Exercise instructor-led functional training programme for stroke survivors in the community

Meriel Norris, Cherry Kilbride, Amir Mohagheghi, Christina Victor

Background: Action for Rehabilitation in Neurological Injury (ARNI) is a novel community-based training programme that promotes functional independence and physical fitness in stroke survivors after formal rehabilitation.

Method: We investigated the experiences of 22 stroke survivors enrolled in the 12-week programme, through their additional participation in one of four focus groups. Guidance topics informed the discussions, which were audio-recorded and transcribed. Thematic analysis was conducted by two independent researchers and consensus reached on the overarching themes.

Results: The programme was described as overwhelmingly positive, with ascribed benefits in physical, functional and social activities, leading to a reported increase in active participation in life. Key contextual factors were discussed as being critical to develop these benefits including: the balance of group and 1:1 training, the nature of challenge in the activities and the de-medicalisation of both the environment and the intervention itself.

Conclusions: Group-based ARNI was reported as having a positive impact on function and participation in life post-stroke. This study indicates a need for further examination of the objective impact of the ARNI programme.

Key words: Stroke, ARNI, Functional training, Community, Qualitative

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An estimated 300 000 people in the UK are living with moderate-to-severe disabilities post stroke (National Audit Office, 2010). The most commonly cited unmet clinical need people experience is reduced mobility (McKevitt et al., 2010). In turn, inactivity is known to be a risk factor for stroke, which leaves people who have had one stroke at greater risk of a further event (Mohan et al., 2009). However, physical training has been shown to improve cardiovascular health and results in a 25% reduction in the incidence of further stroke (Hackman and Spence, 2007).

Encouraging increased activity levels can be seen as essential for improving long-term health and wellbeing. However, stroke survivors have described community-based therapies, in particular physiotherapy, as too brief and time limited to maximise their recovery and facilitate attainment of their personal goals (Stroke Association, 2012; Winchcombe, 2012). Achieving a long-term increase in activity levels in people with stroke is challenging to those with responsibility for providing services across the health and wellbeing spectrum (Stroke Association, 2012; Winchcombe, 2012).

The literature has been reporting an increasing number of community-based exercise programmes for stroke survivors and other neurological conditions, and this is also seen in practice (Best et al., 2010; Harrington et al., 2010; Learmouth et al., 2013). Although the promotion of exercise to improve health and wellbeing post-stroke is relatively new, a developing body of evidence supports its use, despite the literature being largely confined to the more ambulant group of stroke survivors (Cramp et al., 2010; English and Hillier, 2010; Brazzelli et al., 2011).

Community exercise schemes can help improve quality of life in stroke survivors (Reed et al., 2010; Yoo and Yoo 2011; Sharma et al., 2012) and are generally perceived positively by participants, who identified benefits to both their lifestyle and general wellbeing. However, these potential gains

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require a long-term commitment to physical activity and evidence shows the level of engagement for people with stroke is largely insufficient; as such, the effect of many psychological and social factors must also be taken into consideration (Morris et al, 2012). Furthermore, it is unclear how the benefits of exercise translate to improvements in function and increased participation in everyday life post stroke (Mead and Bernhardt, 2011).

Action for Rehabilitation in Neurological Injury (ARNI) is a community-based training approach developed by a stroke survivor, which draws upon the neurological rehabilitation evidence base. ARNI aims to promote functional independence and physical activity in ambulant or wheelchair-using stroke survivors (Balchin, 2011). It is a multimodal programme that addresses a number of factors including aerobic endurance, strengthening, range of movement, balance, coordination and other aspects of sensorimotor function. The ARNI programme also places an emphasis on: psychological interventions, addressing motivation, self-efficacy, exploring attitudes and beliefs; functionally-oriented activities; problem-solving; and experientially-devised compensation strategies (Balchin, 2011). It is these latter attributes that appear to be unique to the ARNI approach and set it apart from other exercise programmes.

ARNI is aimed at those wanting to optimise recovery after cessation of usual NHS rehabilitation and is mostly delivered by exercise instructors rather than health professionals, either on a one-to-one basis or in a group format. Personal testimonies widely reported through the ARNI website (www.arni.uk.com) suggest the approach has positive benefits. Indeed, it has won an innovation award; the UK’s Acquired Brain Injury Forum First Award. Community-based exercise programmes have been commissioned by local authorities in the UK for stroke survivors, despite there currently being no published evidence into its effectiveness.

This 16-month ARNI evaluation study examines both the experiences of participants (reported here) and its efficacy (strength, static and functional balance, proprioception, gait and quality of life [Kilbride et al, unpublished observations]). As this was an evaluation study, the research team did not have any input into the design or delivery of the training programme.

