

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

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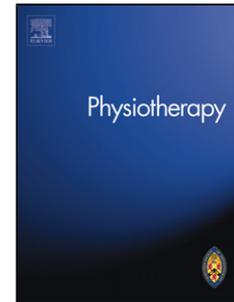
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Experiences of venue based exercise interventions for people with stroke in the UK: a systematic review and thematic synthesis of qualitative research

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Abstract

Background

The physical benefits of exercise following stroke are research evidenced and the UK stroke population is increasingly encouraged to engage with exercise interventions. A synthesis of

qualitative research is required to further understand the perceived experience and psychosocial effect of exercise for people with stroke.

Objectives

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

Data sources

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

Study eligibility criteria

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

Study synthesis and appraisal

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

Results

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

Limitations

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

Conclusion

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

Systematic review registration number: Prospero 2017:CRD42017072483

Contribution of paper

- 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

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

Background

There are 1.2 million people with stroke in the UK and it is a leading cause of disability [1]. Between 2014 and 2017 there was a 2.9% increase in incidence of reported stroke and an 11.8% increase in the 50-59 year-old group [2]. **The effectiveness of aerobic, strength or combined training** interventions to optimise outcome following stroke are increasingly recognised [3]. Exercise following stroke leads to reduced physiological risk factors, improved physical function and mobility [4, 5]. Significant improvements in quality of life associated with exercise participation following stroke are reported [6] and qualitative data related to the effect of exercise following stroke suggest that participants perceive improvements in physical function, participation and psychosocial wellbeing [7,8].

Engagement with exercise amongst the UK stroke population does not meet published recommendations [9,10]. It is recommended that people in the UK with stroke or Transient Ischaemic Attack (TIA) should be supported in accessing exercise opportunities to improve fitness which is individualised and targets personal goals [11]. **Exercise interventions can be delivered and sustained in the home environment but adherence does decline without the added support of venue based sessions [12].** There are various models of **venue based** exercise programme for people with stroke in the UK, including the national Exercise Referral Scheme (ERS) **and these represent the advantage of equipment and space required for progressive strength and aerobic training [13].**

ERS participants from a range of diagnostic groups report improved mental wellbeing and increased personal autonomy associated with being part of a gym based programme [14]. However, there are also reports of ERS participants feeling intimidated in the traditional gym environment and long- term adherence to exercise referral programmes is less than 50% [14]. The transition from physiotherapy led stroke rehabilitation to exercise programmes supervised

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

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

Aim

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

Methods

Definition of a **venue- based exercise intervention**

Preliminary scoping work facilitated the definition of the exercise intervention. For the purpose of this systematic review a **venue- based** exercise intervention was defined as a programme based outside the individuals place of residency, delivered by a physiotherapist, exercise instructor or exercise professional. It was determined that the model of programme delivery could be in the form of a group or individual activity and the intervention should include elements of **aerobic, strength or combined** training to align with conventional components of an exercise intervention.

Review methodology

A thematic synthesis of included research was selected as it comprises the identification of the main and recurrent themes arising within a body of evidence [19]. This technique facilitates the organisation of qualitative data from selected studies and generates a summary of findings, whilst preserving the essential context of qualitative research [20]. **Thematic synthesis represents a process for identifying, grouping and summarising qualitative findings with lower risk of bias than associated with narrative synthesis methods [19].** The ENTREQ framework was used to guide the reporting of findings from the review [21]. The methods are described in detail in the protocol that was developed and registered on the PROSPERO database (Prospero 2017:CRD42017072483).

Literature Search strategy

A comprehensive search was conducted between August and December 2017. The following databases were accessed: Medline, Cinahl, AMED, PsycINFO, SportDiscus, Proquest and ETHOS. Reference lists of selected articles were hand searched and authors were contacted in case of further publications. The grey literature search extended to contact with known researchers in the field. **This generated contact with specific leisure service providers known to have reported on exercise interventions for people with stroke.** Search terms included stroke, cerebrovascular accident, exercise, physical activity, exercise referral, qualitative, interview, perspective, focus group and opinion. Keyword and MeSH terms were integrated in the search process, the controlled search term strategy search can be accessed in supplementary materials (Table SM1). In order to ensure currency of findings the search was limited to studies published from 2000. The search was led by the principal investigator (RY) with guidance from the information scientists at Sheffield Hallam University. The search process was summarised in a Prisma flowchart (Figure 1).

