

A qualitative exploration of the participants' experience of a web-based physiotherapy program for people with multiple sclerosis: does it impact on the ability to increase and sustain engagement in physical activity?

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1 **A qualitative exploration of the participants' experience of a web-based**
2 **physiotherapy programme for people with multiple sclerosis (MS): Does it impact**
3 **on the ability to increase and sustain engagement in physical activity?**

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5
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24 **Abstract (196 words)**

25 **Background** Web-based exercise and physical activity interventions are being
26 developed as a potential way to help people with multiple sclerosis achieve and
27 maintain increased physical activity levels. Seeking feedback from people who
28 have used such interventions will help guide the development process.

29 **Methods** In-depth interviews were used to explore the experiences of participants who
30 used a web-based physiotherapy intervention as part of a feasibility randomized
31 controlled trial. Interviews were audio-recorded, transcribed verbatim and analysed
32 using thematic analysis.

33 **Results** Eleven people (age 28-68) were interviewed. Most perceived that their physical
34 activity had increased, primarily due to completing twice-weekly web-based
35 physiotherapy sessions. Three key themes were identified. 'It's all in one place'
36 encompasses the value of having a convenient and portable program. 'Keeping an eye'
37 captures people's thoughts regarding the supervision offered by the physiotherapist,
38 through the website, and 'Hopes and expectations' reflects the importance of having
39 opportunity to discuss what may be gained from using such a program.

40 **Conclusions** This intervention offered a convenient, flexible and portable
41 physiotherapy program which most people perceived helped them achieve and
42 sustain increased levels of physical activity. Talking with people about
43 expectations is important, particularly if a person's condition is deteriorating.

44 **Keywords:** exercise, rehabilitation, telerehabilitation, internet-based, e Health

45 **Introduction**

46 Achieving and maintaining recommended levels of physical activity is important yet
47 challenging for many people with multiple sclerosis (MS). The use of targeted exercise
48 programmes and physical activity promotion have been demonstrated to lead to a range
49 of physical [1, 2, 3, 4, 5] and emotional [6, 7] benefits which may also extend to
50 minimizing the complications and comorbidities associated with living a more
51 sedentary lifestyle [8]. This has encouraged an increased emphasis within clinical
52 practice to incorporate targeted exercise programmes, and facilitate engagement with
53 increased levels of physical activity [9]. In this study physical activity is considered in
54 line with the Caspersen definition as ‘any bodily movement produced by skeletal
55 muscles that requires energy expenditure’ [10] and as such enables participants to
56 discuss all types of activity such as structured exercise and sport, but also lifestyle
57 activity such as housework, gardening and employment.

58
59 Disease specific guidelines for people with MS [11] have helped guide physical activity
60 prescription, particularly for those with mild to moderate disability, but the challenge to
61 ensure adequate levels are sustained in the long term remains for individuals and those
62 involved in their care. Current physical activity levels in people with MS remain low
63 [12] and this concern has prompted research to identify factors that may have a positive
64 influence on long-term participation. These include: choice of activity [13]; control over
65 level of engagement; advice and support received; self-efficacy [14, 15] and use of goal
66 setting [16]. Evidence also describes some of the barriers to participation that people
67 with MS experience, such as the effort and travel distance required to access
68 rehabilitation venues, fatigue and lack of time [17].

69

70 The use of technology, such as the internet as a mode of delivery of exercise and
71 physical activity interventions, is being increasingly trialled in many areas of healthcare
72 to address some of these barriers. Two systematic reviews evaluating a wide variety of
73 telerehabilitation interventions in MS provide a broad overview of their content, design
74 and outcomes. [18, 19] They suggest that this approach may be effective in increasing
75 physical activity [18, 19] in the short term, although compliance remains a significant
76 issue [20, 21, 22] and an important factor to further explore.

77
78 Telephone interviews [23] and process evaluation questionnaires [23, 24] have been
79 previously used to explore the feasibility and acceptability of different web-based
80 interventions and have provided researchers with areas of development on which to
81 focus. Continuing to capture the user experience about issues broader than the
82 operational aspects of the programme, is likely to provide a deeper understanding of the
83 factors that impact on the use of web-based interventions and may be instrumental in
84 their further development.

85
86 This study aimed to explore the user experience of a web-based intervention which was
87 part of a multi-centre randomised controlled feasibility trial of web-based
88 physiotherapy ((WEBPaMS), registered at ClinicalTrials.gov (Identifier:
89 NCT02508961)), and specifically, whether or not users perceived that it had impacted
90 on their ability to increase and sustain engagement in physical activity.

91

92 **Materials and Methods**

93 ***Ethical Approval***

94 Ethical approval for this study (15/WS/0030) was obtained from the West of
95 Scotland Research Ethics Service, Glasgow. All participants gave written
96 informed consent prior to taking part.

