

1 **Title**

2 The online version of an evidence-based hand exercise program for people with rheumatoid  
3 arthritis: A mixed-method, proof-of-concept study.

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33 None.

34

## Main text

### 35 Background

36 Rheumatoid arthritis (RA) is a chronic inflammatory synovial joint disease prevalent in 1% of  
37 the United Kingdom (UK) population [1, 2]. The hand and wrist joints are frequently affected [3]  
38 and common impairments include pain, stiffness, and reduced finger and wrist mobility, and grip  
39 strength. These hand impairments lead to limitations in activities of daily living and restrictions  
40 in work and leisure activities, thereby reducing quality of life [4].

41 When this program of research began, clinical guidelines [5-7] recommended that patients with  
42 RA be provided with exercises aimed at improving joint flexibility and muscle strength and  
43 reducing impairments. However, despite these recommendations, evidence of the clinical and  
44 cost effectiveness of hand exercises was lacking with very few randomized controlled trials  
45 undertaken [8]. Existing studies had small numbers of participants and evaluated a combination  
46 of mobility and strengthening with most demonstrating increases in grip strength but not  
47 necessarily improvements in hand function [9]. There was little guidance as to the specific  
48 exercises that should be provided for patients [8]. This led to the commissioning of a large  
49 randomized controlled trial and development of the SARAH (Strengthening And Stretching  
50 for Rheumatoid Arthritis of the Hand) program [10, 11]. The SARAH program is a 12-week  
51 tailored and progressive hand exercise program. It includes 7 mobility and 4 strength exercises  
52 with behavioral support strategies such as goal setting, action planning, confidence building, and  
53 self-monitoring to encourage long-term exercise adherence [10]. In the SARAH trial [11], 490  
54 adults with RA affecting their hands/wrists and on a stable drug regimen for at least three months  
55 were randomized across 17 National Health Service (NHS) trusts in the UK between 2009 and  
56 2011. The program was delivered via an initial assessment and five supervised exercise training  
57 and review sessions with a hand therapist over 12 weeks. Participants were taught to progress or  
58 regress the exercises in response to symptoms (e.g. a flare-up), set goals, do their exercises daily,  
59 and use an exercise diary between appointments. After 12 weeks, participants continued the  
60 exercises on their own. The trial showed that the SARAH program improved hand function at 4  
61 and 12 months, was safe to deliver and was cost-effective, compared to usual care [11]. These  
62 findings led to an update of the National Institute for Health and Care Excellence (NICE)  
63 guidelines that recommended the integration of the SARAH program into RA care [12].

64 We have been undertaking a program of implementation work to make the SARAH program  
65 available to clinicians and patients. This includes an online training program for clinicians [13]  
66 (<https://isarrah.octru.ox.ac.uk/>) as well as the development of an online self-guided program  
67 (mySARAH) accessed directly by people with RA [14]. mySARAH is user-centered and theory  
68 based, and incorporates simple heuristic principles recommended for self-guided online health  
69 interventions. The program was tested for usability issues in nine people with RA prior to  
70 commencing this study [14]. In this paper, we report the evaluation of mySARAH in a small  
71 sample of people with RA.

72 The objectives were,

- 73 1. To determine if mySARAH was feasible and acceptable to people with RA, including  
74 whether they could replicate the SARAH exercises on their own.
- 75 2. To collect preliminary data on the clinical impact of mySARAH
- 76 3. To understand patients' experience of mySARAH and incorporate any changes to the final  
77 package for implementation.

## 78 **Methods**

### 79 *Design*

80 A mixed-method, proof-of-concept study design was adopted. Proof-of-concept designs aim to  
81 evaluate the feasibility of an idea or concept in a small cohort [15-17]. A mixed-methods  
82 approach was chosen to address feasibility, acceptability, impact on clinical outcomes and the  
83 patient experience by integrating data from observations, interviews, performance-based  
84 measures and pre-post questionnaires.

85

### 86 *Registration and ethics approval*

87 The study was registered with the Global Research Registry [18], reference number XXXX. The  
88 protocol was approved by the XXXX research ethics committee (reference XXXX).

### 89 *Participants*

90 Adults reporting difficulties with hand function due to RA and on stable drug treatment for at  
91 least three months were eligible to participate. Participants also needed an email address, Internet  
92 access and a computer, laptop, tablet or smart phone, to be living within one hour of the study  
93 center, to understand English and be willing to participate in the observation appointments.  
94 Pregnant women, due to the risk of flare-up or increased disease activity and people who had any  
95 upper limb joint surgery or fracture in the previous six months or awaiting upper limb surgery  
96 were not eligible.

### 97 *Intervention*

98 A detailed description of the development, content, and usability testing of mySARAH is  
99 available [14]. mySARAH mirrors the SARAH program tested in the SARAH trial. It has six  
100 online exercise training and review sessions over a 12-week period. Users register with their  
101 email address and create a password protected account. The program covers education about RA  
102 and joint protection, the SARAH exercises, goal setting, exercise planning, how to progress and  
103 regress the exercises (e.g. during increased pain or flare-ups). It features exercise videos,  
104 exercise diary, exercise checklist, hand pain tracker, a section on frequently asked questions and  
105 facility to download a copy of a session's content upon completion.

**106 Recruitment**

107 Participants were recruited through the rheumatology outpatient clinics at the XXXX. Clinicians  
108 identified eligible patients and provided them with the study information sheet. If patients were  
109 interested in taking part, then, they were phoned by one of the authors (CS or JT) for eligibility  
110 screening. Patients who were eligible and willing to participate were enrolled. Written informed  
111 consent was obtained by CS or JT, from all participants.

**112 Procedure**

113 CS or JT conducted four observation appointments with participants at the study centre or  
114 participant's home. Participants were observed as they worked through four mySARAH sessions  
115 (Sessions 1, 2, 3, & 6). The first three observation appointments were to understand how well  
116 participants navigated the program and completed each session. Any observation appointment  
117 that was missed was rescheduled as soon as was possible. Participants were asked to complete  
118 mySARAH sessions 4 & 5 on their own from home. The fourth observation appointment was  
119 conducted approximately at 12<sup>th</sup> week (Discharge).

