

Experiences of venue based exercise interventions for people with stroke in the UK: a systematic review and thematic synthesis of qualitative research

Young, R. E., Broom, D., Sage, K., Crossland, K. & Smith, C

Author post-print (accepted) deposited by Coventry University's Repository

Original citation & hyperlink:

Young, RE, Broom, D, Sage, K, Crossland, K & Smith, C 2021, 'Experiences of venue based exercise interventions for people with stroke in the UK: a systematic review and thematic synthesis of qualitative research', *Physiotherapy (United Kingdom)*, vol. 110, pp. 5-14. <https://doi.org/10.1016/j.physio.2019.06.001>

DOI 10.1016/j.physio.2019.06.001

ISSN 0031-9406

Publisher: Elsevier

© 2021, Elsevier. Licensed under the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International

<http://creativecommons.org/licenses/by-nc-nd/4.0/>

Copyright © and Moral Rights are retained by the author(s) and/ or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This item cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder(s). The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.

This document is the author's post-print version, incorporating any revisions agreed during the peer-review process. Some differences between the published version and this version may remain and you are advised to consult the published version if you wish to cite from it.

1 **Experiences of venue based exercise interventions for people with stroke in the UK: a**
2 **systematic review and thematic synthesis of qualitative research**

3
4 **Abstract**

5
6 **Background**

7 The physical benefits of exercise following stroke are research evidenced and the UK stroke
8 population is increasingly encouraged to engage with exercise interventions. A synthesis of
9 qualitative research is required to further understand the perceived experience and
10 psychosocial effect of exercise for people with stroke.

11
12 **Objectives**

13 To provide a systematic search and synthesis of evidence about the experiences and
14 reported impact of participation in venue based exercise following stroke in the UK.

15
16 **Data sources**

17 Eligible studies were identified through a rigorous search of Medline, Cinahl, AMED,
18 PsycINFO, SportDiscus, Proquest and ETHOS from January 2000 until December 2017.

19
20 **Study eligibility criteria**

21 Full text qualitative studies or service evaluations conducted in the UK which explored the
22 reported experience of venue based exercise amongst people with stroke.

23
24 **Study synthesis and appraisal**

25 Included studies were evaluated through application of the Consolidated Criteria for
26 Reporting Qualitative Research. Data synthesis using a thematic approach generated
27 descriptive and analytical themes.

28
29 **Results**

30 Six research studies and one service evaluation met the inclusion criteria; methodological
31 quality was variable. These studies highlighted that people with stroke gain confidence and
32 renewed identity through exercise participation. Perceived improvements in physical function
33 were reported and participants enjoyed stroke specific exercise programmes in de-
34 medicalised venues.

35
36 **Limitations**

37 The studies only accessed people who had completed the exercise programmes; non-
38 completers were not represented.

39
40 **Conclusion**

41 Venue based exercise programmes have a positive effect on perceived wellbeing following
42 stroke. Further research into the reasons for discontinuation of exercise participation
43 following stroke is required.

44
45 **Systematic review registration number:** Prospero 2017:CRD42017072483

46
47
48 **Contribution of paper**

49
50
51
52
53
54
55
56
57
58
59
60
61
62
63
64
65
66
67
68
69
70
71
72
73
74
75
76
77
78
79
80
81
82
83
84
85
86
87
88
89
90
91
92
93
94

- This qualitative synthesis provides a detailed analysis of how people with stroke perceive their experiences of participation in venue based exercise programmes
- The review explores the reported impact of varied models of programme delivery; the findings are relevant to the development of future stroke specific exercise schemes

Keywords

Stroke, Exercise, Qualitative, Venue, Systematic review

95 Experiences of venue based exercise interventions for people with stroke in the UK: a
96 systematic review and thematic synthesis of qualitative research

97

98

99 **Background**

100

101 There are 1.2 million people with stroke in the UK and it is a leading cause of disability [1].

102 Between 2014 and 2017 there was a 2.9% increase in incidence of reported stroke and an

103 11.8% increase in the 50-59 year-old group [2]. The effectiveness of aerobic, strength or

104 combined training interventions to optimise outcome following stroke are increasingly

105 recognised [3]. Exercise following stroke leads to reduced physiological risk factors,

106 improved physical function and mobility [4, 5]. Significant improvements in quality of life

107 associated with exercise participation following stroke are reported [6] and qualitative data

108 related to the effect of exercise following stroke suggest that participants perceive

109 improvements in physical function, participation and psychosocial wellbeing [7,8].

110

111 Engagement with exercise amongst the UK stroke population does not meet published

112 recommendations [9,10]. It is recommended that people in the UK with stroke or Transient

113 Ischaemic Attack (TIA) should be supported in accessing exercise opportunities to improve

114 fitness which is individualised and targets personal goals [11]. Exercise interventions can be

115 delivered and sustained in the home environment but adherence does decline without the

116 added support of venue based sessions [12]. There are various models of venue based

117 exercise programme for people with stroke in the UK, including the national Exercise

118 Referral Scheme (ERS) and these represent the advantage of equipment and space

119 required for progressive strength and aerobic training [13].

120

121 ERS participants from a range of diagnostic groups report improved mental wellbeing and

122 increased personal autonomy associated with being part of a gym based programme [14].

123 However, there are also reports of ERS participants feeling intimidated in the traditional gym

124 environment and long- term adherence to exercise referral programmes is less than 50%

125 [14]. The transition from physiotherapy led stroke rehabilitation to exercise programmes

126 supervised by fitness instructors exemplifies a sustainable delivery model; exercise
127 professionals increasingly recognise the need to address the specific needs of people with
128 stroke [15,16].

