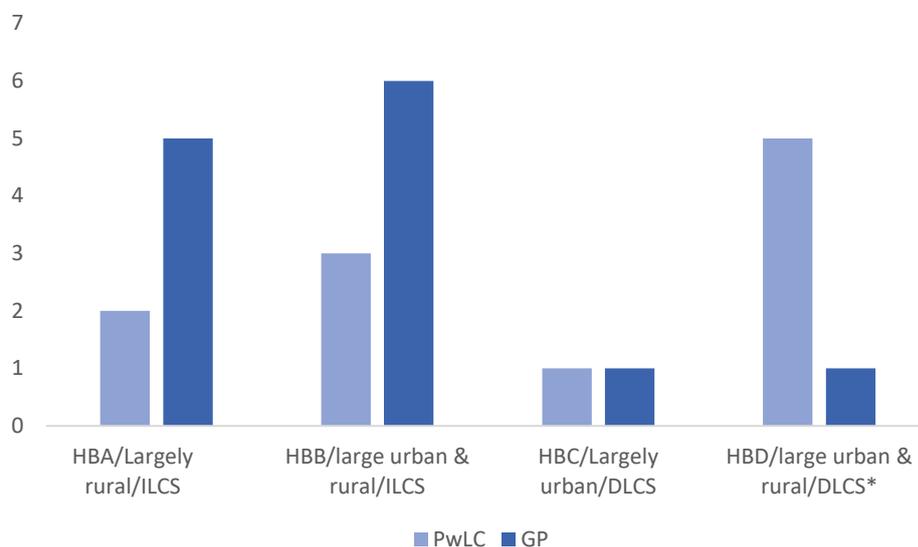
212 Twenty-five PwLC expressed an interest in taking part in the study. Of these 25, one did  
213 not meet the inclusion criteria for this study, but they were invited to take part in the  
214 larger realist evaluation. Thirteen PwLC did not pursue interest in participating in the  
215 study. Sixteen GPs expressed an interest, of whom three did not proceed to interview  
216 due to logistical challenges. Therefore, eleven PwLC (1 male, 10 female; aged 40-65  
217 (mean 53)) and 13 GPs (5 male, 8 female) provided informed consent and took part in  
218 an interview. Figure 1 displays the numbers of participants recruited from each of the  
219 four health boards and Table 1 describes participants' demographics. No participants  
220 who consented withdrew from the study.

#### 221 **Findings**

222 Framework analysis resulted in four overarching themes: i) The lived experience of Long  
223 COVID; ii) The challenges of an emergent and complex chronic condition; iii) Systemic

224 challenges for Long COVID service delivery, and iv) Perceptions and experiences of Long  
 225 COVID and its management, including rehabilitation.

226



227

228 Key: HB=Health Board; ILCS=Integrated Long COVID Service; DLCS=Dedicated Long COVID Service;

229 \*=Dedicated Long COVID Service temporarily halted due to staffing & funding; PwLC=People with Long COVID;

230 GP=General Practitioners

231 **Figure 1: Number of GPs and People with Long COVID recruited from each**  
 232 **health board**

233

234 **Table 1 Participant demographics**

<b>GPs</b>		<b>n (%)</b>	<b>People with Long COVID</b>		<b>n (%)</b>
<b>Sex</b>			<b>Sex</b>		
	<b>Male</b>	5 (38)		<b>Male</b>	1 (9)
	<b>Female</b>	8 (62)		<b>Female</b>	10 (91)
<b>Years experience primary care</b>			<b>Employment status</b>		
	<b>1-10</b>	5 (38)		<b>Employed</b>	4 (36)
	<b>11-20</b>	4 (31)		<b>Long-term sick leave</b>	4 (36)
	<b>&gt;20</b>	2 (23)		<b>Left employment due to Long COVID</b>	3 (27)
	<b>NR</b>	1 (8)			
			<b>Co-morbidities</b>		
				<b>Yes*</b>	5 (45)
				<b>No</b>	6 (55)

235 Key: GP=General Practitioner; NR=Not reported; \*co-morbidities included respiratory and thyroid conditions,  
 236 and ME (Myalgic Encephalomyelitis)

237

238 Table 2 identifies the data and participant groups that contributed to each of these  
239 themes. Throughout the manuscript participants are referred to by a unique, anonymous  
240 identifier (health board A-D, followed by PwLC or GP, followed by participant number).

241 I: The lived experience of Long COVID

242 PwLC spoke of how their symptoms negatively influenced their quality of life. These  
243 included physical symptoms such as breathlessness and mobility issues, as well as  
244 cognitive difficulties such as 'brain fog' and problems concentrating. Fatigue was most  
245 frequently reported, with PwLC describing themselves as feeling physically and  
246 emotionally exhausted, resulting in a reduced capacity to participate in activities. Some  
247 PwLC were unable to engage in relationships or felt the need to reduce their level of  
248 engagement to preserve energy.