120 An observation booklet with a checklist of tasks (navigate home page, complete pain scale, fill  
121 exercise plan form) and to write notes of any difficulties experienced by the participants was  
122 used. Participants were not interrupted or assisted during the observations. However, if they had  
123 significant technical problems, CS or JT assisted them and ensured it was documented.

124 After discharge, participants were asked to do the SARAH exercises at home and record in the  
125 mySARAH exercise diary. They were also asked to report any adverse events due to exercise,  
126 general RA flare-ups, and technical issues encountered with the website.

127 Approximately one month after the 12-week program (4 months), a 30-minute follow-up and an  
128 interview using a semi-structured topic guide (Appendix 1) via the telephone was conducted by  
129 CS. The interviews were recorded using a digital recorder and were transcribed verbatim.

**130 Outcome measures and data collection****131 Feasibility**

132 During the observation appointments, participants were asked to demonstrate each SARAH  
133 exercise (7 mobility exercises in the first appointment and all 11 exercises during the second,  
134 third and fourth observation appointments). During the third and fourth observation  
135 appointments, participants also demonstrated how they would adjust the load using putty or  
136 resistance bands for the strengthening exercises. We used a video recorder to film  
137 demonstrations. The filming was limited to the hands/wrists and upper limb. We took notes and  
138 did not provide any prompts while filming. Incorrect execution of any exercise was corrected  
139 after the filming. A simple 3-point descriptor scale (1- Correctly demonstrated; 2- Incorrectly  
140 demonstrated and assistance required from evaluator or by replaying the video; and 3-Difficulty

141 demonstrating the exercise correctly after being assisted) was used for evaluation [9]. The  
142 demonstrations were evaluated by CS and JT after completing the appointment with the  
143 participant. The ratings and any handwritten notes were documented in the observation booklet.

#### 144 **Acceptability**

145 At the end of sixth online mySARAH session, participants completed the following evaluation  
146 scales. Satisfaction with mySARAH (5-point scale ranging from Very dissatisfied to Very  
147 satisfied); Ease of use (5-point scale ranging from Very difficult to Very easy); Usefulness (5-  
148 point scale ranging from Not at all useful to Extremely useful); and Intention to use mySARAH  
149 in the long-term (3-point scale, Definitely, no, Maybe, Definitely, yes).

#### 150 **Clinical outcomes**

##### 151 a. Hand pain

152 Within each mySARAH session, participants recorded their average pain in hands and wrists on  
153 an 11-point numerical scale (0-No pain; 5-Moderate pain; 10-Worst possible pain) [19]. At 16-  
154 week follow-up, participants completed the same scale over the telephone.

##### 155 b. Hand function

156 Within mySARAH sessions 1 and 6, participants completed the hand function subscale of the  
157 Michigan hand outcomes questionnaire at the start of the session [20]. This scale has 10  
158 questions with scores ranging from 0 to 100 (higher scores indicate better hand function). At 16-  
159 week follow-up, participants completed the scale over the telephone.

##### 160 c. Grip strength

161 At the first and final observation appointment, maximal isometric grip strength was measured  
162 using Jamar hand dynamometer (Jamar Plus +) following the recommendations of the American  
163 Society of Hand Therapists for grip testing [21]. The test was performed 3 times on each hand  
164 and the average grip strength was calculated in kilograms.

##### 165 d. Self-rated improvement

166 Within online mySARAH session 6, participants rated the change in their hand, and wrist  
167 arthritis symptoms using a 7-point scale, ranging from completely recovered to vastly worsened  
168 [22]. At follow-up, participants completed the scale over the telephone.

#### 169 ***Sample size***

170 Proof-of-concept studies enrol as few as three participants [15-17]. We proposed to recruit up to  
171 12 participants considering the study objectives and time constraints.

#### 172 ***Data analysis and reporting***

173 The quantitative and qualitative data were analyzed separately and reported sequentially. In  
174 addition, we compared the changes in clinical outcomes with the SARAH trial findings [11].

175 The quantitative data were analysed by CS using the IBM SPSS statistical software for  
176 Windows, Version 25.0 [23]. The demographic characteristics and clinical outcomes of each  
177 participant are presented. The pre-post median and inter-quartile range (IQR) of pain, hand  
178 function and grip strength are summarized for participants who completed the program. The  
179 individual responses of categorical data are counted. A statistical comparison of outcomes was  
180 not undertaken due to small sample size.

181 The interview transcripts were organized and analyzed using NVivo qualitative analysis  
182 software, Version 11 [24]. A thematic analysis was undertaken [25]. CS coded the transcripts  
183 and identified key themes. The themes were reviewed by another author (EW). Both authors are  
184 physiotherapists trained in qualitative research methods.

## 185 **Results**

### 186 **Feasibility**

187 Figure 1 shows the flow chart of the study. Most of the participants (8/11, 73%) were British,  
188 female (Table 1) and well-educated. The median age of the participants was 63 (IQR, 49 to 66)  
189 years; duration of RA symptoms was 2 (IQR, 1 to 12) years, and time spent on the Internet each  
190 day was 60 (IQR, 60 to 94) minutes.

191 We conducted 40 out of the 44 (91%) planned observation appointments (Table 1). Twenty-  
192 seven appointments were conducted at the study center and 13 at participants' homes. Apart  
193 from occasional issues such as the mySARAH account confirmation notifications going into  
194 their email spam folder during registration or forgetting their password, participants had no  
195 difficulty accessing mySARAH. There were no difficulties completing specific tasks within each  
196 mySARAH session.

197 Eleven (100%) participants provided baseline data, nine provided data at the discharge  
198 appointment (82%) and eight participants provided data at 4-month follow-up (73%).

199 Six participants (55%) were classed as 'completers' as they completed all six mySARAH  
200 sessions. Three participants were 'partial completers' (Participants 06, 07, 08) who had good  
201 attendance at the observation appointments but did not complete the two online mySARAH  
202 sessions on their own from home (Table 1). Two participants (18%) discontinued the program.  
203 One participant (Participant 09) reported wrist pain during exercise as the main reason for  
204 stopping the program as well as lack of time and motivation. Another (Participant 10) reported  
205 difficulty completing the program during the Christmas season.