97 ***Research Approach and Methodology***

98

99 A qualitative research approach was selected to address the aim of the study using a
100 general qualitative inquiry design, underpinned by a pragmatic epistemology and a
101 critical realism ontology. In-depth, individual, face-to-face interviews were undertaken
102 with the participants allocated to the web-based programme at one of the three main
103 WEBPaMS study sites (Plymouth). Interviews were selected to gain depth of
104 understanding about each participant's unique experience of the intervention and in
105 order to explore this in light of their own individual circumstances. They were
106 conducted at the participant's home (or preferred venue) using an interview guide (table
107 1) which was developed and piloted with a person with MS who was unrelated to either
108 this sub-study or the main WEBPaMS study. Open questions, with prompts as required,
109 were used with sufficient flexibility to enable participants to raise issues they
110 considered important. Interviews were conducted by the (female) primary researcher
111 (RD, a PhD student and physiotherapist with 20 years clinical experience). Interviews
112 lasted up to one hour, were audio recorded and transcribed verbatim. This study is
113 reported in line with the COREQ guidelines [25].

114

115

[Table 1 near here]

116 ***Participants and Intervention***

117 Each of the WEBPaMS [26] intervention group participants at the Plymouth site were
118 invited to participate in this sub-study. The entire WEBPaMS sample was not
119 investigated for pragmatic reasons. This study was undertaken as part of the primary
120 researcher's doctoral work exploring adherence to physical activity and physiotherapy
121 programmes and Plymouth was her location of residence. An invitation letter and
122 participant information sheet were sent to the potential participants within one month of
123 their final WEBPaMS follow-up assessment. Each gave consent and were interviewed
124 within six weeks (range 1-6 weeks) of that final assessment. Inclusion criteria for the
125 WEBPaMS study included; adults with a confirmed diagnosis of MS, known to an MS
126 consultant in the study recruiting areas, an Expanded Disability Status Scale (EDSS)
127 score of 4 - 6.5 (indicating mild to moderately impaired walking) and access to a
128 personal computer/tablet or smart television with an email address and internet
129 connection. Potential participants had been excluded if they were already taking part in
130 regular exercise or physiotherapy (two or more times per week), had poor cognitive
131 function as assessed by a Mini Mental State Examination Score (MMSE <24), had any
132 significant change in medication or a relapse requiring treatment within the last 3
133 months, or any significant co-morbidities for which exercise was contra-indicated. They
134 were also excluded if they were unwilling to be randomised to intervention/ control
135 group or were currently participating in another clinical trial (rehabilitation or
136 pharmacological).

137

138 The main WEBPaMS study was a single blind randomised controlled feasibility study.
139 Ninety participants from three centres were randomised to receive either a six-month
140 individualised web-based exercise programme (n=45) (intervention) or a paper based
141 exercise programme (n=45) (active comparator). All participants were assessed by a

142 physiotherapist, had an individualised exercise programme devised and were asked to
143 complete it twice weekly. A range of outcome measures were completed at baseline,
144 three months, six months and nine months (three month follow up). The active
145 comparator group received their exercise programme in paper format
146 (www.physiotherapyexercises.com) and were asked to complete a paper exercise diary.
147 The intervention group accessed their exercise programme via a website
148 (www.webbasedphysio.com). The website included exercises in video format with
149 audio and text description along with MS specific exercise advice. Participants were
150 requested to complete a diary entry after every session to indicate which of the exercises
151 had been completed and to comment on any issues such as if the exercises were too
152 hard or easy. The physiotherapist remotely reviewed the diaries every two weeks and
153 was able to modify the exercise programme in line with any feedback they had received.
154 Participants were informed of any changes to their programme via email and could
155 contact the physiotherapist through the diary or via email or telephone at any point if
156 required. Further information regarding the intervention can be found in the pilot [23]
157 and main study [26] publications.

158

159 ***Data Analysis and Ensuring Rigour***

160

161 Data were analysed using thematic analysis according to the six phase method of
162 identifying and analysing patterns in qualitative data described by Braun and Clarke [27]
163 using a general inductive approach. Initially the audio recordings of each interview were
164 listened to twice and transcripts were read and re-read in order for the researcher to
165 become familiar with the data. Observations were noted on the transcriptions as
166 appropriate during this stage and relevant codes were generated along with appropriate