249 *I was desperate, I just had no quality of life at all. I couldn't speak to my friends*  
250 *for coughing, couldn't look after my family because I had no energy, couldn't get*  
251 *out the house, I was housebound for months. It was just rubbish.* [APwLC05]

252 Living with Long COVID had a profound impact on participants, with many describing the  
253 experience as significantly life changing. PwLC reported the deterioration in their physical  
254 health as leading to a sense of frailty.

255 This often caused frustration around their inability to participate in activities that were  
256 perceived as important, and a need to adapt and find new ways of managing daily life.

257 *It is causing me to think now every time we decide to do something, 'Am I going*  
258 *to be able? What are we going to have to do in order to facilitate that?' And I'm*  
259 *not eighty-five. I wasn't ready to have to start thinking about this right now.*

260 [DPwLC05]

261 The psychological impact was characterised by PwLC as a struggle to come to terms with  
262 a new way of being, and a recognition that the internal expectations that one holds for  
263 oneself were being challenged.

264 **Table 2: Overview of thematic analysis**

<b>Higher order themes</b>	<b>Themes</b>	<b>Subthemes</b>
<b>I: The lived experience of Long COVID</b>	<b>PwLC</b> Impact of Long COVID on daily life	<b>PwLC</b> Psychological impact on Long COVID Physical symptoms of Long COVID Impact of Long COVID on quality of life Impact of Long COVID on ability to work
<b>II: The challenges of an emergent and complex chronic condition</b>	<b>GP</b> Long COVID as a chronic condition  <b>PwLC</b> Long COVID as a new and unknown condition	<b>GP</b> Challenges and uncertainty associated with diagnosis Complexities of Long COVID and similarities with chronic conditions (ME/FM/CFS/post-viral) System challenges associated with chronic conditions <b>PwLC</b> Stigma associated with Long COVID Invisibility of Long COVID Lack of validation Complex symptoms and lack of diagnostic/confirmatory tests Lack of ownership by any given discipline & related difficulty getting referred to secondary care Need for self-advocacy among people with Long COVID
<b>III: Systemic challenges for Long COVID service delivery</b>	<b>GP</b> Long COVID management in primary care  <b>PwLC</b> Barriers & facilitators to accessing healthcare support for Long COVID	<b>GP</b> Current pathways/lack of pathways Resource issues Training needs Safety netting: need for tests and investigations <b>PwLC</b> Lack of referral pathways and access to GP and/or secondary care Lack of available resources with long waiting lists & limited support Need for joined up and person-centred care, especially follow-up on results of tests & investigations Apparent inequities across health boards
<b>IV: Perceptions and experiences of Long COVID and its management, including rehabilitation</b>	<b>GP</b> Perceptions of Long COVID	<b>GP</b> Knowledge & beliefs about Long COVID prevalence Perceptions of symptom presentation Knowledge & beliefs about risk factors

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	<p>Knowledge &amp; beliefs about subgroups affected by Long COVID</p> <p>Work-related issues and need for vocational rehabilitation</p> <p>Psychological impact and need for peer support</p> <p>Beliefs and values relating to Long COVID</p>
<b>PwLC</b>	<b>PwLC</b>
Healthcare professionals' knowledge & attitudes	Experiences of support available
	Importance of validation from primary care
	Perceptions of HCPs lack of knowledge and understanding of Long COVID
	Role of self-management in Long COVID
	Role of pharmacology in Long COVID
<b>GP</b>	<b>GP</b>
Long COVID Rehabilitation	Role of medical staff in Long COVID Rehabilitation
	Role of allied health professionals in Long COVID Rehabilitation
	Rehabilitation needs
<b>PwLC</b>	<b>PwLC</b>
Experience of Long COVID services	Experience of support from allied health professionals : education & symptom management
	Perceptions of usefulness of online resources (mixed views of social media)
	Views on private healthcare
	Perceptions and experience of 3 <sup>rd</sup> sector support
	Perceptions of peer support
	Perceptions and experience of occupational health support

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265 Key: PwLC=People with Long COVID; GP=General Practitioners; ME= Myalgic Encephalomyelitis/Encephalopathy; FM=Fibromyalgia; CFS=chronic fatigue syndrome

266

267 This was described as a sense of losing or reshaping of one's identity, with many  
268 acknowledging that they no longer felt like the person they used to be.