206 We observed 512 exercise and load-setting demonstrations in total and 491 (96%)  
207 demonstrations were performed correctly. Six participants (55%) correctly demonstrated all

208 mobility exercises during all four observation appointments. Of those who had difficulty  
209 performing the exercises, two needed to replay the ‘wrist circles’ exercise video during their first  
210 appointment. Another participant (Participant 06) needed to replay the videos for 6/7 mobility  
211 exercises during the second appointment.

212 Six participants (55%) correctly demonstrated all strengthening exercises and load setting during  
213 the observation appointments. Of those who had difficulty with the exercises, the main exercise  
214 which participants found challenging was the ‘wrist backward bend’ exercise. Three had to  
215 replay the video on the first appointment, two during the second appointment and three during  
216 the final appointment. One of those participants (Participant 06) also had to replay the other  
217 strengthening exercises during the second appointment.

218 In general, participants demonstrated a good understanding of how to adjust the load for  
219 strengthening exercises. Four participants (Participants 03, 06, 07, 08) needed to replay the load  
220 setting videos of wrist backward bending exercise during two observation appointments. One of  
221 those (Participant 08) also needed to replay the videos of setting the load of the other  
222 strengthening exercises during the second appointment.

223 After the video was replayed, the team members ensured that the participants were then able to  
224 do the exercises correctly. Most of the participants who performed the exercises and load-setting  
225 incorrectly were partial completers who had difficulty remembering the exercises.

226 mySARAH completers used the online exercise diary for a median of 55 days (IQR 39 to 84).  
227 They were more likely to report that they completed the mobility exercises (recorded in 99% of  
228 entries) compared to the strengthening exercises (recorded 80% of the time).

229 Partial completers reported low usage of the exercise diary with one participant not using it at all.  
230 Other two participants used the diary for a median of 8 days and more commonly reported doing  
231 the mobility exercises compared to strengthening exercises.

232 Of those two participants who discontinued the program, one participant used the exercise diary  
233 on 23 out of 35 days of participation (64%). The other participant used the diary for five days out  
234 of seven days of their participation. They both recorded performing mobility exercises more  
235 often than the strengthening exercises.

### 236 **Acceptability**

237 Most of the participants found mySARAH easy to use (7/9, 78%), were satisfied with the  
238 program (7/9, 78%) and intended to use it in the future (8/9, 89%). All participants perceived  
239 mySARAH as useful.

### 240 **Clinical outcomes**

241 Hand pain

242 Most participants had mild pain (scores  $\leq 4$ ) that fluctuated ( $\pm 1$  point) across the six sessions  
 243 (Individual pain scores in Appendix 2). Overall, there was very little change between baseline  
 244 and discharge and follow-up (Table 2). Compared to baseline, one participant reported an  
 245 increase in pain of 3 points at discharge (Participant 3) and another (Participant 1) at follow-up.

246 Hand function

247 Improvements in hand function were reported at discharge and follow-up (Table 2).

248 Grip strength

249 Improvements in grip strength were reported at discharge with greater gains observed in the right  
 250 hand (Table 2).

251 Self-rated improvement

252 Most participants perceived improvements in arthritis symptoms of their hands and wrists (6/9,  
 253 67%) at discharge and (6/8, 62.5%) at follow-up. Two participants did not feel any change at  
 254 discharge (2/9, 22%) and follow-up (2/8, 25%). Two participants who reported an increase in  
 255 pain of 3 points perceived slight worsening of symptoms at discharge (1/9, 11%) and follow-up  
 256 (1/8, 12.5%), respectively.

257

258 Table 3 compares the clinical outcomes of the SARA trial and this study.

259

## 260 **Interviews**

261 Eight participants were interviewed which included six who completed the program and two who  
 262 were partial completers. Five themes emerged from our telephone interviews.

### 263 *a. Overall experience*

264 Participants were satisfied with mySARAH and would recommend it to others. They described  
 265 that the content was easy to follow. The exercise videos were perceived as a useful resource to  
 266 refer to the exercises whenever needed.

267 07\_Part-time employed female, 34 years: *“The content actually was very simple to follow, the*  
 268 *way the person showed the exercises and it was very straightforward. It’s not like rocket*  
 269 *science, you could do it, yes, I think everyone who has this rheumatoid arthritis should try the*  
 270 *exercise, I think it would really help”.*

271 04\_Retired female, 66 years: *“I just think it’s a brilliant program and more people should be doing it.”*

272 Overall, there was little the participants disliked about the program. However, one participant felt  
 273 that the sessions’ content was repetitive in the videos. He also mentioned the inconvenience of



274 logging in every time to refresh the mySARAH diary to fill out the exercise days that were  
275 missed earlier.

276 05\_ Retired male, 63 years: *“A couple of things that I found a little bit frustrating was if I didn’t*  
277 *keep the records up to date for a couple of days, and I went back on, I’d have to log out and log*  
278 *back in again to get it to refresh. So, it wasn’t refreshing by me leaving it on because I saved it*  
279 *as a favorite on my screen. So that was just a small irritant, but it was just there....”*

280 Participants made some recommendations to improve mySARAH. The main suggestion was to  
281 record and track exercise progression (loads and number of repetitions), for example, using an  
282 interactive spreadsheet.

283 03\_ Part-time employed female, 59 years: *“...maybe somewhere to write notes, you know when*  
284 *you change strengths of putty or wristbands; maybe somewhere where you can actually make a*  
285 *comment or... and when you’ve fluctuated from one strength to another for whatever reason...*  
286 *You know, like a diary maybe where you could put in there when you’ve changed your color, or*  
287 *you’ve had a flare-up, so you’ve had to go back to a different color or something like that”*

288 Other suggestions were to allow note-taking of any concerns experienced during a session and to  
289 emphasize clearly that all SARAH exercises do not need to be done in one go.