167 data extracts. The next stage of analysis involved the primary researcher considering
168 and collating the codes by hand, rather than through use of a software package and
169 making note of meaningful patterns in the data that were relevant to the research
170 question. These were discussed with the other members of the research team (JF, LP
171 and EC) on a number of occasions and used to create themes and subthemes that
172 captured the essence of the participants' voice and worked in relation to the data set.
173
174 Themes and subthemes are presented using pseudonym quotes (with participant age and
175 EDSS) to illustrate the participant view.
176
177 Rigour was enhanced during the process by ensuring an audit trail of the primary
178 researcher's (RD) process. A second researcher (JF) independently coded and discussed
179 in detail three of the transcripts with RD and the whole team was involved in reviewing
180 each of the themes and subthemes. The principles of credibility, transferability and
181 dependability were followed throughout [28]. Reflexivity was promoted by the primary
182 researcher who is an experienced neuro-physiotherapist. Steps, such as completing a
183 reflexive diary and regularly meeting with the research team were put in place to try and
184 minimise the bias this would bring to interpretation of the data. A summary of the
185 main themes was sent to participants for member checking. Responses indicated that the
186 summary provided an accurate reflection of the interviews content.

187

188 **Results**

189

190 Eleven out of a possible 12 people were interviewed. One person did not respond to the
191 initial invitation letter or to three further attempts to make contact by letter, email and

192 telephone. Participants were 90% female with an age range 28- 68 years; time since
193 diagnosis range 1-40 years and EDSS range 4-6.5. Disease course was: Relapsing
194 Remitting [n=4], Primary Progressive [n= 1] and Secondary Progressive [n=6]. Three
195 participants were employed, two unemployed and six were either retired or medically
196 retired. Demographic information of participants is presented in table 2.

197

198 [Table two near here]

199

200 *Perceived impact on physical activity level*

201

202 Nine of the 11 participants felt that their physical activity levels had increased over the
203 study period. This was attributed to a variety of reasons including improved balance,
204 confidence and general fitness, increased motivation to exercise, and being committed
205 to the study protocol of completing the exercise programme twice-weekly. One
206 participant described an example of when she was more physically active which she
207 attributed to the benefits she had experienced from engaging in the web-based
208 programme.

209

210 “I picked up my daughter and we drove to [local town]; I got lost on the way but
211 we got there. It took ages to get there... we walked all the way round [local
212 town]. Oh my God. It is like really narrow, there’s that little high street. So I had
213 to walk up there. I probably stopped about three times. That’s good for me.
214 That is really good for me and that’s quite a steep road and I made it all the way
215 to the top.” *Debbie (age 45, EDSS 5.0)*

216

217 Further exploration of the potential reasons for her improvement revealed that
218 completing her exercise programme had helped her to feel fitter and be able to achieve
219 more, which in turn provided motivation to continue.

220

221 Well that's [using web-based physio] what started me off isn't it? I wouldn't
222 have bothered otherwise, would I, so yeah, I wouldn't honestly truthfully I
223 wouldn't have bothered. That's what made me get up and go, "what, I can do
224 it!" *Debbie (age 45, EDSS 5.0)*

225

226 Not everyone felt that their activity levels improved however. Two participants shared
227 their thoughts regarding the impact that disease progression had had over the duration of
228 the WEBPaMS study. Both noted a deterioration in their activity level, with one person,
229 to the point that she was no longer able to walk. In this case the participant explained
230 that although she was now not walking, having been able to make direct contact with
231 the physiotherapist by reporting her difficulties on the online diary page, she was able to
232 seek advice early, have her exercise programme modified and was enabled to continue
233 to exercise at a level she could manage. Without this, when her primary activity
234 (walking) was no longer possible she would have had to contact her doctor and wait for
235 referral for a physiotherapy appointment to discuss her situation. The participant's
236 perception was that the programme helped her to be more active than she would
237 otherwise have been and noted that it was the timely remote support through the
238 intervention that had facilitated this.

239

240 Things had got to the point that I wasn't able to take my son to school, a friend
241 was picking him up and another friend bringing him back because I was finding

242 it too difficult to walk... so I was glad to have the exercise programme as well to
243 make up for the lack of exercise that I was getting by not doing the school run,
244 so that was quite good. *Becky (age 54, EDSS 6.5)*

245
246 Only two of the nine participants who perceived that their physical activity levels had
247 improved described this in terms of walking further or more frequently. The majority
248 reported that they had increased physical activity by completing the two web-based
249 exercise sessions in addition to their usual weekly activity.

250

251

252 ***Themes and subthemes.***

253

254 Three key themes were identified from the participant experience data with specific
255 regard to perceived impact on physical activity. They are: (1) “It’s all in one place”, (2)
256 “Keeping an eye” and (3) “Hopes and expectations”. Subthemes were also developed,
257 some of which were linked to more than one of the themes.

258

259 *Theme 1 “It’s all in one place”*

260

261 “It’s all in one place” encompasses the value placed on having an easily accessed,
262 portable and flexible individualised exercise programme. These benefits were reported
263 as important in helping participants use the intervention regularly, which in turn
264 facilitated the increased physical activity they described.