269 *I can't remember the last time when I had a day where I was thinking I feel like*  
270 *my old self...I think that last bit is the longest lasting effect of it and kind of the*  
271 *most debilitating, just feeling like a different and frankly lesser person.*

272 [DPwLC06]

273 PwLC associated their physical health deterioration with a decline in mental health, with  
274 some PwLC experiencing negative feelings such as anxiety and depression. Participants  
275 also expressed a need to seek pharmacological and psychological support for their  
276 emotional wellbeing.

277 *I also had - although it is something I suffer from, but I take Citalopram for*  
278 *anxiety- a very bad anxiety period as a result of COVID because to be honest I*  
279 *thought I was going to die, so that triggered a lot of other problems [DPwLC05]*

280 Living with Long COVID impacted some participants' ability to engage in employment.  
281 Many attempted to return to work following the acute infection, with some returning to  
282 employment on a phased return. There was a perceived lack of support for return to  
283 work however, with some expressing a need for vocational rehabilitation to support  
284 return to work after a prolonged absence. Others spoke of the challenges associated with  
285 presenting at work whilst not able to fully function, which they attributed to a worsening  
286 of their physical symptoms.

287 *Fortunately, I've had it, been off, but then went back to work. I've not stayed off.*  
288 *Maybe that's a problem as well, I've not stayed off long term and listened to my*  
289 *body. I've went back and really threw myself back into my workplace and then*  
290 *suffered in my days off. [CPwLC01]*

291 The inability to work due to Long COVID created feelings of anxiety associated with the  
292 financial implications of losing income, and participants reported a lack of support and  
293 practical resources that could address their financial anxiety.

294 *It is a worry for the future. I'm [age] and I've got a bit to go until retirement. I*  
295 *feel like I'm in limbo, it's like Groundhog Day, and it's kind of scary what's going*  
296 *to happen with my work. I'm going to have to address that at some point*  
297 *because I can't see there there's an end in sight with everything. Yeah, it's*  
298 *another hurdle I'm going to have to address next year at some point. [BPwLC07]*

299 II: The challenges of an emergent and complex chronic condition

300 Due to the symptoms experienced by PwLC in this study, many had presented to  
301 primary care seeking confirmatory tests and onward referral and had felt frustrated  
302 when they encountered GPs who were reluctant to provide a diagnosis. GPs however  
303 spoke of the challenges associated with providing a diagnosis in the absence of a specific  
304 diagnostic test, and the limited treatment options that were available.

305 *I don't know if we will move away from handing out the diagnosis of Long COVID.*  
306 *Because to be honest, I don't often suggest it to the patient as a diagnosis*  
307 *because our options for management are so minimal. So, I tend to, if the patient*  
308 *thinks they've got it, work through that with them. [AGP01]*

309 GPs also drew similarities between Long COVID and existing chronic conditions, such as  
310 chronic fatigue syndrome/ME and Fibromyalgia, and a sense of familiarity around the  
311 uncertainties associated with diagnosis and management of these conditions, conveying  
312 a need for a service for long term conditions inclusive of Long COVID.

313 *I think we are talking about Long COVID now because everyone is looking at*  
314 *COVID, which is great. But I think it's not the only kind of post-[illness] treatment*  
315 *type problem that we have nowhere to send people. And I think it's a problem*  
316 *with the health system. [BGP01]*

317 People with Long COVID recognised the uncertainties associated with Long COVID. Many  
318 felt they were not heard or believed by healthcare professionals and the wider public  
319 however and expressed a desire for their symptoms to be validated, listened to, and  
320 supported. There was a sense of social stigma associated with living with an invisible

321 illness, which was often attributed to a lack of understanding about how Long COVID  
322 affects a person, and a feeling that they were being treated like a malingerer, and  
323 'making up their suffering.'

324 *There's definitely been a lot more media which is very helpful...there was a middle*  
325 *part where people were quite scathing because in the first part I remember*  
326 *friends saying 'I don't know anybody else that's got Long COVID', and that in*  
327 *itself felt a judgement, but then we hit a middle part where loads of folk were*  
328 *getting COVID but they'd been vaccinated or their bodies just dealt with it*  
329 *differently and they weren't ill, so then there was a huge period of judgement*  
330 *came out, 'well, so-and-so had it and they're fine'. [BPwLC06]*

331 Many PwLC felt dissatisfied that symptoms were not being taken seriously enough to  
332 gain access to secondary care and had an awareness of inconsistencies across health  
333 boards in relation to Long COVID services, suggesting a need for a single person to take  
334 ownership of Long COVID in their area.