290 08\_ Part-time employed female, 49 years: *“I would say it’s important to give the message, “If*  
291 *you can’t do all of this, that’s fine, do some, rather than nothing.” Which is not what I did but I*  
292 *think that’s probably quite a good message to get out there.”*

### 293 ***b. Intervention components***

294 Participants found the putty exercises difficult compared to the mobility exercises.

295 01\_ Retired female, 73 years: *“Most of them [Exercises] are fine. In fact, you can get lazy and*  
296 *you can... I can still... The one where you put a squeeze tube between, I can’t do it... That one is*  
297 *incredibly difficult. I don’t know if there are people who can do it but it’s very difficult”.*

298 They considered the exercise diary as a good way of reminding them to do their daily exercises.  
299 However, some mentioned that as they became familiar with the exercises and developed an  
300 exercise routine, they did not feel that they needed to watch the exercise videos or log in and  
301 record them in the exercise diary accounting for the low use of the exercise diary by some  
302 participants.

303 011\_ Retired female, 66 years: *“I like the exercise calendar. It’s like a little pricking your*  
304 *conscious if you haven’t done it for the day, the knowledge that you haven’t actually been online*  
305 *and ticked it off, for me is a very good reminder that I need to get on and do it each day.”*

306 07\_ Part-time employed female, 34 years: *“Yes, yes, yes, I don’t feel like going and ticking*  
307 *because I know all the exercises, I don’t have to watch the videos at the moment, so maybe that’s*

308 *why I didn't want to go and tick them off, but I had them in my mind and I do it and I do it for*  
 309 *myself so, you know, I did not feel like going back and ticking it, but yes, I try my best to do all*  
 310 *the exercise every day”.*

311 Most participants liked setting goals though a few mentioned that they did not achieve their goals  
 312 during the study period.

### 313 ***c. Perceived benefits***

314 Majority of the participants described that they progressed with the exercises. They also felt  
 315 improvements in their hand function and strength. One participant described that she noted  
 316 improvements in forearm pain improved her sleep. Two participants felt no difference in their  
 317 hand function although one of these participants felt improvements in her wrist strength.  
 318 Participants were confident in doing the SARAH exercises correctly and progress or regress the  
 319 exercises on their own.

320 05\_Retired male, 63 years: *“Yes absolutely. I found them very good and I found the strength*  
 321 *exercises very useful because some of the things I wasn't able to do in terms of the grip and*  
 322 *things like that, the strength exercises definitely, definitely helped me”.*

### 323 ***d. Exercise adherence***

324 Most participants described that they were self-motivated and developed an exercise routine.

325 02\_Retired female, 82 years: *“Yes definitely, first thing in the morning after breakfast and then I*  
 326 *got mine into a routine and then in the evening when I'm watching the Telly, I do the*  
 327 *strengthening. I think it's important. I think that is important. It's no good thinking you'll do it*  
 328 *if you've got to do it at a certain time and it becomes like brushing your teeth then”.*

329 Some described they were keen to exercise regularly even during holidays. Two participants who  
 330 had flare-ups during the study period described they continued to exercise by adjusting to do the  
 331 exercises as much as tolerated. Participants also strongly indicated they would continue to do  
 332 SARAH exercises in the long-term.

333 03\_ Part-time employed female, 59 years: *“I did, yeah, I had a couple of flare-ups. I was away*  
 334 *on holiday and my husband was admitted to hospital so that was quite stressful, and I have*  
 335 *discovered my rheumatoid does flare up when I'm stressed. So had a flare-up then. Only in my*  
 336 *left hand and my left hand is still very painful now but I am left-handed, so that's my dominant*  
 337 *hand...I still did them, to be perfectly honest. Well I'm still doing them, yeah... And even if*  
 338 *you're having a flare, to try and do whatever you can do, not to think, “Oh I'm not doing it today*  
 339 *because I'm in pain.”*

340 Of the two participants who did not complete the home-based mySARAH sessions, one  
 341 participant (Participant 07) mentioned she struggled to allocate a regular time but managed to do

342 them whenever she found time in her busy schedule. However, she did not want to do the  
343 exercise diary or watch exercise videos as she knew the exercises very well.

344 07\_ Part-time employed female, 34 years: *“Yes, it’s always the time, you know, I think it’s just  
345 me because I’m a full time mum and I have to juggle and when sometimes in the night when I do  
346 the actual exercises after dinner, maybe I feel a bit too lazy (laughter). Yes, but you know, I was  
347 just doing it for myself and it’s all about me and I just wanted to do it for myself. I think maybe  
348 because of that, I didn’t tick mark, or you know, finish the program”.*

349 Another participant (Participant 08) felt the SARAH exercises were time-consuming and said she  
350 could not fit them in her daily routine. She suggested that mySARAH users should be clearly  
351 informed that the SARAH exercises need not be done all at once in a day.

352 08\_ Part-time employed female, 49 years: *“I haven’t really done the exercises at all, apart from  
353 on the assessment because I found them too time consuming, I just could not fit them in and so I  
354 didn’t even attempt ... rather than kind of do them in a half fashion I just didn’t do them at all.  
355 So, I haven’t done the program...I like to think that when I have more time available to me, I will  
356 do them, but I won’t be doing them daily, I’ll never have enough time to do them every day”*

#### 357 ***e. Support needed for target users***

358 Participants perceived the observation appointments as supervised and supported exercise  
359 sessions though they were not meant to be.

360 01\_ Retired female, 73 years: *“I had a very good teacher.....I think your enthusiasm and your  
361 colleague, you know, the fact that they're trying to help and so you feel as though, well I said I'd  
362 do it, so I think I ought to keep going.”*

363 Participants suggested that some form of support or feedback from a health professional was  
364 desirable. This could be provided face-to-face or remotely.

365 011\_ Retired female, 66 years: *“I think once you have been into the (Study center) and gone  
366 through the program a couple of times, that’s a bonus. If somebody had said, “Okay this is the  
367 program, you’ve just got to get on and do it on your own,” then that probably would have been  
368 okay but I guess, you might have run a risk of getting into the habit of doing a certain exercise in  
369 the wrong way, whereas by always coming in to see you in the early days, you could point out, if  
370 you were doing it wrong.”*

371 They recommended face-to-face or group therapy sessions and phone calls or Skype meetings  
372 alongside online mySARAH sessions to support the individual needs of people of different age  
373 groups, digital literacy, and confidence levels.