265

266 ***Subtheme: Accessibility***

267

268 Five participants reported that the ease of accessibility provided by having their exercise
269 programme accessed on their electronic device (e.g. computer, tablet, or phone) made it
270 much more convenient. This meant they were more likely to complete their programme,
271 and in turn increase their physical activity that day. One participant [Hannah (age 28,
272 EDSS 5.5)] commented: “the web is part of my life”, reflecting that she used her
273 electronic devices regularly.

274

275 Additional reasons were reported as to why ease of access was a benefit to participants.

276 One participant described previous experience of having written paper exercise
277 programmes, which on occasions she had lost. She noted that having the program in one
278 place (on her computer) not only meant she didn't have to worry about losing it, she had
279 the added benefit of not having to physically struggle around the house to find where
280 she had put it.

281

282 I just find it quite difficult to manage lots of bits of paper which seems silly but I
283 do, so having it online actually I found easier way to keep on track with
284 it...papers do easily get lost, or dog-eared, or thrown away by mistake so it was
285 good to have it all on computer in one place so you always know where your
286 laptop is... Because it's there and easier to find and you're not faffing
287 [colloquialism, struggling to get things together] around because of not being
288 able to move very easily, I don't know, you value it more in a way.

289

Becky (age 54, EDSS 6.5)

290

291

292 In some cases, when using their electronic device as part of their daily life, simply
293 seeing the link website address to web-based physio prompted access to the site and
294 completion of their exercise programme.

295

296 Well, if I'd have had a bit of paper and there wasn't the incentive to look on the
297 website and um you know, I am fairly computer literate and I use the computer a lot
298 and then you know it just becomes second nature to check and um and if I hadn't had
299 that incentive it would have just been a bit of paper exercises I'd have put them or
300 pinned them up on the wall and um then said oh I better do some exercises today as an
301 after-thought. It wouldn't have been at the front of my mind... When I am on the
302 computer, I see that and it incentivises me. *Simon (age 63, EDSS 6.5)*

303

304

305 One person reported that seeing the website link on her iPad motivated her to get out
306 and walk more, so increasing her overall level of physical activity. At no point other
307 than the very start of the study did she choose to access her web-based physio
308 programme on the website. For her, simply the visual prompt to exercise played a
309 significant role.

310

311 I've done a little bit more walking um, perhaps like popped into town on a day
312 when I wouldn't have normally gone into town because I've seen it [the website
313 link] and I've thought "oh, yeah, you know, I'd like to do that today" that's kind
314 of helped me; reminded me to do some exercise... rather than sitting there like
315 perhaps going on Facebook or something, going "well it's actually quite sunny
316 and nice today, go out and take a walk".

317

Hannah (age 28, EDSS 5.5)

318

319 One aspect of the programme that some participants were less positive about was being

320 asked to complete the online exercise diary to show what exercises had been done.

321 Although the purpose was to enable the physiotherapist to remotely monitor and

322 progress the exercise programme this was not always completed, especially as people

323 became more familiar with their exercises and did not rely as much on this aspect of the

324 intervention. Two participants commented that once they had got to a stage where they

325 were confident with their exercise programme, they did not feel the need to access the

326 website and as such it would have been helpful to have been able to go back to the

327 website and add comments retrospectively rather than every time. These views were

328 also reported by some of the participants who took part in exit interviews following the

329 main study as part of the process of exploring the intervention feasibility and

330 acceptability. [26]

331

332 Sometimes I did feel it was a bit annoying having to go back and do the ticking

333 when you'd done your exercises like "oh right! Yes, need to do that part" as well

334 so sometimes it could be a bit of a nuisance to think you had to do the filling in

335 as well.

336

Becky (age 54, EDSS 6.5)

337

338 The vast majority of the participants reported the intervention was easy to access

339 however one noted difficulties setting up a link on her computer and suggested having

340 an app to click on would have been easier.

341

342 When I first started going on it I kept forgetting what the web address was and I
343 kept having to go into the, I think it was in the email to the link to get on it cuz I
344 couldn't remember what it was.

345 Debbie (age 45, EDSS 5.0)

346

347 **Subtheme: Flexibility**

348

349 The opportunity to choose when and where to access the website was also reported as a
350 benefit of this approach to delivering physiotherapy programmes. Some people reported
351 a preference to exercise in the privacy of their own home where they didn't experience
352 embarrassment they had previously felt when exercising in front of others, In addition,
353 flexibility in terms of exercising at a time that fitted with family life or around the
354 presence of symptoms was described.