335 *"There needs to be at least one thing for each trust. Even if there's only one place*  
336 *in the whole of [Health Board], and obviously I know that I'm from [place] and*  
337 *that would mean it would be here, I just think there should be at least one that*  
338 *people aren't having to travel that long a distance to get to. Just somebody that*  
339 *has studied Long COVID, understands the complexities of it...[ BPwLC05]*

340 The disconnection between patients' expectations and their experiences led some to the  
341 realisation that they needed to take control of their own health. One participant stated,  
342 "You're almost left to fend for yourself" [BPwLC07], whilst others highlighted the  
343 importance of advocating for themselves through researching symptoms, obtaining  
344 information from online resources, and using exercise to self-manage.

345 *Oh, I've turned to Twitter...there is kind of a few people on Twitter that I follow*  
346 *that have been really good and kind of published research papers...I go back to*  
347 *the GP and ask about stuff, so I'm just having to kind of search for it myself...So*

348 *you're not only having to deal with the illness you have to kind of then navigate*  
349 *kind of like, where am I going to get help from? [DPwLC02]*

350 III: Systemic challenges for Long COVID service delivery

351 Healthcare system-related challenges included the lack of clear pathways to access,  
352 siloed specialised services, limited resources (long waiting times for appointments in  
353 primary and secondary care), and the lack of holistic care. PwLC described these  
354 challenges as contributing to communication breakdowns, a lack of accountability over  
355 chronic conditions, and the need for self-advocacy amongst people with Long COVID.

356 *Every NHS trust should have at least one Long Covid clinic. It needs to have*  
357 *specialist people. All the therapists and all the scans and everything I've had have*  
358 *been done as standalone things, whereas at least if it was something centralised*  
359 *in a COVID clinic you would feel like you were having every part of your body*  
360 *tested and checked with Long COVID in mind..... It's the piecemeal part of it*  
361 *that's not looking at it in a holistic way. [BPwLC05]*

362 GPs reported a lack of pathways and processes for managing patients with Long COVID,  
363 including identifying and tracking patients along the care trajectory and establishing  
364 consistent approaches to management. The nature of the emergent condition made it  
365 challenging to identify appropriate services to refer patients on to.

366 *It's less easy to identify one individual you could refer them to so without an*  
367 *over-arching service it's hard to know where to direct the patients. [AGP02]*

368 GPs reported that patients seldom met the criteria for existing rehabilitation programmes  
369 (e.g., cardiac/respiratory). They also reported that they often carried out tests and  
370 investigations to exclude other differential diagnoses as a means of 'safety-netting', but  
371 some were mindful that this could delay rehabilitation and recovery.

372 *There is a risk that we hold up rehabilitative inputs until we fully investigated*  
373 *things and we are entirely assured that there's nothing going on. So, we should*  
374 *perhaps be blending things a little better. [BGP02]*

375 Both participant groups felt that limited resource was one of the main barriers to Long  
376 COVID management. People with Long COVID experienced difficulty accessing both  
377 primary and secondary care.

378 *I didn't have the energy to argue with the receptionist at the GP surgery, and*  
379 *that's the honest truth, I just didn't have it in me to phone and try and explain it*  
380 *all again. So, I lost nineteen pounds in four weeks because I just couldn't eat*  
381 *because I felt sick. But even that wasn't worth the battle I would have to get past*  
382 *a GP receptionist. [APwLC05]*

383 GPs were aware of the significant pressure secondary care were facing which often  
384 resulted in long waiting times for specialties. As a result, patients often re-presented to  
385 primary care for ongoing issues leaving GPs with limited options for referrals and  
386 treatments.

387 *We were getting a bit frustrated referring patients to secondary care for help.*  
388 *There wasn't much coming through. They were already dealing with backlog*  
389 *enough and they're getting piled up with these other things happening. I*  
390 *understand their limitations, entirely...I don't think that any I have referred [to*  
391 *respiratory or cardiovascular] have been seen yet. ... [CGP03]*

392 Variation in models of access for rehabilitation led PwLC to question the equity of care  
393 across health boards as they were aware of Long COVID services provided in other parts  
394 of Scotland and in England. Some PwLC who were able to afford it sought private health  
395 care and experienced improvements in their condition.

396 *I've taken it upon myself to see a physio privately who is helping me because*  
397 *that's the hardest thing is this pacing business...Because I do too much one day,*  
398 *then I can't do anything the following day, maybe even two days...It's been very*

399 *helpful because she, she's guiding me because what I would I think is*  
400 *manageable and doable is very different to what she says is manageable and*  
401 *doable. [DPwLC01]*

402 People with Long COVID emphasised the need for a more joined-up service to improve  
403 communication and coordination of care.

404 *I should have had the results in six weeks, but I've not had them, I don't know*  
405 *who to contact to get them, because it was through the neurologist rather than*  
406 *my GP. [APwLC03]*

407 They also felt that specialists focused only on specific aspects of their health but not the  
408 condition as a whole.