374 05\_ Retired male, 63 years: *“I think having a point of contact that they can actually ask questions  
375 would be quite important because I think again, you've got to allow for people who are maybe*

376 *not savvy technology where the software, they're not comfortable with and not sure of their way*  
377 *around. So, having someone making just a call or email or something just to give them that*  
378 *confidence or reassurance or that direction will be quite useful”.*

379

## 380 **Discussion**

381 This study explored the feasibility, acceptability and the clinical impact of the online SARAH  
382 program for people with RA. Our findings indicate that the program was feasible and acceptable  
383 to people with RA. They reported mySARAH to be a useful and easy resource to use.

384 Participants did most of the exercises correctly. On the occasion that a participant had difficulty  
385 with an exercise, after watching the video, they were then able to do the exercises correctly.  
386 Difficulties were mainly related to the backward bend wrist exercise, which is a challenging  
387 exercise for people with RA but an important impairment to address through exercise.

388 More than 50% of the study participants completed the program. Participants’ perceived  
389 treatment benefits and actual improvements indicate that mySARAH is safe and beneficial. The  
390 impact of mySARAH on clinical outcomes showed a trend toward improvements in hand  
391 strength and function with no detrimental effect on pain levels as in the SARAH trial (Table 3).

392 Poor adherence is a common problem in online health interventions [26]. Fifty-five percent of  
393 our participants completed all mySARAH sessions. This completion rate is better than other  
394 examples of online exercise interventions. For example, a self-directed, online 9-week physical  
395 activity intervention for people with knee or hip osteoarthritis [27] had nine modules.  
396 Approximately 20% (19/100) of participants completed all modules and 46% completed a  
397 minimum of 6 modules [27].

398 In our study, participants considered the observation appointments to be supervised exercise  
399 sessions, even though this was not the intention. This may be one reason we had higher  
400 completion rates. There were 3 participants who participated in the observation appointments but  
401 did not engage with their online sessions independently. We were able to interview 2 of these  
402 participants. Their behavior suggested that they preferred a more traditional delivery of the  
403 SARAH program although their feedback was positive about mySARAH. Our interviews also  
404 indicated that participants preferred some form of support from health professionals to complete  
405 mySARAH sessions and to adhere to the exercises. These findings are similar to another  
406 qualitative study with older people using digital health interventions [28] that showed that  
407 support from therapists is critical to initial engagement and ongoing use of digital health  
408 interventions. Completion rates were higher in the SARAH main trial which used a traditional  
409 model of face-to-face visits to deliver the program.

410 Finding ways to engage people with completing an online intervention and doing the exercises is  
 411 an ongoing challenge [29]. The exercise diary was intended as a tool to motivate people to do  
 412 their exercises, but its use varied amongst participants. Suggestions were made to improve this  
 413 feature and to reduce repetition and streamline login procedures to encourage uptake and  
 414 completion of the program. This feedback will inform our next iteration. Time and difficulty  
 415 fitting exercises into the routine were the commonly reported barriers similar to the qualitative  
 416 study results of the SARAH trial [30].

417 This is the first mixed-method study to evaluate the online version of an evidence-based hand  
 418 exercise program in people with RA. Our qualitative findings provided rich details that  
 419 elaborated and confirmed our quantitative findings, e.g. exercise adherence and clinical  
 420 outcomes. Our study has some limitations. The study participants were predominantly British  
 421 females, educated and daily Internet users and hence do not represent the general UK population  
 422 with RA. Less educated people or those who use the Internet less may have had different  
 423 experiences. The patient-reported hand function, pain and home exercise adherence are prone to  
 424 subjective bias. Interviews were conducted with volunteers who had positive experiences with  
 425 mySARAH. The experience of participants who discontinued the program would have been  
 426 valuable to understand why they chose to drop-out. But, we were unable to interview them. The  
 427 small sample size means that the clinical outcomes must be interpreted with caution.

## 428 **Conclusions**

429 Our study demonstrated that the online mySARAH was feasible, acceptable and showed positive  
 430 trends in improving clinical outcomes like the SARAH trial. Findings suggest that a blended  
 431 delivery model with support from health professionals would be the best way to facilitate uptake  
 432 of mySARAH by people with RA. This model requires further development and evaluation.

## 433 **References**

434

- 435 1) Wasserman AM. Diagnosis and management of rheumatoid arthritis. *Am Fam Physician*.  
 436 2011; 84(11):1245-52.
- 437 2) Symmons D, Turner G, Webb R, Asten P, Barrett E, Lunt M, et al. The prevalence of  
 438 rheumatoid arthritis in the United Kingdom: new estimates for a new century. *Rheumatology*  
 439 (Oxford). 2002; 41(7):793-800.
- 440 3) Horsten NC, Ursum J, Roorda LD, van Schaardenburg D, Dekker J, Hoeksma AF.  
 441 Prevalence of hand symptoms, impairments and activity limitations in rheumatoid arthritis in  
 442 relation to disease duration. *J Rehabil Med*. 2010; 42(10):916-21.
- 443 4) Rydholm M, Book C, Wikström I, Jacobsson L, Turesson C. Course of grip force impairment  
 444 in patients with early rheumatoid arthritis over the first five years after diagnosis. *Arthritis*  
 445 *Care Res*. 2018; 70(4):491-8.