129
130 The barriers to exercise participation following stroke are complex and survivors can
131 experience frustration when there is dissonance between their motivation and capability to
132 be active [17]. Multiple barriers to accessing the external world are reported following stroke
133 including lack of confidence to navigate public settings and perceived stigma of disability
134 [18]. In order to understand the experiences of the UK stroke population when participating
135 in venue based exercise programmes, exploration of relevant qualitative data was
136 undertaken. This synthesis of qualitative data will enrich insight into the perspectives of
137 people with stroke, inform the design of stroke specific exercise programmes and highlight
138 areas for future research.

139
140
141 **Aim**

142
143 The aim of this review of qualitative data is to provide a systematic search and synthesis of
144 evidence about the experiences and reported impact of participation in venue based
145 exercise following stroke in the UK.

146
147 **Methods**

148
149
150 **Definition of a venue- based exercise intervention**

151 Preliminary scoping work facilitated the definition of the exercise intervention. For the
152 purpose of this systematic review a venue- based exercise intervention was defined as a
153 programme based outside the individuals place of residency, delivered by a physiotherapist,
154 exercise instructor or exercise professional. It was determined that the model of programme
155 delivery could be in the form of a group or individual activity and the intervention should

156 include elements of aerobic, strength or combined training to align with conventional
157 components of an exercise intervention.

158

159 **Review methodology**

160 A thematic synthesis of included research was selected as it comprises the identification of
161 the main and recurrent themes arising within a body of evidence [19]. This technique
162 facilitates the organisation of qualitative data from selected studies and generates a
163 summary of findings, whilst preserving the essential context of qualitative research [20].

164 Thematic synthesis represents a process for identifying, grouping and summarising
165 qualitative findings with lower risk of bias than associated with narrative synthesis methods
166 [19]. The ENTREQ framework was used to guide the reporting of findings from the review
167 [21]. The methods are described in detail in the protocol that was developed and registered
168 on the PROSPERO database (Prospero 2017:CRD42017072483).

169

170

171 **Literature Search strategy**

172 A comprehensive search was conducted between August and December 2017. The
173 following databases were accessed: Medline, Cinahl, AMED, PsycINFO, SportDiscus,
174 Proquest and ETHOS. Reference lists of selected articles were hand searched and authors
175 were contacted in case of further publications. The grey literature search extended to contact
176 with known researchers in the field. This generated contact with specific leisure service
177 providers known to have reported on exercise interventions for people with stroke. Search
178 terms included stroke, cerebrovascular accident, exercise, physical activity, exercise referral,
179 qualitative, interview, perspective, focus group and opinion. Keyword and MeSH terms were
180 integrated in the search process, the controlled search term strategy search can be
181 accessed in supplementary materials (Table SM1). In order to ensure currency of findings
182 the search was limited to studies published from 2000. The search was led by the principal

183 investigator (RY) with guidance from the information scientists at Sheffield Hallam University.

184 The search process was summarised in a Prisma flowchart (Figure 1).

185

186

187 **Eligibility criteria**

188

189 The scope of the review was limited to the UK due to global variation in stroke service

190 delivery [22] and to contribute towards the evidence base on exercise uptake amongst

191 clinical populations in the UK [13]. The inclusion criteria were: (1) studies which had

192 recruited community dwelling people with diagnosis of stroke or transient ischaemic attack

193 (TIA), (2) studies which had evaluated the impact of a venue based exercise programme

194 located in a leisure, health centre or outpatient venue, (3) studies which had incorporated

195 qualitative data collection methods, (4) studies which had adhered to a recognised research

196 or service evaluation protocol.

197

198 The aim was to maintain a focus upon the experiences of venue centred exercise.

199 Therefore, the following exclusion criteria was applied; (1) studies which evaluated inpatient

200 programmes or exercise interventions delivered at the participant's home or place of

201 residency, (2) studies which evaluated specialist rehabilitative technology, (3) studies

202 focussed on gaming interventions or specific therapeutic approaches, (4) studies which

203 included participants without a diagnosis of stroke or TIA.

204

205 Two reviewers (RY, KC) independently screened titles and abstracts to identify relevant

206 studies which met the inclusion criteria for full text screening. Uncertainty regarding

207 suitability for inclusion of selected publications was resolved through discussion with two

208 other members of the review team (CS, DB).

209

210 **Quality assessment**

211

212 The consolidated criteria for reporting qualitative research (COREQ) was used to facilitate

213 an explicit and comprehensive evaluation of study quality [23]. The COREQ comprises a

214 checklist devised to identify opportunities for bias, is well suited for focus group or interview
215 data collection methods and more sensitive than alternative quality assessment tools [24].
216 Two members of the review team (RY, KC) independently applied the 32- point criteria which
217 evaluate the reporting related to research team, study design, analysis and findings. Since
218 this review adhered to a thematic methodology, the quality assessment was used to inform
219 the findings of the review and identify recommendations for future research. No publications
220 were excluded due to methodological limitations.

221

222 **Data extraction**

223

224 Data extraction was standardised through development of a tabulated format adapted from
225 Pope et al [19]. In line with the methods recommended by Thomas and Harden [20], all text
226 labelled as results or findings including participant quotes and author's interpretations were
227 extracted for analysis and generation of themes.

228

229

230 **Data synthesis**

231

232 The data synthesis process followed three key stages; data coding, development of
233 descriptive themes and generation of analytical themes [19,20]. An iterative approach was
234 adopted by the principal investigator (RY) to gain in-depth familiarity with the included
235 studies. Line by line coding was conducted by three members of the review team (RY, DB,
236 CS) and a coding tree was developed (Figure 2). Scheduled workshops with the review team
237 facilitated discussion and agreement on the descriptive themes which emerged from the
238 data. Comparison of findings facilitated exploration of relationships between the studies and
239 L421 generated a third order interpretation by the principal investigator (RY). The emergent
240 analytical themes were explored and agreed by the review team (CS, DB, KS) [21].