355

356 If I was doing it in a group session, I would be conscious of being clumsy and
357 messing up and something like that. At least at home, I am more comfortable at
358 doing it at my own pace and my own way and then monitoring it. So I feel better
359 doing it that way. *Simon (age 63, EDSS 6.5)*

360

361 I don't particularly want to be part of a group um, I'm much happier doing at my
362 own level and my own pace really um, and so that was good for me and it was
363 good for me because I'm reasonably computer literate so it was easy, I did it on
364 my phone.... It's difficult for me, not physically, to get to the same place
365 regularly in the course of a week cos I just find work's quite, encroaches on my
366 free time and also the children. *Sarah (age 51, EDSS 4.0)*

367

368

369 Literature suggests that to achieve the potential benefits of exercise, people with MS
370 should be completing exercises at a challenging level [29]. For some people, the web-
371 based programme provided an opportunity to exercise in a safe and familiar
372 environment where they felt able to challenge themselves and perhaps achieve increased
373 benefits.

374

375 I was in familiar surroundings, so I was able to push myself a bit more as well
376 because of the surroundings I felt happy in my home... I knew where things were.
377 You know, I did have wobbles when I was doing them [balance exercises] but it
378 was great because I knew where everything was, so I could stop myself...
379 whereas if I was doing that in a group and especially if I'd been in the middle of a
380 group somewhere or something I'd have been right down on the floor. I didn't
381 have to think, "oh I have to make the effort or I have got to make myself look
382 presentable before I go out the door". I could just you know be in my jimjams
383 [colloquialism pyjamas] if I wanted to do it, which was great, you know, it didn't
384 really matter, you know. If I couldn't do one for any reason, or did it stupidly, or
385 lost my balance or anything, it wasn't a problem because I was at home.

386

Emily (age 48, EDSS 6.0)

387

388 For another participant, the flexibility of being able to exercise at home and with her
389 children, was an important factor that helped her remain motivated to exercise.

390

391 Me and my littlies [colloquialism, children], because they love exercising,
392 they're really sporty and they've done it with me before when I've been upstairs
393 in the bedroom and I've had it on and they've been doing exercises with me so
394 they give me more incentive to do it then because they want to do it, "oh do your
395 exercises mummy!" *Debbie (age 45, EDSS 5.0)*

396

397 In contrast, others reported missing the rapport and social aspect of exercising with
398 others.

399

400 I did miss the action of the [local MS exercise group], I do like the interaction
401 with the group, it's the social side as much as anything isn't it?

402

Mary (age 61, EDSS 6.0)

403

404 There's nothing negative about it apart from the fact that it's just not social is it?

405

Debbie (age 45, EDSS 5.0)

406

407 As such, it is perhaps the flexibility in choice of environment in which to exercise
408 which is important. Facilitating choice of exercise was also reported as a benefit by
409 some participants who liked being able to choose from their individualised programme
410 which exercises to do and when (perhaps encouraging self-management and reflection).

411

412 ***Subtheme: Portability***

413

414 Portability was an issue raised as a benefit by three people. They each described
415 situations where they had been able to continue using their exercise programme when

416 working away from home or travelling on holiday. Each suggested that their programme
417 worked well away from the house and that they would have been much less likely to
418 have chosen to take a paper exercise programme with them.

419

420 You can take it with you because it's on your phone, and the first time I did it I
421 put it on the iPad and we went away for the weekend and I thought it was great
422 because I could do it, take it with me. It's been to Malta.... Tenerife, been to
423 France. *Wendy (age 60, EDSS 4.0)*

424

425 Having the website there, like I said at the beginning, is an incentive, whereas if
426 you see a physio, you see the physio for a period and then you are left to go
427 away and then it is up to you to ring them up again if you want more help and
428 then again it is difficult to get appointments. It is accessible wherever I am. So
429 even if you are travelling you can still access it.

430

Simon (age 63, EDSS 6.5)

431

432 *Theme 2: "Keeping an eye"*

433

434 There were mixed views regarding the type and level of remote support provided by the
435 physiotherapist through the website. Around half of the participants felt it was
436 sufficient, suggesting that the support enabled discussion and progression of their
437 exercise programme and potentially facilitated longer-term engagement with it.

438

439 I liked the fact that someone was keeping an eye so I wasn't doing something
440 stupid [exercise technique] that, you know, I shouldn't have been doing, and
441 also so that I knew that I would carry on doing it.

442 *Mary (age 61, EDSS 6.0)*

443

444 I always knew if I wanted to change something, all I had to do was contact the
445 physio or write something in [the online diary] and they would respond. I'm
446 quite independent in that way [choosing and modifying exercises], maybe that
447 doesn't work for everybody but I think I'm quite, er, self-critical, you know, I
448 can appraise what I'm doing quite well, quite honestly I think.

449 *Sarah (age 51, EDSS 4.0)*

450

451 Others however did not feel that the support was sufficient to keep them engaged and
452 resulted in them only accessing the site for four of the possible six months.