409 *I just feel sometimes having that one person, like I know a lot of people have a*  
410 *consultant that they go to and that's the person that they speak to, or the centre*  
411 *that they go to, for support. There's a group of people perhaps that they deal*  
412 *with, but they get it. They're a familiar face and that makes sense. But you feel a*  
413 *bit of a pariah, to be honest, with Long COVID. [BPwLC06]*

414 GPs acknowledged the importance of a more holistic approach to Long COVID care  
415 including psychological as well as physical support. They suggested the need for  
416 integrated multidisciplinary management that provides support for a complex range of  
417 symptoms.

418 IV: Perceptions and experiences of Long COVID and its management, including  
419 rehabilitation

420 This theme comprised data on GPs knowledge, attitudes, and perceptions of Long  
421 COVID, as well as participants' perceptions and experiences of Long COVID services.

422 *GPs knowledge, attitudes, and perceptions of Long COVID*

423 In health boards where Long COVID management was integrated into existing  
424 community services with less clear pathways to rehabilitation (health boards A & B),

425 there was a perceived lack of demand by GPs for Long COVID-specific services. GPs in  
426 this study reported low numbers (1-6 per week) of people presenting to their practices  
427 for support with symptoms of Long COVID.

428 *Maybe 10-12 [Long COVID patients have presented] in total. But I don't know*  
429 *whether they're all coming to us. They might be just suffering in silence. [CGP03]*

430 Patients were commonly reported to be of working age and were perceived to be fit and  
431 healthy prior to coronavirus infection. Some GPs also reported that females were more  
432 commonly presenting with symptoms associated with Long COVID than males.

433 Some GPs attributed the low patient numbers to natural resolution and the ability to self-  
434 manage on the basis that patients were not reconsulting or requesting further sick lines.

435 *I think with time most of their symptoms do seem to ease and pass. [AGP01]*

436 However, some GPs and most PwLC believed that people with Long COVID were not  
437 presenting to primary care because they believed there was no support available for  
438 Long COVID.

439 *A lot of patients don't necessarily consult because probably they are seeing things*  
440 *in the media and things, you know aware that there aren't particular treatments.*  
441 *So, they just think it's par for the course that they feel like that. [AGP02]*

442 *"I stopped contacting the GP because I just feel I'm wasting their time"*  
443 *[APwLC03]*

444 PwLC expressed some concerns associated with GPs being under pressure and attributed  
445 their reduced attendance at GP practices to feeling like they were an additional burden  
446 on the healthcare system. They spoke of withholding information related to their  
447 symptoms due to an awareness that GPs were time pressured, and expressed concerns  
448 associated with ensuring appointments were productive.

449 *I know there are things that I haven't raised with a GP because I'm aware that*  
450 *they're time pressured, I've raised about ten symptoms already in my*

451 *consultation with them and I know I've got another three sitting on my list, but I*  
452 *can't bring that into the situation...and I'm potentially sitting on stuff that I should*  
453 *have discussed [BPwLC06]*

454 PwLC also noted their concerns over the lack of specialist knowledge and expressed a  
455 sense of apprehension when GPs were unable to demonstrate an appropriate level of  
456 knowledge concerning the condition.

457 *But the last time I went to the GP they said, 'we find people with Long COVID*  
458 *know more about it than we do.'* And I thought that doesn't really fill you with  
459 *great enthusiasm. [DPwLC04]*

460 Most GPs acknowledged that Long COVID has impacted people living with the condition  
461 and conveyed a need for education associated with recovery and returning to work. They  
462 spoke of patients feeling pressured to return to work without appropriate support in  
463 place to assist their workplace integration. The need for psychological support was also  
464 expressed by both GPs and PwLC. Specifically, peer support was identified as a useful  
465 resource for people with Long COVID, where they can be supported by others  
466 experiencing similar symptoms.

467 *It's just reassuring to know that you're not alone in this. Misery loves company,*  
468 *and it's good to know that there are other people who have this, because*  
469 *otherwise it would become kind of depressing. And it helps put things in*  
470 *perspective, that you know that as bad as you feel someone else is probably*  
471 *feeling worse. [DPwLC06]*

472 A Minority of GPs did not perceive the need for a specialised Long COVID service. Some  
473 GPs referred to a scepticism among their colleagues about Long COVID in general:

474 *It's not only for people, it's also for the medical professionals to believe as well*  
475 *that this is a problem. I think there is still some scepticism among medical*  
476 *professionals as well, still, about this being accepted and treated. [CGP03]*

477 One GP participant described themselves as being slightly cynical about Long COVID and  
478 wary of the need for rehabilitation, suggesting that patients should "wait it out" and they  
479 will get better, likening Long COVID and its impact to 'flu.