- 446 5) Kennedy T, McCabe C, Struthers G, Sinclair H, Chakravaty K, Bax D, et al. BSR  
447 guidelines on standards of care for persons with rheumatoid arthritis. *Rheumatology* 2005;  
448 44:553–6. <http://dx.doi.org/10.1093/rheumatology/keh554>
- 449 6) Scottish Intercollegiate Guidelines Network (SIGN). Management of Early Rheumatoid  
450 Arthritis. A National Clinical Guideline. SIGN publication number 48. 2000. URL:  
451 [www.sign.ac.uk/guidelines/fulltext/48/index.html](http://www.sign.ac.uk/guidelines/fulltext/48/index.html) (accessed 31 March 2009).
- 452 7) National Institute for Health and Clinical Excellence (NICE). Rheumatoid Arthritis: The  
453 Management of Rheumatoid Arthritis in Adults. London; NICE: 2009.
- 454 8) Wessel J. The effectiveness of hand exercises for persons with rheumatoid arthritis: a  
455 systematic review. *Journal of Hand Therapy*. 2004 Apr 1; 17(2):174-80.
- 456 9) Williams MA, Williamson EM, Heine PJ, Nichols V, Glover MJ, Dritsaki M, Adams J,  
457 Dosanjh S, Underwood M, Rahman A, McConkey C. Strengthening And stretching for  
458 Rheumatoid Arthritis of the Hand (SARAH). A randomised controlled trial and economic  
459 evaluation.
- 460 10) Heine PJ, Williams MA, Williamson E, Bridle C, Adams J, O'Brien A, et al. Development  
461 and delivery of an exercise intervention for rheumatoid arthritis: strengthening and stretching  
462 for rheumatoid arthritis of the hand (SARAH) trial. *Physiotherapy*. 2012; 98(2):121-30.
- 463 11) Lamb SE, Williamson EM, Heine PJ, Adams J, Dosanjh S, Dritsaki M, et al. Exercises to  
464 improve function of the rheumatoid hand (SARAH): a randomised controlled trial. *Lancet*.  
465 2015; 385(9966):421-9.
- 466 12) Rheumatoid arthritis in adults: management NICE guideline [NG100] 2018 [Available from:  
467 <https://www.nice.org.uk/guidance/ng100>].
- 468 13) Srikesavan CS, Williamson E, Eldridge L, Heine P, Adams J, Cranston T, Lamb SE. A web-  
469 based training resource for therapists to deliver an evidence-based exercise program for  
470 rheumatoid arthritis of the hand (iSARAH): design, development, and usability testing.  
471 *Journal of medical Internet research*. 2017; 19(12):e411.
- 472 14) Srikesavan C, Williamson E, Cranston T, Hunter J, Adams J, Lamb SE. An Online Hand  
473 Exercise Intervention for Adults With Rheumatoid Arthritis (mySARAH): Design,  
474 Development, and Usability Testing. *J Med Internet Res*. 2018; 20(6): e10457.
- 475 15) O'Connor RJ, Jackson A, Makower SG, Cozens A, Levesley M. A proof of concept study  
476 investigating the Stoller, O., Schindelholz, M., Bichsel, L., Schuster, C., de Bie, R. A., de  
477 Bruin, E. D., & Hunt, K. J. (2014). Feedback-controlled robotics-assisted treadmill exercise  
478 to assess and influence aerobic capacity early after stroke: a proof-of-concept  
479 study. *Disability and Rehabilitation: Assistive Technology*, 9(4), 271-278.
- 480 16) Stoller, O., de Bruin, E. D., Schindelholz, M., Schuster, C., de Bie, R. A., & Hunt, K. J.  
481 (2013). Evaluation of exercise capacity after severe stroke using robotics-assisted treadmill  
482 exercise: a proof-of-concept study. *Technology and Health Care*, 21(2), 157-166.
- 483 17) Kemper, K. J., & Yun, J. (2015). Group online mindfulness training: proof of  
484 concept. *Journal of evidence-based complementary & alternative medicine*, 20(1), 73-75.
- 485 18) Research Registry UIN:XXXX [Available from: <https://www.researchregistry.com/>]

- 486 19) Haefeli M, Elfering A. Pain assessment. *European Spine Journal*. 2006 Jan 1; 15(1): S17-24.
- 487 20) Durmus D, Uzuner B, Durmaz Y, Bilgici A, Kuru O. Michigan Hand Outcomes  
488 Questionnaire in rheumatoid arthritis patients: relationship with disease activity, quality of  
489 life, and handgrip strength. *J Back Musculoskelet Rehabil*. 2013; 26(4):467-73.
- 490 21) Roberts HC, Denison HJ, Martin HJ, Patel HP, Syddall H, Cooper C, et al. A review of the  
491 measurement of grip strength in clinical and epidemiological studies: towards a standardised  
492 approach. *Age Ageing*. 2011; 40(4):423-9.
- 493 22) Kamper SJ, Maher CG, Mackay G. Global rating of change scales: a review of strengths and  
494 weaknesses and considerations for design. *Journal of Manual & Manipulative Therapy*. 2009  
495 Jul 1; 17(3):163-70.
- 496 23) IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp 2013. [Available  
497 from: <https://www.ibm.com/analytics/spss-statistics-software>].
- 498 24) NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018.  
499 [Available from: <https://www.qsrinternational.com/nvivo/home>].
- 500 25) Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res in Psychology*. 2006;  
501 3(2):77-101.
- 502 26) Wangberg SC, Bergmo TS, Johnsen JA. Adherence in Internet-based interventions. *Patient*  
503 *preference and adherence*. 2008; 2:57.
- 504 27) Bossen D, Buskermolen M, Veenhof C, de Bakker D, Dekker J. Adherence to a web-based  
505 physical activity intervention for patients with knee and/or hip osteoarthritis: a mixed method  
506 study. *Journal of Medical Internet research*. 2013; 15(10): e223.
- 507 28) van Middelaar T, Beishuizen CRL, Guillemont J, et al. Engaging older people in an internet  
508 platform for cardiovascular risk self-management: a qualitative study among Dutch HATICE  
509 participants. *BMJ Open* 2018; 8(1): e019683. doi: 10.1136/bmjopen-2017-019683 [published  
510 Online First: 2018/01/24].
- 511 29) Schubart JR, Stuckey HL, Ganeshamoorthy MA, Sciamanna CN. Chronic health conditions  
512 and internet behavioral interventions: a review of factors to enhance user engagement.  
513 *Computers, informatics, nursing: CIN*. 2011 Feb; 29(2):81.
- 514 30) Nichols VP, Williamson E, Toye F, Lamb SE. A longitudinal, qualitative study exploring  
515 sustained adherence to a hand exercise programme for rheumatoid arthritis evaluated in the  
516 SARAH trial. *Disability and rehabilitation*. 2017 Aug 28; 39(18):1856-63.
- 517