453

454 [I needed someone] saying "Debbie, get on the website, you're doing really
455 well, you need to exercise, don't give up". I'm one of those that needs a push all
456 the time; that's the sort of person I am. It's the contact isn't it, it's the interaction

457 I suppose [that wasn't enough]. *Debbie (age 45, EDSS 5.0)*

458

459 One person discussed the importance of building a relationship with someone who
460 could support and encourage them to continue to be active long-term. Her experience
461 was that this did not happen for her through the website.

462

463 When you're having like regular [face to face] physio more often, I think you're
464 more likely to, or I personally am more likely to engage in your activities
465 because you're, you're being reminded on a weekly basis by a, by a physio.. but
466 when you're not seeing a physio so often, it's hard to self-motivate yourself to
467 do your exercises. *Hannah (age 28, EDSS 5.5)*

468
469 A related issue raised by three participants was that of the website allowing immediate
470 access to a physiotherapist for advice regarding difficulties with an exercise or
471 symptom. Each described previous experience of having to wait a considerable length
472 of time to see a physiotherapist.

473
474 If you see a physio, you see the physio for a period and then you are left to go
475 away and then it is up to you to ring them up again if you want more help and
476 then again it is difficult to get appointments. *Simon (age 53, EDSS 6.5)*

477
478 Yeah some people would prefer that they don't have [only remote support]
479 waiting perhaps several months for an appointment so they can have face to face
480 contact. But for other people who are maybe more disabled and can't get there
481 so easily or are perhaps working and haven't got the time they could just have a
482 quicker contact with the physio. *Claire (age 65, EDSS 6.0)*

483
484 The most frequently reported aspects of the website that participants found helpful were
485 the exercise videos, (in line with the pilot study [23]), and the opportunity to email for
486 advice. This support enabled some participants to continue exercising without the need
487 for face-to-face contact throughout the study.

488

489 I think it's okay with the computer because as I say the videos are there for you
490 to watch. If you didn't have that and you just had it written down as a diagram
491 you might want to see the physio more in order that they could demonstrate to
492 you what you are supposed to be doing. *Claire (age 65, EDSS 6.0)*

493

494 Further thoughts from participants suggested the potential benefit of such a system to
495 the clinician, who could oversee and maintain close contact with many more patients
496 rather than relying on face-to-face assessments.

497

498 It would free up more time for the physio to see other people as well if they
499 weren't constantly needing to have an appointment that lasted half an hour or
500 something. If they could just be in touch with the person that had a problem they
501 might be able to deal with it in five minutes rather than half an hour. They might
502 know straight away what the problem is and say just do it this way instead and
503 then it could be sorted out. I think it would free up their time more.

504

Claire (age 65, EDSS 6.0)

505

506 *Theme 3: Hopes and Expectations*

507

508 This particularly challenging theme highlighted that clinicians and researchers need to
509 openly discuss and better understand people's hopes and expectations of the potential
510 benefits of exercise and physical activity for them. Sarah described the emotional
511 impact that not achieving what she had hoped for during the study.

512

513 If I'm being brutally honest with myself, I think I've gone down even though
514 I've been working quite hard and that has been quite hard [emotionally] I think.
515 I think I'm quite good at burying my head in the sand...I didn't expect to feel
516 the way I felt when I started doing it. I didn't expect that to be the way I would
517 be feeling at say six, seven, eight months...maybe it's because I was coming to
518 the end [of the study] and I haven't achieved what I thought I might.

519 Sarah (age 51, EDSS 4.0)

520

521 One participant in particular clearly explained how disappointed she was in not seeing
522 the improvements she had hoped for and how this had affected her motivation to
523 continue. She challenged clinicians to consider how to manage her expectations more
524 effectively.

525

526 I thought that by doing the exercises I'd build up some stamina and I wouldn't
527 have noticed it [fatigue] quite so much... but it was the fatigue... that was the
528 annoying bit if you like, you know, I had hoped that I'd go through a barrier and
529 come out the other side. I think it's the nature of the beast, perhaps it was my
530 expectations that needed to be managed... because I carried on with it and did
531 everything, but....I always feel that I could be doing more, and then on some
532 days when I try and do more I get disappointed because I haven't actually been
533 able to do it. And I don't know whether that's because I'm judging myself on
534 too high a standard or whether somebody should be behind me going "go on",
535 "keep on".... "Am I giving in to this?" "Should I be going that extra mile?"
536 ...do you know what I mean, how, how far do you push yourself?

537

Mary (age 61, EDSS 6.0)

538

539 In contrast, being motivated to exercise and walk more in one case, and stick to, and
540 progress their web-based programme in another, helped two participants exercise
541 beyond their own hopes and expectations.