241

242 **Results**

243

244 **Study selection**

245

246 The combined search terms for stroke, exercise and qualitative data retrieved 730
247 references. After screening for duplicates, 492 articles were shortlisted for title and abstract
248 screening. Eighteen papers were read in full and six published references were selected for
249 inclusion in the review. The Prisma flowchart (Figure 1) outlines the article selection process.
250 The search for grey literature identified two service evaluations based within leisure centre
251 venues. One complete report was accessed and accepted for inclusion within the review. A
252 full report of the second service evaluation was not available.

253

254 The total number of participants across the selected studies was 76 (n = 48 male, n = 28
255 female) aged between 18 and 84 years. Time since stroke ranged from 6 months to 13
256 years. None of the studies had captured the perspectives of non-completers and two studies
257 [25,26] incorporated an educational component. A summary of the studies and respective
258 interventions is detailed in table 1.

259

260 **Figure 1: Prisma flow chart**

261

262

263 **Table 1: Summary of included studies**

264

265

266

267 **Quality assessment and sensitivity analysis**

268

269 The COREQ defines 32 criteria for quality appraisal which detail reporting on the research
270 team, study design and data analysis [23]. Two members of the review team (RY, KC)
271 independently applied the criteria to the seven selected studies. The individual scores were
272 discussed by RY and KC to establish agreement for each study (Table 2). Quality ratings
273 using the COREQ ranged from 14-30 with a mean score of 21/32. Studies with lower scores
274 tended to provide insufficient information about the research team which refers to how the
275 researchers critically examined their own role, potential bias and influence during data

276 collection. Studies with lower scores were included because of the value of the content
277 associated with reported physical impact of the interventions.

278
279 **Table 2: COREQ criteria**

280
281 **Data analysis**

282
283 Three members of the review team (CS, DB, RY) initiated independent coding of the
284 selected papers. Twenty three individual codes were identified and two overarching thematic
285 categories were identified: perception of programme and impact on self. Six descriptive
286 themes emerged from these two categories; sustained behaviours (1), psychosocial impact
287 (2), physical impact (3), influence of group (4), programme design (5) and comparison with
288 healthcare services (6). The themes and their supporting codes are represented in the
289 coding tree (Figure 2). Comparison between and synthesis of the descriptive themes
290 facilitated the development of inductive, analytical themes (Table 3).

291
292 **Figure 2: Coding tree**

293
294
295 **Descriptive themes**

296
297 **1. Sustained behaviours**

298
299 Sustained activity behaviours were explored in several studies [8,25,26,27,28]. Engagement
300 with home exercise programmes was variable, the participants from the Carin-Levy et al [23]
301 study shared mixed views, with fear of falling identified as a barrier to continuing with
302 exercises at home. Several studies specifically reported an increased commitment to
303 community based physical activity [8,25,28,29] including swimming, exercise classes and
304 gym membership. Two studies [25,26] had incorporated an educational programme. A
305 greater awareness of lifestyle factors and risk reduction was reported, however, the impact
306 of this knowledge on lifestyle was variable.

307
308
309 .

310 **2. Psychosocial impact**

311

312 The psychosocial impact of exercise participation was a strong recurrent descriptive theme
313 across the included studies. Three studies [8,25,29] reported that participants had exceeded
314 their personal expectations. With the exception of Wiles et al [28], the data from all studies
315 associated exercise participation with the resumption of pre-stroke activities including
316 hobbies, spiritual fellowship, vocation, family and social engagements. Improved self-
317 confidence was strongly reported in four studies [8,27,29,30] and two studies [25,29]
318 described the creation of a “new self,” triggered by the exercise programme. A positive
319 impact on relationships was identified as over-protective behaviours from carers or partners
320 decreased [8,26,29].

321

322 **3. Physical impact**

323

324 The perceived physical impact of the exercise programme was reported by all included
325 studies. The gym setting appeared to be associated with improved physical performance in
326 terms of strength, stamina and technique [8,27,28,29,30]. Participants described improved
327 mobility [27,28,29], reduced dependence on walking aids [8,27,29], improved balance
328 [20,28,29] and recovered movement [8,27,29]. The impact of exercise upon Activities of
329 Daily Living (ADL) was mixed, with participants from two of the studies [28,30] suggesting
330 that they did not experience improved performance in ADL. In contrast, participants who had
331 engaged with the ARNI programmes identified specific improvements in ADL including
332 eating, dressing and household tasks [8,29].

333

334 **4. Influence of group**

335

336 The influence of the group and impact of peer support was a major recurrent theme.
337 Participants shared that they had compared themselves to other people with stroke
338 [18,25,26,27]. Downward comparison with other group members was reported by Hillsden et
339 al [26], this was mostly alongside people with a cardiac diagnosis which was perceived as
340 more serious than minor stroke or TIA. Those studies which had collected data from stroke

341 specific exercise programmes reported high levels of mutual encouragement and group
342 support between participants [8,25,28,29]. In contrast, participants recruited from the
343 standard ERS described by Wiles et al [28] commented on limited opportunity to meet with
344 or speak to other people within the gym setting.

345
346
347
348
349

5. Programme design

350 Attendance at an external venue was viewed as an opportunity to “get out of the house”
351 [8,28]. Although some individuals had regarded public gymnasiums with trepidation [27], the
352 overriding opinion was that the participants enjoyed building confidence within a de-
353 medicalised setting [8,25,27,30]. Participants also identified accessible car park, good
354 transport links and the coffee shop as important factors related to their experience of the
355 venue [8]. Two studies [26,30] were based within health rehabilitation centres, this did not
356 appear to directly influence the reported experience. Positive relationships with the
357 professional team were described [8,25,27] and several participants would have liked the
358 duration of the programme to be increased [8,25,27,29].