Eligibility criteria

The scope of the review was limited to the UK due to global variation in stroke service delivery [22] and to contribute towards the evidence base on exercise uptake amongst clinical populations in the UK [13]. The inclusion criteria were: (1) studies which had recruited community dwelling people with diagnosis of stroke or transient ischaemic attack (TIA), (2) studies which had evaluated the impact of a venue based exercise programme located in a leisure, health centre or outpatient venue, (3) studies which had incorporated qualitative data collection methods, (4) studies which had adhered to a recognised research or service evaluation protocol.

The aim was to maintain a focus upon the experiences of venue centred exercise. Therefore, the following exclusion criteria was applied; (1) studies which evaluated inpatient programmes or exercise interventions delivered at the participant's home or place of residency, (2) studies which evaluated specialist rehabilitative technology, (3) studies focussed on gaming interventions or specific therapeutic approaches, (4) studies which included participants without a diagnosis of stroke or TIA.

Two reviewers (RY, KC) independently screened titles and abstracts to identify relevant studies which met the inclusion criteria for full text screening. Uncertainty regarding suitability for inclusion of selected publications was resolved through discussion with two other members of the review team (CS, DB).

Quality assessment

The consolidated criteria for reporting qualitative research (COREQ) was used to facilitate an explicit and comprehensive evaluation of study quality [23]. The COREQ comprises a checklist devised to identify opportunities for bias, is well suited for focus group or interview data collection methods and more sensitive than alternative quality assessment tools [24]. Two

members of the review team (RY, KC) independently applied the 32- point criteria which evaluate the reporting related to research team, study design, analysis and findings. Since this review adhered to a thematic methodology, the quality assessment was used to inform the findings of the review and identify recommendations for future research. No publications were excluded due to methodological limitations.

Data extraction

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

Data synthesis

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

Results

Study selection

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

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

Figure 1: Prisma flow chart

Table 1: Summary of included studies

Quality assessment and sensitivity analysis

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

Table 2: COREQ criteria**Data analysis**

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

Figure 2: Coding tree**Descriptive themes****1. Sustained behaviours**

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

2. Psychosocial impact

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

3. Physical impact

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

4. Influence of group

The influence of the group and impact of peer support was a major recurrent theme. Participants shared that they had compared themselves to other people with stroke [18,25,26,27]. Downward comparison with other group members was reported by Hillsden et al [26], this was mostly alongside people with a cardiac diagnosis which was perceived as more serious than minor stroke or TIA. Those studies which had collected data from stroke specific exercise programmes reported high levels of mutual encouragement and group support between participants [8,25,28,29]. In contrast, participants recruited from the standard

ERS described by Wiles et al [28] commented on limited opportunity to meet with or speak to other people within the gym setting.

5. Programme design

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

6. Comparison with healthcare services

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

Analytical themes

Three analytical themes evolved from in-depth analysis of the descriptive themes; these are summarised alongside illustrative quotes in table 3.

1. “Training principles as a foundation for programme design”

Training principles including specificity, overload and progression were implicit in the views shared by participants. Specificity of training response is identified as those interventions which focussed on functional mobility [8,29] triggered perceived improvements in balance and walking ability. The interventions which had emphasised conventional aerobic and resistance training activities [27,28,30] were associated with changes in physical performance, for example, improved strength and stamina. In alignment with the principles of overload and progression, the programmes were recalled as challenging; participants were encouraged to push their physical boundaries and progress during the course of the intervention. Participants enjoyed being challenged in a “place of work” and the perceived intensity of the intervention made the sessions worthwhile.

2. “I’m not just a stroke patient anymore”

The exercise programmes facilitated transition from being a stroke patient to a new identity as an exerciser. The participants felt that they had to do it for themselves with tapered support from the professional team. This was in contrast to the experience of health care rehabilitation in which participants had felt protected but disempowered [8,27]. The distinction between conventional rehabilitation and exercise interventions was evident across the included studies. Although perspectives regarding the respective value of fitness instruction compared to traditional physiotherapy were mixed, there was an overriding sentiment of personal achievement associated with completion of the exercise interventions. The importance of peer support in group interventions is highlighted and these findings indicate extended value generated through group interventions. Intervention delivery in de-medicalised venues

normalised the experience and participants were empowered to recover their pre-stroke identity.

3. “Restoration of an internal locus of control.”