480 *"I think it's exactly like flu. The same applies in flu. You get lots of people that get*  
481 *it. Most people are not terribly well with it, few people get flu without knowing*  
482 *they've had it. Some people recover quickly, some take a longer time to recover*  
483 *and some die" [AGP04]*

484 *Perceptions and experiences of rehabilitation and other Long COVID services*

485 A range of perceptions regarding Long COVID rehabilitation were held by both  
486 participant groups. Some PwLC lacked knowledge of the potential role of rehabilitation  
487 professionals in supporting people with Long COVID. This view was shared by some GPs  
488 who reported a limited understanding of the role of rehabilitation in the management of  
489 Long COVID.

490 *Physio, I can't really see much of a role. But that could be my lack of knowledge*  
491 *about it because with the patients I have spoken to it's not really so much of a*  
492 *physical thing, it's not like a particular joint pain as such that they would benefit*  
493 *from a physio. It's more the kind of cognitive aspect, maybe an OT, but I don't*  
494 *know what they would add. [BGP05]*

495 Some PwLC had enough knowledge of rehabilitation to request referral or refer  
496 themselves to rehabilitation services where this was an option. In most cases these  
497 participants were on waiting lists and had been for some time. Although we did not  
498 record participants' job titles (for those in employment), several participants in this  
499 category disclosed during the interviews that they were healthcare professionals, with  
500 prior knowledge of, or colleagues working in, rehabilitation services. A third group of  
501 PwLC reported a need for Long COVID rehabilitation services in their health board area,  
502 suggesting a lack of services and/or their promotion.

503 The small number of participants who had received rehabilitation for Long COVID (n=3)  
504 were generally positive about their experience, reporting benefits from specific  
505 professions (e.g., physiotherapy, speech and language therapy) and interventions (e.g.,  
506 breathing exercises), with information and advice on Long COVID and symptom  
507 management, particularly the use of pacing, being highly valued.

508 *The biggest help was speaking to Speech and Language... she gave me lots of*  
509 *information that was very interesting, and lots about the biology of what's going*  
510 *on with my [laryngeal] spasms. [DPwLC04]*

511 *Just having somebody to help you manage what that should look like, what is too*  
512 *much, because you can read about pacing, you can chat about it online with other*  
513 *people with Long COVID, but trying to get a model that fits for you as an*  
514 *individual is actually really hard without support. [DPwLC06]*

515 This contrasted with the views of PwLC of generic self-management booklets, which were  
516 commonly reported as lacking person-centredness.

517 *When I did refer myself to the [specialist] team, I got a booklet, a massive*  
518 *booklet through the post, that says this that and the other. But it's such an*  
519 *individual, highly differentiated set of symptoms that any one person can have,*  
520 *just none of it was particularly relevant to me. [DPwLC01]*

521 One participant had sought informal rehabilitation from a personal trainer but felt that  
522 was not helpful as it was too intense, and the trainer did not have the requisite Long  
523 COVID knowledge to support patients effectively to avoid rehabilitation being 'too  
524 intense.'

525 *"Just with having this discussion it's like a wee light bulb moment that I'm*  
526 *having, that I'm thinking I've tried the PT [personal training], it was too intense,*  
527 *threw the towel in. See all that weights and lunges and dah, dah, dah, I thought I*  
528 *haven't got the energy for it. So maybe physio, as you're saying, if they know all*

529            *about the disease, they know about what they would recommend and maybe be a*  
530            *bit more gentle” [DPwLC01]*

531    Despite the lack of knowledge of the potential role of rehabilitation demonstrated by  
532    some GPs, most reported that they would engage with a dedicated Long COVID  
533    rehabilitation service, as it would provide an onward referral route for patients,  
534    particularly as they commonly reported being limited by secondary care referral criteria.  
535    Several GPs felt that a multidisciplinary team approach could be beneficial for their  
536    patients and could provide the validation that patients needed.