359
360
361

6. Comparison with healthcare services

362 Comparison with health service rehabilitation and physiotherapy was the final descriptive
363 theme identified within the thematic analysis. The sentiment that exercise required mental
364 toughness and determination was shared across several studies [25,27,30]. Participants
365 referred to the need for willpower and determination to engage with exercise and optimise
366 their physical outcome. Exercise referral schemes were perceived as a substitute for
367 physiotherapy [25,28]. In contrast, participants from the Norris et al [8] study shared that they
368 had felt “mollycoddled in hospital” and that the ARNI programme was the opposite to “half-
369 baked physiotherapy.” Overall, participants across all of the included studies had
370 appreciated the opportunity for further physical progression following stroke rehabilitation
371 within a de-medicalised setting.

372

373

374 **Analytical themes**

375

376 Three analytical themes evolved from in-depth analysis of the descriptive themes; these are

377 summarised alongside illustrative quotes in table 3.

378

379

380 “Training principles as a foundation for programme design”

381 Training principles including specificity, overload and progression were implicit in the views

382 shared by participants. Specificity of training response is identified as those interventions

383 which focussed on functional mobility [8,29] triggered perceived improvements in balance

384 and walking ability. The interventions which had emphasised conventional aerobic and

385 resistance training activities [27,28,30] were associated with changes in physical

386 performance, for example, improved strength and stamina. In alignment with the principles of

387 overload and progression, the programmes were recalled as challenging; participants were

388 encouraged to push their physical boundaries and progress during the course of the

389 intervention. Participants enjoyed being challenged in a “place of work” and the perceived

390 intensity of the intervention made the sessions worthwhile.

391

392 “I’m not just a stroke patient anymore”

393 The exercise programmes facilitated transition from being a stroke patient to a new identity

394 as an exerciser. The participants felt that they had to do it for themselves with tapered

395 support from the professional team. This was in contrast to the experience of health care

396 rehabilitation in which participants had felt protected but disempowered [8,27]. The

397 distinction between conventional rehabilitation and exercise interventions was evident across

398 the included studies. Although perspectives regarding the respective value of fitness

399 instruction compared to traditional physiotherapy were mixed, there was an overriding

400 sentiment of personal achievement associated with completion of the exercise interventions.

401 The importance of peer support in group interventions is highlighted and these findings

402 indicate extended value generated through group interventions. Intervention delivery in de-
403 medicalised venues normalised the experience and participants were empowered to recover
404 their pre-stroke identity.

405

406 “Restoration of an internal locus of control.”

407 Restoration of an internal locus of control is evident as recovery of personal autonomy and
408 valued life roles is strongly associated with the exercise interventions. Participants recovered
409 a sense of control over their own destiny through exercise and physical achievement. They
410 reported that they started to feel that they could move forwards from the impact of their
411 stroke, resume their previous roles and re-engage with valued activities [27]. The reported
412 effect of the intervention extended beyond physical changes as the restoration of the “old
413 self” is evident. Participants felt elevated and their standing within family and social circles
414 was enhanced. The evaluation of exercise interventions following stroke needs to routinely
415 incorporate measurement of reported quality of life and participation to ensure a valid
416 reflection of their real value.

417

418 Table 3: Analytical themes and illustrative quotes

419

420

421 **Discussion**

422

423 This review provides a synthesis of qualitative studies after a systematic search for the
424 perspectives of people with stroke who have participated in venue based exercise
425 programmes. The findings facilitate a more comprehensive understanding of the perceived
426 benefits and reported experiences associated with exercise following stroke in the UK. Three
427 analytical themes contribute to our understanding of how people with stroke perceive their
428 experience of participation in venue- based exercise.

429

430

431 Training principles as a foundation for programme design

432 Generic training principles for physical training should be applied to the stroke population
433 [31] and there are clear links between the activities performed and perceived physical
434 benefits reported. A continuum of variety should underpin all training programmes to avoid
435 onset of tedium and achieve greater improvements [32]. Norris et al [8] concluded that a
436 group intervention combined with a focus on individual needs is critical to the capacity to
437 develop a challenging environment. People with stroke respond positively to high intensity
438 training as there is perceived benefit associated with working hard [33]. This sentiment is
439 shared amongst the participants included in this review who felt that they could push the
440 boundaries and achieve beyond their expectations in alignment with the principles of
441 overload and progression.

442

443 I'm not just a stroke patient anymore

444 The second analytical theme encapsulates a change in identity associated with the exercise
445 programmes; participants liked being challenged in a working environment. The location of
446 the programmes symbolised a step away from medicalised systems, although the transition
447 from physiotherapy to an exercise professional led intervention generated mixed views [8,27,
448 28]. The findings of this review indicate that physiotherapy guided interventions delivered by
449 supported exercise professionals may have the optimal perceived benefit [27]. Exercise
450 professionals are interested in working with people with stroke but report a perceived lack of
451 relevant experience and training [15]. Increased collaboration between physiotherapy
452 services and exercise professionals may enhance uptake and engagement in exercise
453 following stroke, enabling people with stroke to progress towards a de-medicalised identity.

454

455 Internal confidence following stroke should be facilitated by creating opportunities for positive
456 social interaction [18] and stroke specific exercise groups emerged as the preferred model
457 amongst the studies reviewed. The resourcing of group interventions with integrated

458 individual support represents a challenge for leisure providers [15]; cost-benefit analysis of
459 different exercise delivery models for people with stroke is required. The integration of
460 people with stroke into a cardiac rehabilitation programme appeared to generate a social
461 dynamic of downward comparison between group participants and a higher dropout rate was
462 recorded [26]. Cardiac rehabilitation teams report limited confidence in supporting people
463 with stroke [16]; further training and programme adaptation is required to effectively integrate
464 cardiac and stroke rehabilitation.