542

543 ...it's um the like a rewarding process that when you get home you're like
544 "actually I've done this today, I've walked this far" rather than just, kind of like,
545 staying at home and perhaps watching something on tele so it's, it's been, yeah
546 it, it's been quite nice actually. Hannah (age 28, EDSS 5.5)

547

548 I've got the feeling that I'm actually doing more than I thought I could do.

549

Wendy (age 60, EDSS 4.0)

550

551

552 **Discussion**

553

554 The purpose of this research was to explore the user experience of the web-based physio
555 intervention and further, whether or not participants perceived it had impacted on their
556 ability to increase and sustain engagement in physical activity. The interview data
557 demonstrated that the majority of participants felt that the intervention had helped them
558 achieve increased physical activity levels, typically by the addition of the twice-weekly
559 web-based exercise sessions. This perception of having increased physical activity
560 levels contrasts however with the objective accelerometry data from the main study
561 which demonstrated a decline in steps per day over the nine month study period. [26]
562 Such disparity between self-report and objective measures is well reported [30] and

563 underlines the complexity of this issue, particularly in a progressive condition such as
564 MS where physical activity levels fluctuate and where people's perspectives are
565 constantly recalibrated as they adjust expectations within their changing context.

566

567

568 It is important to consider the role that factors other than the intervention itself may
569 have played when considering perceived increase in activity. Some participants in this
570 sub-study reported that it was their commitment to the study that was the motivator.

571 However, having not interviewed the active comparator group participants it is not
572 possible to know whether committing to the study provided a positive influence on their
573 exercise behaviour. Further research is required to better understand this.

574

575

576 Some strengths of this study are that it sought the experiences of people with all MS
577 disease types and that of those with moderate as well as mild disability. Participants
578 reported a variety of experiences of the intervention that do not appear to be related to
579 disability level or indeed age, as demonstrated by the quotes from participants across
580 the age spectrum (28, 54 and 63 years) regarding the accessibility of this intervention.

581 The different opinions represented in this study highlight the importance of
582 acknowledging that a variety of models of service delivery may be required to meet
583 differing needs. Further, that discussing with people their preferences with respect to

584 intervention and delivery type within the constraints of health service funding

585 challenges is crucial.

586

587 In the first theme “All in one place”, the subthemes of accessibility, flexibility and
588 portability describe some of the benefits that participants in this study felt they gained
589 from this intervention and go some way to address some of the reported barriers to
590 exercise [13, 15, 17]. The qualitative data supports the notion that the intervention made
591 it easier for some people to integrate regular exercise into their daily lives. The accounts
592 of the participants also suggest that this mode of exercise programme delivery may be
593 particularly helpful for people who are technology literate, value flexibility in terms of
594 location, time of day and choice of exercise, and who are confident to exercise at a
595 challenging level independently. It may be that the ability to modify and progress
596 exercise programmes online result in these interventions being better able to deliver the
597 ongoing change and challenge that is required to achieve positive clinical outcomes.
598 This is yet to be determined in a definitive randomised controlled trial.

599
600 “Keeping an eye” was the second theme identified. For an intervention such as this to
601 be effective in supporting people to be more physically active long-term, it is important
602 for people to remain engaged. In this study, some participants reported that having their
603 exercise diary monitored remotely and receiving timely support from the
604 physiotherapist were important in maintaining adherence. Although each participant’s
605 web-based programme was reviewed every two weeks, the amount of support each
606 individual received depended upon the feedback they provided via their online diary,
607 email or telephone. It is likely that this will have influenced their experience of the
608 supervision received. Other studies describing the development of a different web-based
609 intervention have demonstrated an improvement in adherence by the addition of video
610 coaching sessions [24, 31, 32].

611

612 Whilst the views expressed by our participants regarding satisfaction with the level and
613 type of support provided were mixed, with those most satisfied tended to also describe
614 feelings of confidence in self-managing their condition. It appears that this intervention
615 helped some people develop the confidence to exercise at a challenging level. Results
616 from a nominal group study conducted as part of the development of a balance, safe
617 mobility and falls management programme for people with multiple sclerosis [33]
618 identified that people may need significant encouragement and support to develop the
619 confidence to undertake highly challenging balance exercise. For some people, this
620 intervention may have facilitated this.

621
622 The important issues regarding the theme “hopes and expectations” draw focus on how
623 best to support people with MS to be as physically active as possible. For some people
624 this may be to achieve improvements such as getting fitter, walking further or gaining
625 confidence but for others achievement may be in terms of minimising the effects of
626 disease progression on mobility. It is therefore imperative that clinicians and researchers
627 attend to this range of expectations and consider carefully choice of outcomes when
628 establishing programs such as this. In this study, some participants described the
629 disappointment, frustration and distress experienced by not meeting their own, or what
630 they perceived to be the clinician’s expectations. Similar issues were raised in other
631 explorative studies in people with MS. One [34], in relation to a gaming intervention
632 where some participants reflected negatively on their physical abilities and limitations
633 in light of Nintendo Wii Fit feedback, and a second [35] evaluating a physical activity
634 programme, where issues of disappointment and frustration were described concerning
635 the way in which their MS prevented them from being able to engage in pre-morbid
636 activities. It is likely that on some occasions in this study, discussion regarding the

637 expectations of the intervention by both the person with MS and the physiotherapist
638 would have highlighted differences that could have been talked through and may not
639 have led to the individuals becoming disappointed and demotivated by their lack of
640 improvement.