Figure 1: Study flow diagram

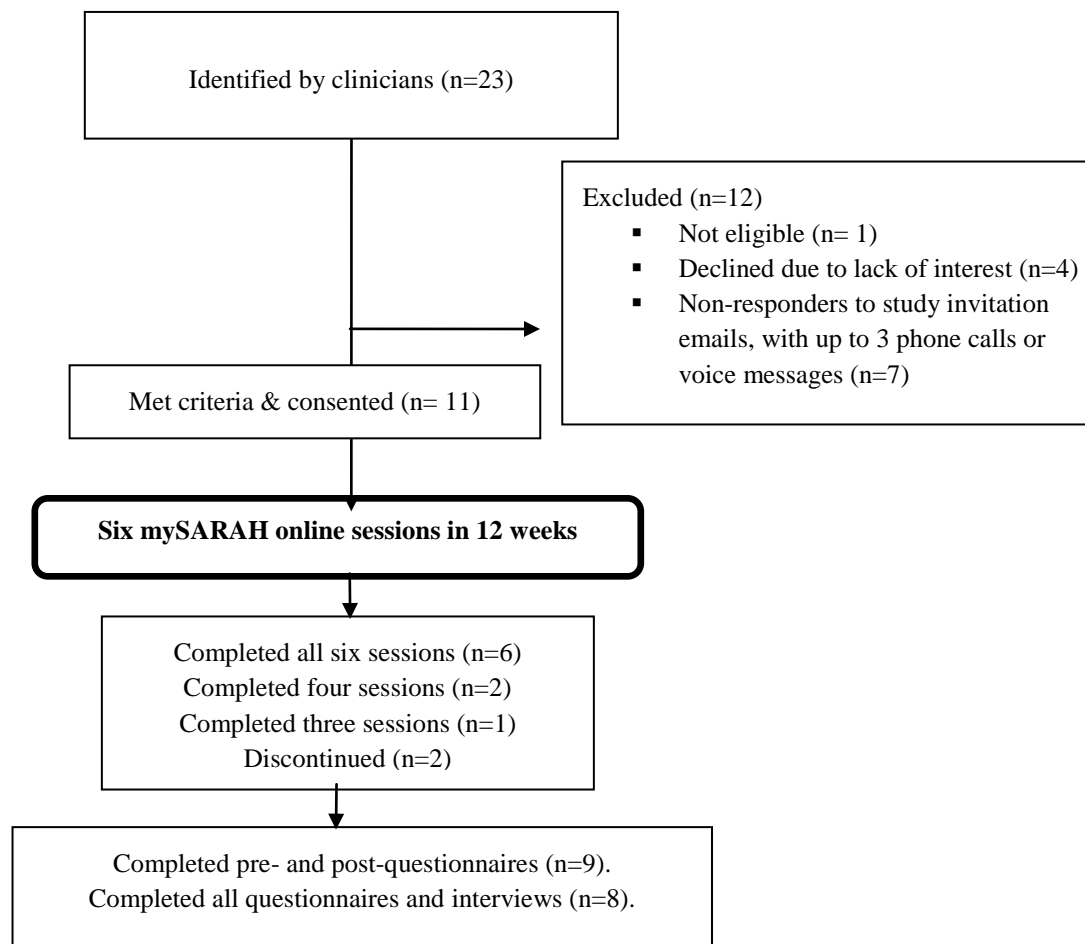




Table 1: Characteristics of study participants and number of mySARAH sessions completed

Participants	Gender	Age (Years)	Ethnicity	Disease duration (Years)	Education	Daily internet use (Minutes)	Session 1	Session 2	Session 3	Session 4 (Home)	Session 5 (Home)	Session 6	Telephone Follow-up
01	Female	73	White	19	Graduate	94	✓	✓	✓	✓	✓	✓	✓
02	Female	82	White	20	Diploma	60	✓	✓	✓	✓	✓	✓	✓
03	Female	59	White	12	≤ High school	60	✓	✓	✓	✓	✓	✓	✓
04	Female	66	White	0.75	≤ High school	45	✓	✓	✓	✓	✓	✓	✓
05	Male	63	White	2	Post-graduate	60	✓	✓	✓	✓	✓	✓	✓
11	Female	66	White	10	Graduate	60	✓	✓	✓	✓	✓	✓	✓
06	Male	41	Pakistani	1	Post-graduate	60	✓	✓	✗	✗	✗	✓	✗
07	Female	34	Indian	1	Post-graduate	60	✓	✓	✓	✗	✗	✓	✓
08	Female	49	White	1	Diploma	300	✓	✓	✓	✗	✗	✓	✓
09	Male	53	White	1	≤ High school	60	✓	✓	✓	✓	Discontinued		
10	Female	64	White	12	Diploma	360	✓	✓	Discontinued				

Online mySARAH sessions 1, 2, 3 and 6 were completed during observation appointments with the researcher; Online mySARAH sessions 4 and 5 were completed by participants on their own from home; ✓ Online sessions completed; ✗ Online sessions not completed.

Table 2: Pre-Post scores and changes in grip strength, hand pain, and hand function.

<b>Participants</b>	<b>Time points</b>	<b>Grip strength (R) Kgs</b>	<b>Grip strength (L) Kgs</b>	<b>Hand pain (0-10)</b>	<b>Hand function (0-100)</b>
Participants who provided discharge data (n=9)	Median (IQR) at Baseline	12.9 (10.8 to 17.4)	14.4 (10.3 to 20.5)	3 (1.5 to 3.5)	60 (50 to 62.5)
	Median (IQR) at Discharge	20.4 (10.2 to 27)	21.1 (9.4 to 27.5)	3 (1 to 4)	67.5 (61.3 to 77.5)
	Median difference (95% CI)	5.8 (-2.4 to 9.9)	1.1 (-2.7 to 11)	0 (0 to 2)	15 (0 to 25)
Participants who also provided follow-up data (n=8)	Median (IQR) at Follow-up			3 (2 to 4.8)	68.8 (61.3 to 78.1)
	Median difference (95% CI)			0.5 (-1 to 1)	10 (2.5 to 20)

IQR: Inter-quartile range; CI: Confidence Interval.