465

466

467 Restoration of an internal locus of control

468 The emergence of an internal locus of control through which participants felt empowered and
469 in charge of their own destiny is evident. The psychological benefits of exercise following
470 stroke are increasingly reported alongside the physical benefits and contributes to functional
471 autonomy and improved quality of life [34]. Improvements in mood and self-esteem are key
472 motivators for sustained engagement [35]. Across the studies reviewed there are recurrent
473 reports of resumption of pre-stroke activities alongside enhanced social and familial roles.
474 The severity of physical impairment did not appear to influence the reported experience or
475 value of participating in exercise. In fact, those with the mildest impairments appeared to
476 place less value on exercise [26]. The majority of trials which have evaluated exercise
477 following stroke have excluded non-ambulatory participants [5]. Future research should
478 prioritise the development of exercise facilities and programmes which meet the needs of
479 non-ambulant people with stroke.

480

481

482

483 Strengths and limitations of this review

484

485 This review of qualitative research included primary studies and grey literature. The
486 application of COREQ criteria highlighted the strengths and limitations of the selected
487 research publications. Sensitivity analysis and exclusion of inadequately reported studies
488 from qualitative systematic reviews is debated in the literature [36]. In this review, higher
489 rated studies generated those themes focussed on the psychological effect of the
490 intervention [8,27]. In contrast, the lower quality publications informed development of
491 themes which reflected the physical impact of the intervention and experience of the
492 environment [28,29]. A potential source of bias is the geographical representation of the
493 included samples; with one exception, [30] all of the studies were based in south England.
494 The influence of regional demographics can have a significant bearing upon exercise beliefs
495 and behaviours [37] and further research is required to capture the views and experiences of
496 the UK wide stroke population.

497

498 The scope of the review was limited to the UK as this enabled a specific focus upon the UK
499 health service combined with third sector partners. Similar research has been conducted
500 within the international community [38] and a larger scale review would facilitate a global
501 perspective. The included studies only captured the views of participants who had completed
502 the programmes. Future research should prioritise following up people who do not enrol on
503 or adhere to exercise programmes following stroke. This would enable training providers to
504 identify those factors which disengage people from exercise following stroke which may
505 include fear, tedium or progression to other forms of physical activity [32]. A further area for
506 future study could focus on comparison between home and venue based exercise
507 programmes as home based or non-traditional exercise settings may be preferred by some
508 people with stroke [35].

509

510 **Conclusion**

511

512 The results of this systematic review highlight that exercise for people with stroke has a
513 positive impact on perceived physical ability, identity and participation. Stroke specific

514 groups engender peer support and a new social network. De-medicalised venues are
515 associated with a positive challenge and restoration of an internal locus of control. The
516 findings of this review suggest that people with stroke will benefit from sustained support in
517 exercise participation and programmes adapted for all levels of physical ability should be
518 available. Rehabilitation services need to collaborate with exercise providers to facilitate a
519 positive transition towards long term exercise participation. Future qualitative research
520 should focus on people who opt out of exercise interventions following stroke and a multi-
521 regional perspective across the UK is required in relation to this field of evidence.

522

523

524 **Author declaration**

525 No funding sources were accessed to support the development of this review. The authors
526 declare that there are no conflicts of interest.

527

528

529

530

531

532

533

534

535

536

537

538

539

540

541

542

543

544

545

546

547

548

549

550

551 **References**

552
553
554
555
556
557
558
559
560
561
562
563
564
565
566
567
568
569
570
571
572
573
574
575
576
577
578
579
580
581
582
583
584
585
586
587
588
589
590
591
592
593
594
595
596
597
598
599
600
601
602
603
604
605

[Dataset] [1] Stroke Association: State of the Nation, Stroke statistics January 2017.
https://www.stroke.org.uk/sites/default/files/state_of_the_nation_2017_final_1.pdf

[Dataset] [2] Sentinel Stroke National Audit Programme (SSNAP): National Results. 2016.
<https://www.strokeaudit.org/results/Clinical-audit/National-Results.aspx>

[3] Royal College of Physicians. National clinical guideline for stroke. 2016.
[https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx)

[4] D'Isabella NT, Shkredova DA, Richardson JA, Tang A. Effects of exercise on cardiovascular risk factors following stroke or transient ischemic attack: a systematic review and meta-analysis. *Clin Rehabil* 2017;31(12):1561-72.

[5] Saunders DH, Sanderson M, Hayes S, Kilrane M, Greig CA, Brazzelli M, et al. Physical fitness training for stroke patients. *Cochrane Database of Syst Rev* 2016.

[6] Dunn A, Marsden DL, Barker D, Van Vliet P, Spratt NJ, Callister R. Cardiorespiratory fitness and walking endurance improvements after 12 months of an individualized home and community based exercise programme for people after stroke. *Brain Inj* 2017;31(12):1617-24.

[7] White JH, Bynon BL, Marquez J, Sweetapple A, Pollack M. Masterstroke: a pilot group stroke prevention program for community dwelling stroke survivors. *Disabil Rehabil* 2013;35(11):931-8.

[8] Norris M, Kilbride C, Mohagheghi A, Victor C. Exercise instructor-led functional training programme for community dwelling stroke survivors: A qualitative study. *Int J Ther Rehabil* 2010; 20(12):597-605.

[9] Billinger SA, Arena R, Bernhardt J, Eng JJ, Franklin BA, Johnson CM et al. Physical activity and exercise recommendations for stroke survivors: a statement for healthcare professionals from the American Heart Association. *Stroke* 2014;45(8): 2532-53.

[10] Paul L, Brewster S, Wyke S, Gill JM, Alexander G, Dybus A et al. Physical activity profiles and sedentary behaviour in people following stroke: a cross sectional study. *Disabil Rehabil* 2016;38(4):362-7.

[11] Royal College of Physicians. National clinical guideline for stroke. 2016.
[https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-\(1\).aspx](https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx)

[12] Jurkiewicz MT, Marzolini S, Oh P. Adherence to a Home-Based Exercise Program for Individuals After Stroke. *TOP STROKE REHABIL* 2011 May;18(3):277-284.

[13] Rowley N, Mann S, Steele J, Horton E, Jimenez A. The effects of exercise referral schemes in the United Kingdom in those with cardiovascular, mental health, and musculoskeletal disorders: a preliminary systematic review. *BMC Public Health* 2018;18(1).