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

Table 3: Analytical themes and illustrative quotes

Discussion

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

Training principles as a foundation for programme design

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

I'm not just a stroke patient anymore

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

Internal confidence following stroke should be facilitated by creating opportunities for positive social interaction [18] and stroke specific exercise groups emerged as the preferred model amongst the studies reviewed. The resourcing of group interventions with integrated individual support represents a challenge for leisure providers [15]; cost-benefit analysis of different exercise delivery models for people with stroke is required. The integration of people with

stroke into a cardiac rehabilitation programme appeared to generate a social dynamic of downward comparison between group participants and a higher dropout rate was recorded [26]. Cardiac rehabilitation teams report limited confidence in supporting people with stroke [16]; further training and programme adaptation is required to effectively integrate cardiac and stroke rehabilitation.

Restoration of an internal locus of control

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

Strengths and limitations of this review

This review of qualitative research included primary studies and grey literature. The application of COREQ criteria highlighted the strengths and limitations of the selected research publications. Sensitivity analysis and exclusion of inadequately reported studies from qualitative systematic reviews is debated in the literature [36]. In this review, higher rated studies generated those themes focussed on the psychological effect of the intervention [8,27].

In contrast, the lower quality publications informed development of themes which reflected the physical impact of the intervention and experience of the environment [28,29]. A potential source of bias is the geographical representation of the included samples; with one exception, [30] all of the studies were based in south England. The influence of regional demographics can have a significant bearing upon exercise beliefs and behaviours [37] and further research is required to capture the views and experiences of the UK wide stroke population.

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

Conclusion

The results of this systematic review highlight that exercise for people with stroke has a positive impact on perceived physical ability, identity and participation. Stroke specific groups engender peer support and a new social network. De-medicalised venues are associated with a positive challenge and restoration of an internal locus of control. The findings of this review suggest that people with stroke will benefit from sustained support in exercise participation and programmes adapted for all levels of physical ability should be available. Rehabilitation services need to collaborate with exercise providers to facilitate a positive transition towards long term exercise participation. Future qualitative research should focus on people who opt

out of exercise interventions following stroke and a multi- regional perspective across the UK is required in relation to this field of evidence.

Author declaration

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References

[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.
- [15] Condon M, Guidon M. A survey of exercise professionals' barriers and facilitators to working with stroke survivors. *HEALTH SOC CARE COMMUNITY* 2018;26(2):250-258.
- [16] Clague-Baker N, Robinson T, Drewry S, Hagenberg A, Singh S. Cardiac rehabilitation and stroke teams attitudes to people with stroke taking part in cardiac rehabilitation: focus group study. *Clin Rehabil* 2018;32(10):1416.

- [17] Morris JH, Oliver T, Kroll T, Joice S, Williams B Physical activity participation in community dwelling stroke survivors: synergy and dissonance between motivation and capability. A qualitative study. *Physiotherapy* 2017; 103(3):311-21.
- [18] Reed MC, Wood V, Harrington R, Paterson J. Developing stroke rehabilitation and community services: a meta-synthesis of qualitative literature. *Disabil Rehabil* 2012;34(7):553-563.
- [19] Pope C, Mays N, Popay J, Synthesizing qualitative and quantitative health evidence: A guide to methods. Open University Press; 2007.
- [20] Thomas J, Harden A. Methods for thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* 2008;8:45-59.
- [21] Tong A, Flemming K, McInnes E, Oliver S, Craig J. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol* 2012;12:181-9
- [22] Johnson W, Onuma O, Owolabi M, Sachdev S (2016) Stroke: a global response is needed. *Bull World Health Organ* 2016;94(9):633-708.
- [23] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6):349-57.
- [24] Peditto K. Reporting Qualitative Research: Standards, Challenges, and Implications for Health Design. *HEALTH ENVIRONMENTS RES DESIGN J (SAGE)* 2018;11(2):16-19.
- [25] Reed M, Harrington R, Duggan A, Wood VA. Meeting stroke survivors' perceived needs: a qualitative study of a community-based exercise and education scheme. *Clin Rehabil* 2010;24(1):16-25.
- [26] Hillsdon KM, Kersten P, Kirk HJS. A qualitative study exploring patients' experiences of standard care or cardiac rehabilitation post minor stroke and transient ischaemic attack. *Clin Rehabil* 2013;27(9):845-53.
- [27] Sharma H, Bulley C, Wijck FMJ. Experiences of an exercise referral scheme from the perspective of people with chronic stroke: a qualitative study. *Physiotherapy* 2012;98:336-43.
- [28] Wiles R, Demain S, Robison J, Kileff J, Ellis-Hill C, McPherson K. Exercise on prescription schemes for stroke patients post discharge from physiotherapy. *Disabil Rehabil* 2008;30(26):1966-75.
- [29] Smith A, Joy R, Parsons A. ARNI techniques for chronic stage of stroke in a group setting- a pilot programme research report. Central and North West London NHS Foundation Trust 2014.
- [30] Carin-Levy G, Kendall M, Young A, Mead G. The psychosocial effects of exercise and relaxation classes for persons surviving a stroke. *Can J Occup Ther* 2009; 76(2):73-80.
- [31] Ammann BC, Knols RH, Baschung P, Bie RA, Bruin ED (2014) Application of principles of exercise training in sub-acute and chronic stroke survivors: a systematic review. *BMC Neurol* 2014;14:167-78.