Table 3: Clinical outcomes: SARAH trial vs mySARAH

<b>Variables</b>	<b>At 4-month follow-up</b>
<p><b><i>Treatment attendance rate (%)</i></b></p> <p>SARAH trial, n=246 mySARAH, n=11</p>	<p>75% completed all face-to-face SARAH sessions.</p> <p>55% completed all online mySARAH sessions.</p>
<p><b><i>Follow-up rate (%)</i></b></p> <p>SARAH trial, n=224 mySARAH, n=8</p>	<p>91%</p> <p>73%</p>
<p><b><i>Overall hand function (0-100)</i></b></p> <p>SARAH trial, n=222 mySARAH, n=8</p>	<p>Mean change [95% CI] 8.73 [6.83 to 10.64]</p> <p>Median change (95% CI) 10 (2.5 to 20)</p>
<p><b><i>Grip strength (Kgs)</i></b></p> <p>SARAH trial, n=245  mySARAH, n= 9</p>	<p>Mean change [95% CI] <i>Average grip strength of both hands</i> 1.59 [1.04 to 2.13]</p> <p>Median change (95% CI) at discharge <i>Grip strength of right hand</i> 5.8 (-2.4 to 9.9)</p>
<p><b><i>Pain</i></b></p> <p>SARAH trial, n=219  mySARAH, n= 8</p>	<p>Mean change [95% CI] -7.60 (-9.94 to -5.26)</p> <p>Median change (95% CI) 0.5 (-1 to 1)</p>

SARAH: Strengthening And stretching for Rheumatoid Arthritis of the Hand; IQR: Interquartile range; CI: Confidence Interval.  
mySARAH: Online version of SARAH programme

### Telephone Interview Guide (At 16 weeks)

The following questions will be asked in the telephone session scheduled around one month after participants completing the 12-week mySARAH programme.

#### I. Open –ended questions to participants who completed mySARAH programme

##### Principal question

- Can you tell me about your experiences of working through the mySARAH programme?

##### Sub-questions

- Can you tell me why you decided to take part in this project about mySARAH?
- Can you tell us what features you liked/disliked in mySARAH? -Prompts on online forms, exercise videos, exercise diary, interviews with patients & clinicians, content
- Did you have any concerns about doing the programme on your own?
- How confident did you feel that you were doing the exercises correctly?
- What type of support do you think people need to be able to complete the programme?
- Can you tell me what helped you to stick with my SARAH programme?
- Tell us about any problems you had with mySARAH
- How could we improve mySARAH?

##### Closing question

- Is there anything else you would like to tell us today?

#### II. Open –ended questions to participants who withdrew/did not complete the mySARAH programme

##### Principal question

- Can you tell me about your experiences of working through the mySARAH programme?

##### Sub-questions

- Can you tell us why you decided to take part in this project about mySARAH?

- Can you tell us what features you liked/disliked in mySARAH? -Prompts on online forms, exercise videos, exercise diary, interviews with patients & clinicians, content
- I understand that you did not manage to complete the 12 week programme. Can you tell me about that?
- Tell us about any problems you had with mySARAH

**Closing question**

- Is there anything else you would like to tell us today?

Appendix 2: Individual pain scores (0-No pain; 5-Moderate pain; 10-Worst possible pain)

Participants	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6	Telephone Follow-up
01	3	6	5	4	4	3	6
02	3	4	5	2	5	5	3
03	4	3	8	5	4	7	5
04	4	3	1	0	0	1	2
05	3	5	3	6	2	3	4
11	3	2	2	2	2	2	2
06	0	0	Did not complete	Did not complete	Did not complete	0	Did not complete
07	2	2	3	Did not complete	Did not complete	3	3
08	1	3	2	0 Did not complete	Did not complete	1	0
09	0	1	2	0	Did not continue		
10	1	0	Did not continue				

Online mySARAH sessions 1, 2, 3 and 6 were completed during observation appointments with the researcher; Online mySARAH sessions 4 and 5 were completed by participants on their own from home; Participant 08 did not complete home session 4, but recorded pain on mySARAH pain scale.

## Abstract

### Introduction

The Strengthening And stretching for Rheumatoid Arthritis of the Hand (SARAH) program is a tailored, 12-week hand and arm exercise program recommended in the National Institute for Health and Care Excellence (NICE) guidelines. It includes seven mobility exercises and four strength exercises against resistance. An online version of the SARAH program (mySARAH) has been developed to allow direct access for people with rheumatoid arthritis.

### Purpose

To assess the feasibility, acceptability, and clinical impact of mySARAH in people with rheumatoid arthritis.

### Study design

Mixed-method, proof-of-concept study.

### Methods

mySARAH is a self-guided, online version of the SARAH program with six exercise training and review sessions. Participants were observed as they worked through four of the six online sessions. They were also asked to demonstrate the SARAH exercises. Participants undertook two sessions independently at home.

At baseline and 12 weeks, hand pain, hand function, and grip strength were measured. At 12 weeks, feedback on mySARAH, and perceived recovery were also collected. Approximately one month later, a telephone follow-up was conducted to explore participants' experiences with mySARAH. Pain, hand function, and perceived recovery were also assessed.

### Results

Eleven participants (Males/Females: 3/8) with a median (Inter-quartile range) age of 63 (17) years took part. Six participants completed all mySARAH sessions. 512 exercise and load-setting demonstrations were observed and 491 (96%) were performed correctly. Improvements in grip strength and hand function were observed with no increase in pain. Most of the participants reported improvement and provided positive feedback. All participants perceived mySARAH as a useful resource. Features to improve the online exercise diary such as recording and tracking exercise dose and face-to-face or *remote support* by phone or Skype from health professionals were suggested to optimize user engagement.

### Conclusions

Initial evaluation of mySARAH indicates that mySARAH was feasible, acceptable, and beneficial to participants. Further iteration and evaluation are needed before large-scale implementation.

**Key words**

Hand function; Online exercise intervention; Proof-of-concept; Feasibility; Acceptability.