[14] Morgan F, Battersby A, Weightman AL, Seachfield L, Turley R, Morgan H et al. Adherence to exercise referral schemes by participants- what do providers and commissioners need to know. A systematic review of barriers and facilitators. *BMC Public Health* 2016;16:227.

- 606 [15] Condon M, Guidon M. A survey of exercise professionals' barriers and facilitators to
607 working with stroke survivors. *HEALTH SOC CARE COMMUNITY* 2018;26(2):250-258.
608
- 609 [16] Clague-Baker N, Robinson T, Drewry S, Hagenberg A, Singh S. Cardiac rehabilitation
610 and stroke teams attitudes to people with stroke taking part in cardiac rehabilitation: focus
611 group study. *Clin Rehabil* 2018;32(10):1416.
612
- 613 [17] Morris JH, Oliver T, Kroll T, Joice S, Williams B Physical activity participation in
614 community dwelling stroke survivors: synergy and dissonance between motivation and
615 capability. A qualitative study. *Physiotherapy* 2017; 103(3):311-21.
616
- 617 [18] Reed MC, Wood V, Harrington R, Paterson J. Developing stroke rehabilitation and
618 community services: a meta-synthesis of qualitative literature. *Disabil Rehabil*
619 2012;34(7):553-563.
620
- 621 [19] Pope C, Mays N, Popay J, Synthesizing qualitative and quantitative health evidence: A
622 guide to methods. Open University Press; 2007.
623
- 624 [20] Thomas J, Harden A. Methods for thematic synthesis of qualitative research in
625 systematic reviews. *BMC Med Res Methodol* 2008;8:45-59.
626
- 627 [21] Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting
628 the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12:181-9
629
- 630 [22] Johnson W, Onuma O, Owolabi M, Sachdev S (2016) Stroke: a global response is
631 needed. *Bull World Health Organ* 2016;94(9):633-708.
632
- 633 [23] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research
634 (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*
635 2007;19(6):349-57.
636
- 637 [24] Peditto K. Reporting Qualitative Research: Standards, Challenges, and Implications for
638 Health Design. *HEALTH ENVIRONMENTS RES DESIGN J (SAGE)* 2018;11(2):16-19.
639
- 640 [25] Reed M, Harrington R, Duggan A, Wood VA. Meeting stroke survivors' perceived needs:
641 a qualitative study of a community-based exercise and education scheme. *Clin Rehabil*
642 2010;24(1):16-25.
643
- 644 [26] Hillsdon KM, Kersten P, Kirk HJS. A qualitative study exploring patients' experiences of
645 standard care or cardiac rehabilitation post minor stroke and transient ischaemic attack. *Clin*
646 *Rehabil* 2013;27(9):845-53.
647
- 648 [27] Sharma H, Bulley C, Wijck FMJ. Experiences of an exercise referral scheme from the
649 perspective of people with chronic stroke: a qualitative study. *Physiotherapy* 2012;98:336-
650 43.
651
- 652 [28] Wiles R, Demain S, Robison J, Kileff J, Ellis-Hill C, McPherson K. Exercise on
653 prescription schemes for stroke patients post discharge from physiotherapy. *Disabil Rehabil*
654 2008;30(26):1966-75.
655
- 656 [29] Smith A, Joy R, Parsons A. ARNI techniques for chronic stage of stroke in a group
657 setting-a pilot programme research report. Central and North West London NHS Foundation
658 Trust 2014.
659

660 [30] Carin-Levy G, Kendall M, Young A, Mead G. The psychosocial effects of exercise and
661 relaxation classes for persons surviving a stroke. *Can J Occup Ther* 2009; 76(2):73-80.
662

663 [31] Ammann BC, Knols RH, Baschung P, Bie RA, Bruin ED (2014) Application of principles
664 of exercise training in sub-acute and chronic stroke survivors: a systematic review. *BMC*
665 *Neurol* 2014;14:167-78.
666

667 [32] Farrow D, Robertson S. Development of a Skill Acquisition Periodisation Framework for
668 High-Performance Sport. *Sports Med* 2017;47(6):1043-1054.
669

670 [33] Signal N, McPherson K, Lewis G, Kayes N, Saywell N, Mudge S, et al. What influences
671 acceptability and engagement with a high intensity exercise programme for people with
672 stroke? A qualitative descriptive study. *NEUROREHABILITATION* 2016;39(4):507-517.
673

674 [34] Belfiore P, Miele A, Galle F, Liguri G. Adapted physical activity and stroke: a systematic
675 review. *J Sports Med Phys Fitness* 2018;58(12):1867-1875.
676

677 [35] Poltawski L, Boddy K, Forster A, Goodwin VA, Pavey AC, Dean S. Motivators for uptake
678 and maintenance of exercise: perceptions of long-term stroke survivors and implications for
679 design of exercise programmes. *Disabil Rehabil* 2015;37(9):795-801.
680

681 [36] Carroll C, Booth A, Lloyd-Jones M. Should We Exclude Inadequately Reported Studies
682 From Qualitative Systematic Reviews? An Evaluation of Sensitivity Analyses in Two Case
683 Study Reviews. *Qual Health Res* 2012;22(10):1425-1434.
684

685 [37] Jackson S, Mercer C, Singer BJ. An exploration of factors influencing physical activity
686 levels amongst a cohort of people living in the community after stroke in the south of
687 England. *Disabil Rehabil* 2016;40(4):414-24.
688

689 [38] White JH, Bynon BL, Marquez J, Sweetapple A, Pollack M. Masterstroke: a pilot group
690 stroke prevention program for community dwelling stroke survivors. *Disabil Rehabil* 2013;35
691 (11): 931-8.
692
693
694
695
696
697
698
699
700