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

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

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

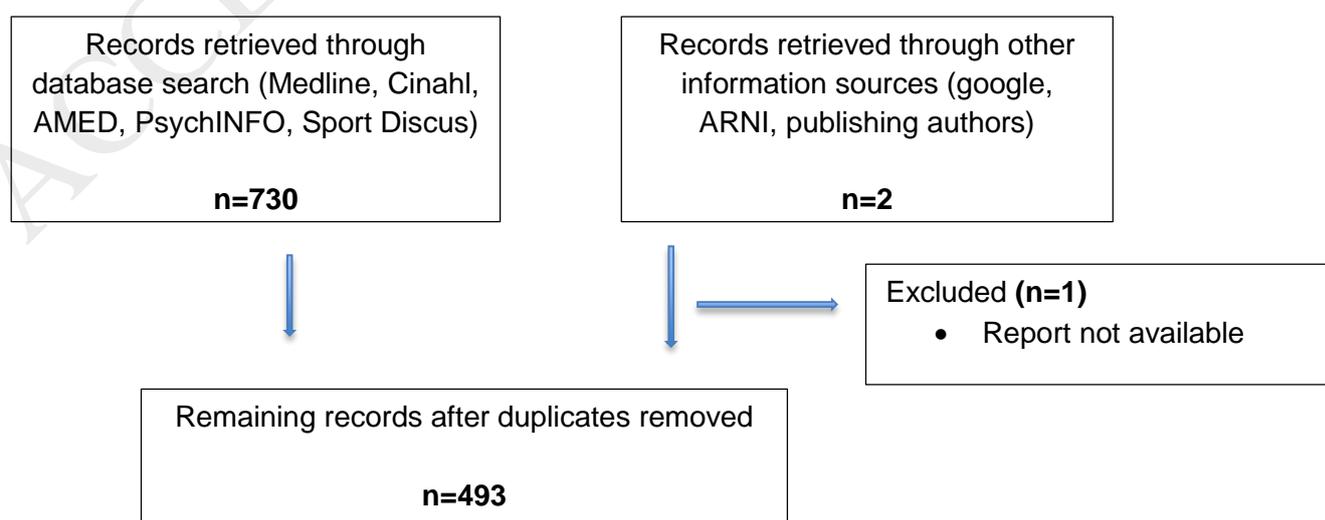
[35] Poltawski L, Boddy K, Forster A, Goodwin VA, Pavey AC, Dean S. Motivators for uptake and maintenance of exercise: perceptions of long-term stroke survivors and implications for design of exercise programmes. *Disabil Rehabil* 2015;37(9):795-801.

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

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

[38] 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.