537            *I think they feel quite isolated actually and I think it would be useful even if*  
538            *objectively...there’s not a huge improvement. I think psychologically it would be*  
539            *really important for them. Someone to believe them, to see what’s happening,*  
540            *and just thinking someone’s looking out for them. [BGP01]*

541    Some also believed that earlier pulmonary rehabilitation could contribute to better  
542    functional recovery.

543    PwLC reported accessing a range of other Long COVID services and sources of support.  
544    For some, a helpful source of advice and support came from occupational health services  
545    when they were returning to work after a period of Long COVID-related absence. Some  
546    PwLC had accessed support from a charity, with some finding it useful and others finding  
547    it too generic for their needs. Some participants found support from peers with similar  
548    experience of Long COVID was helpful and provided validation. For some this positive  
549    peer support was accessed via social media. Others reported negative experiences of  
550    social media including finding social media platforms unsafe and unhelpful for sharing  
551    lived experiences. The lack of monitoring in online forums contributed to PwLC feeling  
552    vulnerable to receiving incorrect information and negativity from others. Many PwLC  
553    reported that they resorted to online information, with some taking this information to  
554    their GP consultation. Finally, as reported above, some turned to private healthcare in

555 response to access issues and long waiting times, including psychological therapy, GP,  
556 medical specialties, and physiotherapy.

## 557 **DISCUSSION**

558 We explored the issue of access to community rehabilitation for Long COVID from the  
559 perspectives of PwLC and GPs in four Scottish health boards. PwLC described a range of  
560 symptoms affecting their physical and mental health and having a profoundly negative  
561 impact on their daily life, employment, and relationships. We found a tension between  
562 PwLC seeking diagnosis and onward referral and GPs lacking diagnostic tests and limited  
563 options for managing Long COVID. This tension could manifest itself in PwLC perceiving  
564 themselves as socially stigmatised by their 'invisible' condition. We also identified several  
565 systemic challenges for Long COVID service delivery which related to access, siloed  
566 services, limited resources, and a perceived lack of holistic care, causing frustration for  
567 both GPs and PwLC. We found that although a minority of GPs expressed scepticism  
568 about Long COVID and the need for rehabilitation and other services for this patient  
569 group, there was general agreement between PwLC and GPs on the need for accessible,  
570 person-centred services and support. Regarding community rehabilitation, we found  
571 that: i) some PwLC and some GPs lacked knowledge on the potential role of community  
572 rehabilitation in the management of Long COVID; ii) having prior knowledge of  
573 rehabilitation or being a healthcare professional appeared to facilitate access to  
574 community rehabilitation, and iii) PwLC who had received rehabilitation generally found it  
575 beneficial. Due to the lack of knowledge and difficulty accessing rehabilitation however,  
576 PwLC had accessed a range of other services and sources of support, with varying  
577 success.

578 The relationship between Long COVID and reduction in physical and mental health  
579 outcomes and quality of life is becoming increasingly known [29 30]. A large Scottish  
580 population cohort study found that almost 50% of PwLC had not recovered 6-18 months  
581 after symptomatic infection, and that PwLC experienced a wide range of symptoms  
582 affecting daily activities and quality of life [31]. This study adds to that growing

583 evidence-base and demonstrates the influence of the condition on a sample of PwLC  
584 living in Scotland almost 3-years on from the start of the pandemic. The persisting  
585 prevalence and impact of Long COVID on people's lives further emphasises the need for  
586 support and services such as community rehabilitation to be available, in keeping with  
587 recommendations [168].

588 These recommendations are that PwLC should have access to personalised and  
589 multidisciplinary rehabilitation; such rehabilitation is reportedly available throughout  
590 Scotland [12] delivered by a variety of service models. Our previous research, however,  
591 observed low numbers of PwLC receiving community rehabilitation in some areas of  
592 Scotland [15]. This study has shed some light on the potential reasons for the mismatch  
593 between recommendations, reported service availability and numbers of PwLC accessing  
594 community rehabilitation.

595 Lack of GP knowledge regarding community rehabilitation and its potential role in Long  
596 COVID may, in part, be attributed to the nature of Long COVID as a new condition that  
597 health professionals are still learning how to manage. Previous research has reported a  
598 lack of GP understanding of the role of rehabilitation professionals in the management of  
599 conditions commonly encountered in primary care; for example, the role of  
600 physiotherapists in osteoarthritis management [32]. Furthermore, international public  
601 understanding of the role of occupational therapy has been reported as limited [33].  
602 Therefore, in the context of a new condition with an evolving evidence-base, it is  
603 perhaps not surprising that GPs and PwLC may have limited understanding of what  
604 rehabilitation professionals can offer to this patient population. Furthermore, the  
605 reluctance to promote the availability of services in some areas, due to pre-existing  
606 resourcing and anticipated demand-capacity issues may have further limited access to  
607 Long COVID rehabilitation [15]. Issues with promotion of services, clarity of pathways  
608 and interdisciplinary communication between GPs and rehabilitation professionals have  
609 been reported previously[32 34]. The findings of this study suggest that further  
610 improvements in communication and collaborative working may be required to enhance

611 access to community rehabilitation for PwLC [32]. Indeed, the finding that prior  
612 knowledge of rehabilitation, and being a healthcare professional facilitated access to  
613 community rehabilitation for PwLC, is further evidence that successfully navigating the  
614 referral system is challenging.