701

702

703

704

705

706

707

708

709

Figure 1: Prisma Flowchart

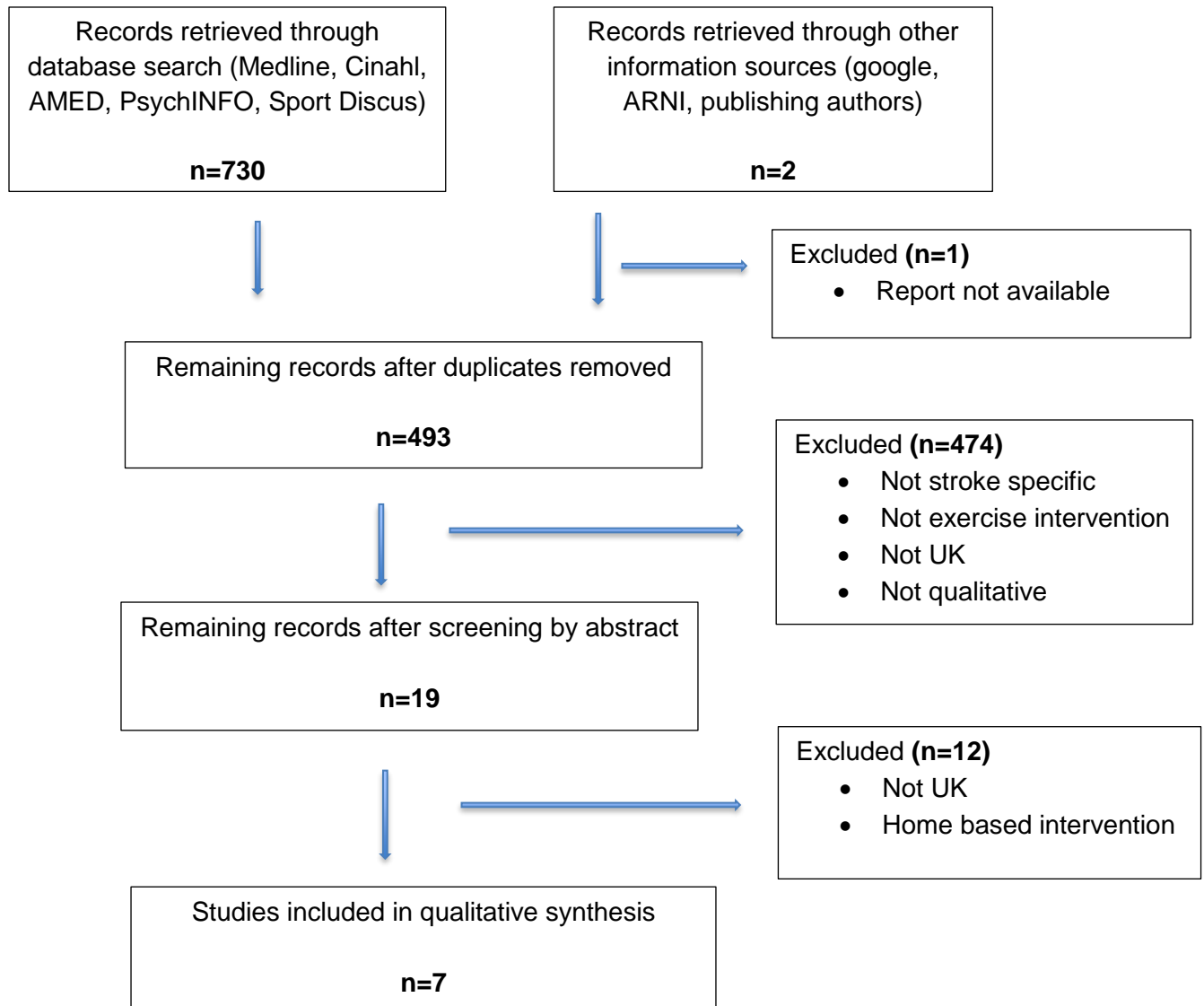


Figure 2: See separate attachment

Table 1: Characteristics of included studies

Study characteristics	Participant characteristics	Intervention and setting	Data findings & themes
Carin-Levy et al [30]			
Pragmatic, qualitative programme evaluation using semi-structured interviews. Follow up from a quantitative randomized exploratory trial which compared exercise and relaxation classes.	Independent and ambulant community dwelling people with stroke. Four males and two females who had been randomized to the exercise group. Age range 49-76 years, mean age 65.3 years. Data from relaxation class participants not included in the review.	Intervention entailed three group sessions per week at a rehabilitation hospital. The class was delivered by an exercise instructor and included circuits, resistance training and flexibility exercises. Duration of programme was 12 weeks.	Five themes identified; enjoyment, motivation, self-perceived quality of life, empowerment and long term effects. Some common benefits identified between exercise and relaxation class. Exercise class participants emphasised perceived physical benefits.
Hillsdon et al [26]			
Pre-planned qualitative arm of a randomized controlled trial which compared standard care with cardiac rehabilitation following minor CVA or TIA. Semi-structured interviews conducted in participant homes or the hospital.	Independent and ambulant community dwelling people with history of minor stroke or TIA. Seven males and three females who had been randomized to cardiac rehabilitation participated in the interviews. Age range 47-84 years.	There was one group session per week for eight weeks comprising of a cardiovascular circuit session plus education integrated with the established cardiac rehabilitation programme. The sessions were based in a health centre and instructed by the cardiac rehabilitation team.	Four primary themes identified; information delivery, comparison with others, psychological impact and risk factor reduction. Authors concluded that the sessions had lacked specificity to people with cerebrovascular disease.
Norris et al [8]			
Qualitative study drawing on interpretative traditions. Data collected through four focus groups conducted in the leisure centre.	Ambulatory or wheelchair dependent community dwelling people with stroke. 16 males and 8 females participated in the four focus groups. The age range was 19-84 years.	One group session per week for 12 weeks at a newly built leisure centre. The sessions were based on the Action for Recovery from Neurological Injury (ARNI) approach and lead by two ARNI instructors.	Key themes were; "I never thought I'd be able to do that again," "It challenges you," "whatever you do don't medicalise it." Authors commented that group support and leadership from peers with history of stroke were central to the positive impact of the programme.
Sharma et al [27]			
Qualitative study using a constructivist approach, an interpretivist perspective and	Community dwelling people with primary diagnosis of stroke who had attended the ERS within previous two years. 4 females	Intervention was a physiotherapy supervised neurological exercise referral scheme based at a South London	Four categories were identified; exercise engagement, control, confidence and improvement. An overarching master