Figure 1: Prisma Flowchart



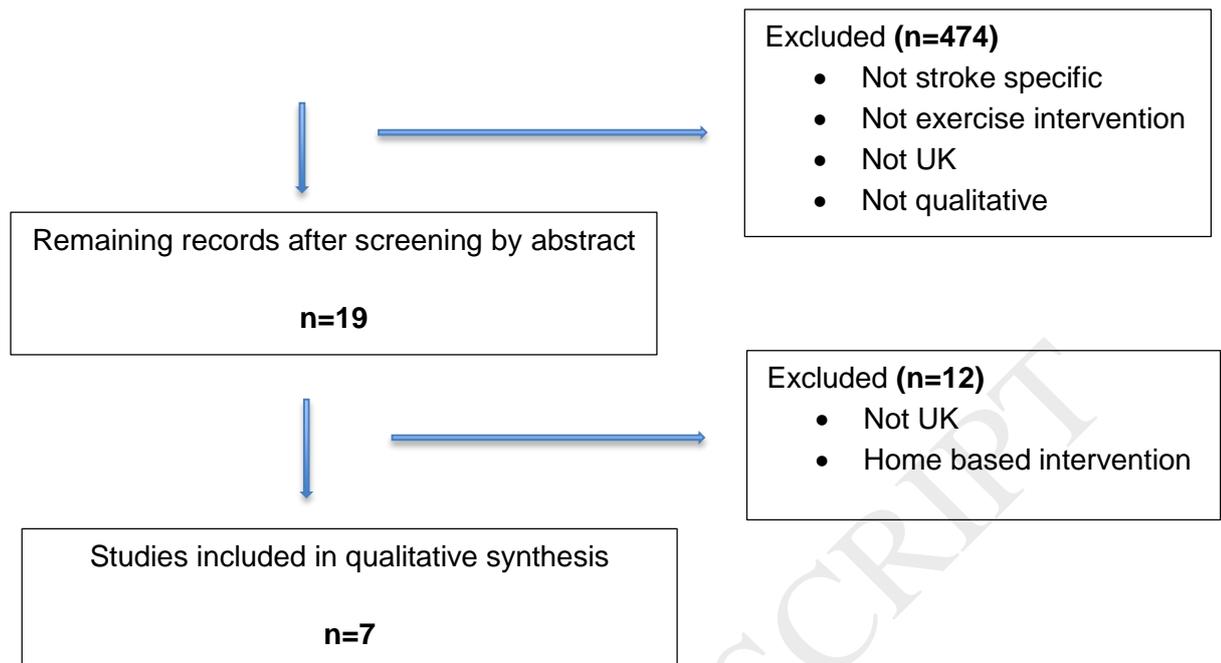


Figure 2: See separate attachment
Figure 2: Coding Tree

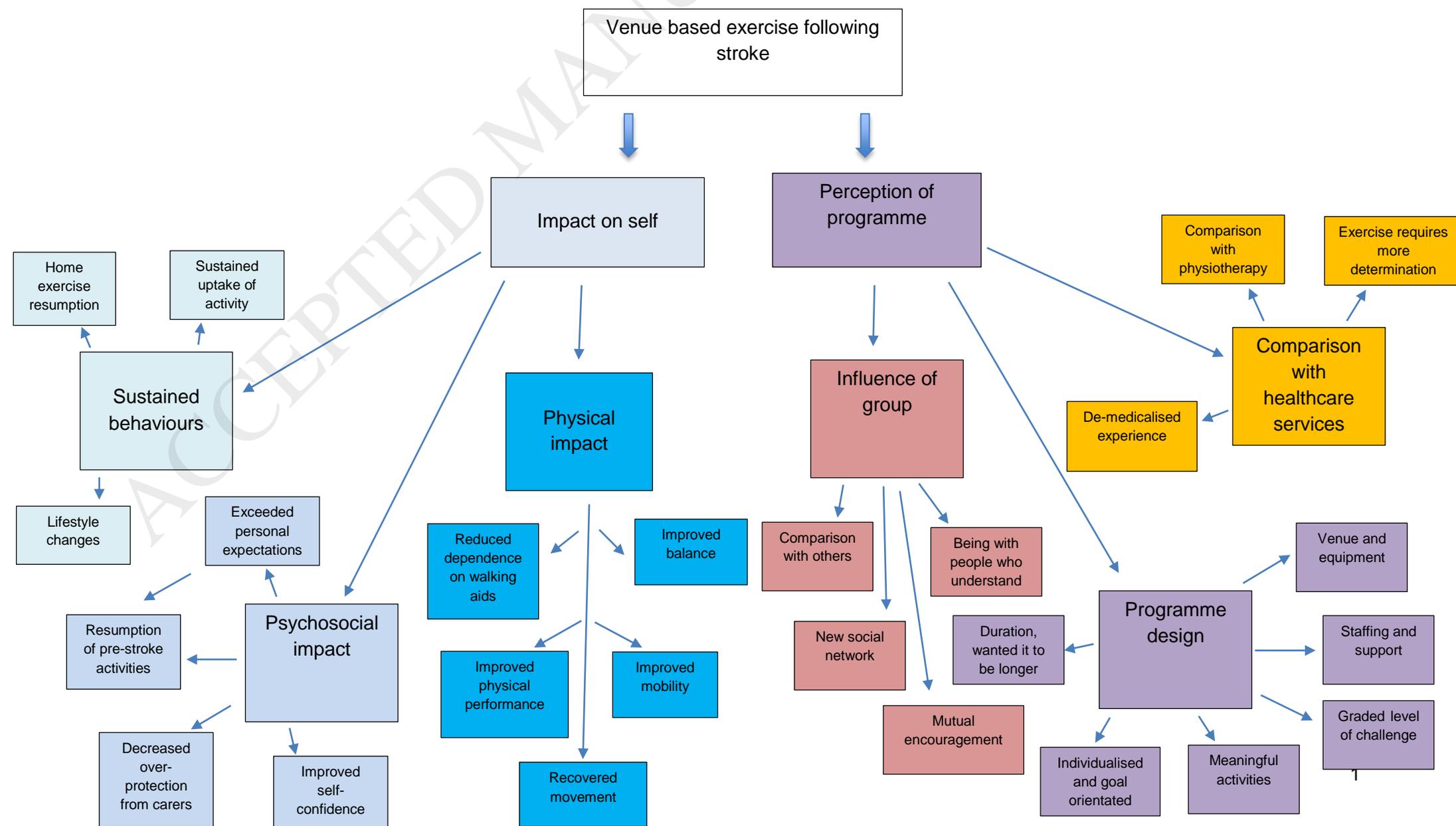


Table 1: Characteristics of included studies

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 phenomenological methodology.	Community dwelling people with primary diagnosis of stroke who had attended the ERS within previous two years. 4 females and 5 males participated in interview. Age range was 37-61 years. The physical ability of participants was not reported.	Intervention was a physiotherapy supervised neurological exercise referral scheme based at a South London leisure centre. Individually tailored gym-based exercise in group format scheduled twice per week for twelve weeks.	Four categories were identified; exercise engagement, control, confidence and improvement. An overarching master 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 2: COREQ Criteria

Domain 1: Research Team	Study						
	Carin-Levy [23]	Hillsdon [21]	Norris [8]	Reed [20]	Sharma [22]	Smith [24]	Wiles [25]
1. Interviewer/facilitator	Y	Y	Y	Y	Y	Y	N
2. Credentials	Y	N	N	N	Y	N	N
3. Occupation	Y	N	Y	N	Y	N	Y
4. Gender	Y	Y	Y	Y	Y	N	Y
5. Experience & training	N	N	Y	Y	Y	Y	N
6. Relationship established	N	N	Y	N	Y	Y	N
7. Participant knowledge of interviewer	N	N	N	N	Y	N	N
8. Interviewer characteristics	N	N	Y	N	Y	N	N
Domain 2: Study Design							