615 The findings of PwLC who had managed to access community rehabilitation being  
616 satisfied with it, and GPs wanting a Long COVID service to refer patients to are in  
617 keeping with previous research [17]. The challenge not only lies in availability of such  
618 services, but clearly in PwLC and GPs awareness of the benefits of these services, their  
619 active promotion, and clear and timely accessibility of rehabilitation services. There is  
620 therefore a need to overcome the systemic challenges to accessing timely rehabilitation  
621 reported in this study. Considering the ongoing nature of living with Long COVID, these  
622 challenges are likely to continue beyond the time and resource constraints of  
623 Government funding provision for existing Long COVID rehabilitation within rehabilitation  
624 services that were already historically underfunded and considered 'Cinderella services'  
625 [15].

### 626 ***Strengths and limitations***

627 This was the first study to explore the issue of accessing community rehabilitation in the  
628 Scottish context and included the perspectives of those referring and potentially being  
629 referred to community rehabilitation. One researcher conducted all interviews to ensure  
630 consistency and multiple researchers were involved in analysing and interpreting the  
631 data, including people with lived experience of Long COVID. There are, however, some  
632 limitations. As this study was an extension of our original study, we had insufficient  
633 resources to enable larger participant samples. We realised from the outset that we  
634 would be unable to describe achieving data saturation. Although we recruited to target  
635 for the GP sample, there was under-representation from the two health boards with  
636 dedicated Long COVID services (one newly launched and one halted). Therefore, the  
637 data largely represents the views of GPs from health boards where Long COVID services  
638 were integrated into existing community rehabilitation services; it is possible that GPs

639 views of dedicated Long COVID services may be different. We recruited a small, mostly  
640 female sample of PwLC, and mostly from health boards with integrated or a halted  
641 dedicated Long COVID service. Their views on accessing Long COVID services may  
642 therefore have been biased. Recruitment of PwLC was likely limited by our reliance on  
643 social media and one Long COVID charity; however, both mechanisms had the potential  
644 to reach many people. Despite these challenges, both the PwLC and GP participant  
645 groups provided consistent understandings of the challenges they faced when dealing  
646 with Long COVID. Therefore, while data saturation is not claimed, it does appear that we  
647 achieved adequate data sufficiency to be confident that the findings reflect key issues  
648 within each participant group.

#### 649 **Implications for practice and research**

650 There is a need for greater understanding by the public, GPs, and other potential  
651 referrers of the role of community rehabilitation professionals in the management of  
652 Long COVID. There is an equally important need for community rehabilitation services to  
653 be well promoted and accessible to the PwLC for whom they may be appropriate. Long  
654 COVID is still a prevalent condition whose impact on individuals can be profound. The  
655 need for community rehabilitation for PwLC is likely to persist. Service providers should  
656 therefore consider availability and accessibility of Long COVID rehabilitation and ensure  
657 adequate interprofessional communication and collaboration to enhance the experience  
658 for PwLC.

#### 659 **CONCLUSION**

660 We have provided further understanding of the barriers to accessing Long COVID  
661 community rehabilitation by exploring the perceptions and experiences of key  
662 stakeholders in the referral process. These findings can be used by those (re)designing  
663 community rehabilitation services for people with Long COVID and potentially for other  
664 conditions. There remains a need for greater public and GP awareness of the role of  
665 rehabilitation professionals in Long COVID.

666 **AUTHOR CONTRIBUTIONS**

667 KC, ED, JM, LA, JP, JO, AL, PS contributed to the study's conception and design. EHW  
668 undertook data collection. ED, KC, EHW, TT, JC, JS, ES undertook analyses and drafted  
669 the first version of the manuscript. KC led future iterations of the manuscript. All authors  
670 read and commented on the manuscript and approved the final version of it. The  
671 corresponding author attests that all authors meet authorship criteria and that nobody  
672 meeting the criteria have been omitted. ED and KC have joint responsibility for the  
673 research conduct of the study, had access to the data, and controlled the decision to  
674 publish.

675 **COMPETING INTERESTS**

676 All authors have completed the ICMJE uniform disclosure form at  
677 [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) and declare: all authors had financial support from the  
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682 are declared by any of the authors.

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686 **DATA AVAILABILITY**

687 All data produced in the present study are available upon reasonable request. Robert  
688 Gordon University holds the copyright for the full interview transcripts and may grant  
689 data sharing permission on request.

690 **ETHICS APPROVAL**

691 Ethical approval was granted from the Wales Research Ethics Committee 6 [21/WA/0118  
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