phenomenological methodology.	and 5 males participated in interview. Age range was 37-61 years. The physical ability of participants was not reported.	leisure centre. Individually tailored gym-based exercise in group format scheduled twice per week for twelve weeks.	theme, "ERS as a catalyst for regaining independence" emerged through the analysis.
Reed et al [25]			
Qualitative study using a phenomenological approach to explore whether a community stroke scheme met the needs of people with stroke. Data was collected through semi-structured interviews.	Five males and seven females participated. Minimum Barthel Index score was 10/20 and most participants were aged > 70 years. Mean time since stroke was 26 months.	Intervention was a stroke specific group exercise and education scheme based in leisure or community venues. Sessions were scheduled twice per week for an eight-week duration.	Three primary themes were identified; creating a social self, provision of responsive services in the community and informal support network. The authors concluded that people with stroke need a variety of internal and external resources to reconstruct their lives.
Wiles et al [28]			
Qualitative data was collected from participants through semi-structured interviews. Fitness instructors were interviewed and local physiotherapists participated in a focus group.	Eight males and one female participated. Age range was 18-78 years, with a mean age of 56. The physical ability of participants was not reported.	Intervention was an exercise on prescription scheme, led by fitness instructors and based in leisure centres. Participants followed an individual programme. Duration and frequency of sessions is not reported.	Four primary themes were identified; continuity with physiotherapy, risk and safety, monitoring and scheme improvement. Authors concluded that the scheme offered limited social support and was not viewed as a substitute for physiotherapy.
Smith et al [29]			
This was a service evaluation which implemented semi-structured interviews to capture the experiences and impact of the programme on participants.	Six people with stroke participated. Four were ambulant and two were wheelchair users. The age range was 52-72 years.	The programme was based on the ARNI approach and comprised weekly group sessions for 6 weeks plus monthly follow up. Sessions were in a leisure centre and led by ARNI instructors.	Multiple data categories were identified including impact on mobility, activities and future goals. The authors concluded that the group setting generated peer support and that the ARNI intervention re-introduced experimentation following stroke.

Table 2: See separate attachment

Table 3: Analytical themes and illustrative quotes

Theme	Participant Quotes	Author interpretation
<p>Analytical theme 1: “Training principles as a foundation for programme design.”</p>	<p>“I’m finding I can stand up now without having to push myself up on my hands. I’m doing that more often. I’ve even tried a couple of times from the settee, which is low down, and I’ve done it” [29].</p> <p>“Challenging, I found it was very challenging, just the first day when we had to sort of actually walk on a mat without a stick...I felt that was really challenging...but also encouraging, to do more than I thought I could” [8].</p> <p>“Once they’ve assessed you, you’ve got this key you put in the machine, it tells you how long you’ve got to do and everything. With a computer you don’t need an instructor” [28].</p>	<p>All participants had experimented with attempting new things, and tasks they thought they could not do. Participation in the ARNI programme had re-introduced experimentation which is likely to have increased confidence [29].</p> <p>The training was described as a physical challenge both in its intensity but also the activities undertaken in the programme [8].</p> <p>Some participants viewed the focus of gyms to be on fitness rather than rehabilitation and whatever they did in the gym would not further their functional ability [28].</p>
<p>Analytical theme 2: “I’m not just a stroke patient anymore”</p>	<p>“The fact that I could contribute and I still had something to give, I wouldn’t say to society. But I wasn’t just a has-been. When you do come home from having stroke you do feel that you are a has-been” [25].</p> <p>“Whatever you do don’t medicalise it .. I think one of the key benefits of this is that it’s not another bloody appointment. You know it’s not the hospital ... it’s also a community facility .. it</p>	<p>The post stroke self was portrayed as fragile. Lack of confidence and purpose and perceptions of how people viewed them post stroke made it easy for participants to retreat into “safe environments” [25].</p> <p>There was a sentiment that the individuals’ capacity had been artificially limited and that was now being tested. Implicit in many of these comments was</p>

	<p>introduces you and makes other things accessible" [8].</p> <p>"Because when I do exercise, when I go out, it puts me back to normal. And when I see others walking, what would make me not walk? I am not disabled. The stroke has not made me disabled, so I walk" [27].</p>	<p>the idea that the individual had been challenged to reconceive their own possibilities [8].</p> <p>The ERS facilitated increases in activity levels within sessions, and outside the ERS. Increased activity generated feelings of normality and independence [27].</p>
<p>Analytical theme 3: "Restoration of an internal locus of control"</p>	<p>"I felt very proud of myself at that stage because I'd been so much and I'd been, I suppose you'd call it brave but that's being big-headed. But brave as in I've not let it beat me" [25].</p> <p>"I started work and I was able to start where I left off...and if I had not gone through this I would not have had the confidence....it is not the medication that has made me better, it is the exercise" [27].</p>	<p>Stroke survivors wish to continue to work towards reconstructing their lives post-stroke. In order to do this they need internal resources of confidence and sense of purpose, to 'create their social self', external resources in the form of 'responsive services'; and an 'informal support network', to support and encourage the development of their internal resources [25].</p> <p>Locus of control appeared to shift from predominantly external during rehabilitation, to more internal during ERS [27].</p>