9. Methodological orientation/theory	Y	N	Y	Y	Y	N	Y
10. Sampling	Y	Y	Y	Y	Y	Y	Y
11. Method of approach	Y	N	N	N	Y	N	Y
12. Sample size	Y	Y	Y	Y	Y	Y	Y
13. Non-participation	Y	Y	Y	N	Y	Y	Y
14. Setting of data collection	Y	Y	Y	Y	Y	N	Y
15. Presence of non-participants	N	Y	Y	N	Y	N	Y
16. Description of sample	Y	Y	Y	Y	Y	Y	Y
17. Interview guide/Pilot	Y/N	Y/N	N/N	Y/Y	Y/Y	Y/N	N/N
18. Repeat interviews	N	N	N	N	N	Y	N
19. Audio/visual recording	Y	Y	Y	Y	Y	N	Y
20. Field notes	N	N	Y	Y	Y	N	N
21. Duration	N	Y	Y	Y	Y	N	Y
22. Data saturation	N	Y	N	N	Y	N	N
23. Transcripts returned	N	N	N	N	N	N	N
Domain 3: analysis and findings							
24. Number of data coders	Y	Y	Y	Y	Y	N	Y
25. Description of the coding tree	Y	Y	Y	N	Y	N	N
26. Derivation of themes	Y	Y	Y	Y	Y	Y	Y
27. Software	Y	N	Y	N	Y	N	N
28. Participant checking	N	Y	Y	N	N	N	N
29. Quotations presented	Y	Y	Y	Y	Y	Y	Y
30. Data and findings consistent	Y	Y	Y	Y	Y	Y	Y
31. Clarity of major themes	Y	Y	Y	Y	Y	Y	Y
32. Clarity of minor themes	Y	Y	Y	Y	Y	Y	Y

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 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 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 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>
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Analytical theme 3: "Restoration of an internal locus of control"	<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>
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