641

642 Effective strategies are required to enable honest and open discussions especially when
643 introducing the idea of exercise and its benefits to people with progressive disease. This
644 is a key clinical area that warrants further exploration.

645

646

647 **Limitations**

648

649 There are a several limitations of this study. Firstly, participants knew the primary
650 researcher (RD) through her role as the Plymouth site WEBPaMS intervention
651 physiotherapist. This potentially may have resulted in participants feeling they needed
652 to share experiences that were more positive. Secondly, all of the researchers are
653 physiotherapists which will have influenced the reading and interpretation of data.
654 Every attempt was made to explore all participant experiences through use of the
655 interview guide and ensure the trustworthiness and credibility of the interpretation of
656 the data by using several strategies to ensure decisions could be evaluated and defended
657 [36]. Thirdly, only intervention group participants at one site were interviewed in this
658 study as it was conducted as part of the doctoral work of the primary researcher. There
659 is no reason to suggest however that there would be notable differences in data from
660 either of the other two sites, and this was confirmed by the results of the process
661 mapping exercise, which was undertaken as part of the feasibility trial. [26] Because the

662 aim of the study was to explore user experience of the web-based physio intervention
663 only intervention group participants were interviewed. Finally, the small numbers of
664 participants in this study has the potential to limit its findings, however, the last two
665 interviews did not add new themes to the data and as such, it is likely that data
666 saturation had been reached.

667

668 **Conclusion**

669

670 The findings of this study demonstrate that most of the participants, perceived that the
671 web-based physio had facilitated an increase in their day-to-day physical activity. Also
672 highlighted is the importance of building in conversations with people with MS about
673 expectations of exercise and its potential benefits, particularly for those whose condition
674 is deteriorating. Finally, it is important to consider who will benefit most from a
675 remotely delivered and monitored exercise programme such as web-based physio. This
676 data suggests that the target population may be those who are technology literate (or
677 have a significant other who are), value the flexibility that such interventions can offer,
678 prefer to exercise independently in an environment of their choice and have confidence
679 and skills to self-manage without face to face contact.

680

681 **Declaration of Interest**

682 The authors report no conflict of interest

683 6614 words

684

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- 782
- 783

784 **Table 1: Interview guide**

785

<p>It has been a little while since you finished using the web based physiotherapy programme... perhaps you can start by telling me what you thought of it?</p>
<p>Have you seen a physiotherapist before?</p> <p>Prompt: One-to-one? Exercise programme? Group? National Health Service?</p> <p>Did web-based physiotherapy differ? How? Why?</p>
<p>As part of the WEBPaMS study you were asked to follow your programme twice a week. Did you find you could stick to that? Prompt: What stopped/ helped you?</p>
<p>Did you manage to do any other physical activity as well as this?</p> <p>Prompt; What do you do? Day to day routine? Around the house/ elsewhere?</p>
<p>Has using the web-based programme made any difference to how active you are now?</p> <p>Prompt: compare with activity prior to starting the programme i.e. what did you do day to day? Exercise/ general activity? At home? Out and about? What do you think may have affected this?</p>
<p>Do you imagine using the website long term?</p> <p>Prompt- key points in condition/ stepping stone/ with/out online support</p>
<p>Is there anything else you like to tell me about your experience of web-based physio?</p>

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790

791 Table 2: Demographic information of interview participants (n=11)

792

Participant pseudonym	Gender	Age	EDSS	Disease course	Employment status
Mary	F	61	6.0	SPMS	Part time employed
Hannah	F	28	5.5	RRMS	Unemployed
Debbie	F	45	5.0	RRMS	Unemployed
Simon	M	63	6.5	SPMS	Retired/ medically retired
Becky	F	54	6.5	SPMS	Retired/ medically retired
Fay	F	68	6.5	SPMS	Retired/ medically retired
Wendy	F	60	4.0	RRMS	Part time employed
Claire	F	65	6.0	SPMS	Retired/ medically retired
Emily	F	48	6.0	RRMS	Retired/ medically retired
Jane	F	59	4.5	SPMS	Retired/ medically retired
Sarah	F	51	4.0	PPMS	Part time employed

793 Legend: EDSS = Expanded Disability Status Scale; F = female; M = male; RRMS =
 794 relapse remitting multiple sclerosis; SPMS = secondary progressive multiple sclerosis;
 795 PPMS = primary progressive multiple sclerosis

796

797