METHODS

Study design
To explore the experience of participation in the ARNI programme, a qualitative approach drawing on interpretative traditions was selected as the most appropriate for this study (Finlay, 2011). The authors chose focus groups (FG) as the best method to draw upon the stroke training group participants’ experiences as FGs enable in-depth exploration of individual insights, and draw on the interaction between people who may share or differ in their experiences. This approach is particularly effective in previously-formed groups and may facilitate a greater depth of discussion than individual interviews (Morgan, 1997; Kitzinger, 2006).

Participants and recruitment
Participants for the FG were all enrolled in the ARNI programme. Prior to starting the training programme, participants were invited to volunteer for the different arms of the evaluation, including the FGs. All participants received a participant information sheet, which they were given a minimum of 24 hours prior to the FG, and they had an opportunity to ask questions prior to volunteering. All participants signed a consent form. Their inclusion or absence in the FG had no bearing on participation in the training programme and the ARNI instructor was blinded to who had volunteered to participate.

Stroke survivors were recruited to the ARNI programme on a voluntary basis through community and hospital physiotherapy services and snowballing, a technique whereby recruited participants suggests others known to them who may be suitable and interested. To be eligible to take part, participants had to:
- Be community-dwelling stroke survivors (ambulatory or wheelchair users)
- Be able to give informed consent
- Have finished formal physical rehabilitation
- Be able to follow simple instructions.

All participants received medical clearance prior to joining the group. The participants and exercise instructors were unknown to the researchers prior to the project.

Training programme
The training was a 1.5 hour weekly group-based ARNI programme that ran consecutively for 12 weeks, and was delivered by two trained instructors for a maximum of eight participants. This ratio ensured safety and maximised the opportunity for individuals to have some one-to-one time with an instructor to address personal goals (while the remaining people continued exercising as part of the group). In total, four groups completed the training programme, which took place in a newly-built leisure centre facility in West London, UK. Balchin (2011) describes the content of the ARNI programme in detail.
Data collection

Four FGs corresponding to the four completed training groups were conducted in a private room in the leisure centre complex and followed the final training session. All participants gave informed written consent. Two facilitators were present (Meriel Norris and Cherry Kilbride) undertaking the role of conversation facilitator and scribe. Both facilitators are physiotherapists with knowledge of the theoretical basis of the training programme and are experienced qualitative researchers; neither of the facilitators were ARNI trained and both were completely independent of the programme delivery.

Personal experiences of how participants understood the programme, what was good about it and what could have been improved formed the main structure of the FGs. As appropriate, the facilitator prompted additional questions to clarify the nature of that experience and whether it was shared by the group. Three participants had communication difficulties as a result of their stroke, but wanted to be included in the discussion and were important voices to capture. Following advice from a communication expert, preparatory work regarding the initial questions and communication tools was undertaken and a ‘communication buddy’ was allocated for the FG. The FGs lasted 1.5–2 hours and were audio-recorded with permission and were transcribed verbatim, managed and these themes were discussed with the wider research team to check for implicit assumptions. Participant-confirmed notes taken within the FGs, final agreed themes were also compared with the data and context. Discrepancies between the two analyses inductively by two independent researchers (Meriel Norris and Cherry Kilbride) (Braun and Clarke, 2006). This involved coding at sentence level, and developing categories and overarching themes while remaining firmly wedded to the data and context. Discrepancies between the two researchers were discussed and consensus reached. Final agreed themes were also compared with the participant-confirmed notes taken within the FGs, and these themes were discussed with the wider research team to check for implicit assumptions. The study was approved by the Brunel University Ethics Committee (RE51-09).

<table>
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<tr>
<th>Table 1. A summary of participant characteristics</th>
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<td><strong>Characteristic</strong></td>
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<td>Total participants</td>
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<tr>
<td>Gender</td>
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<td>Age: mean (range) years</td>
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<td>Time since stroke: mean (range) years</td>
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<td>Modified Rankin Scale*</td>
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* 2=mild or slight disability, able to look after self but unable to do all previous activities; 3=moderate disability, requiring some help but able to walk unassisted; 4=moderately disabled, unable to attend to own bodily needs without assistance and unable to walk unassisted

RESULTS

Thirty people across the four groups completed the ARNI training. Attendance rates at classes ranged from 75–100%. Twenty four people (16 men, 8 women) volunteered to participate for one of the four FGs: 22 people (75%) took part, with two people (33-year-old male, 69-year-old male) unable to attend on the day of the FG due to other personal commitments. The mean age of FG participants was 61 years, they were on average 3.18 years post stroke, and had a range of physical deficits with modified Rankin Scores ranging from 2–4 points (Bonita and Beaglehole, 1988). All participants were recruited from community physiotherapy and all had been recently discharged from formal physical rehabilitation (see Table 1). No details of the six patients who did not volunteer are known.

Three main themes emerged from the data. The first, ‘I never thought I’d be able to do that again’, highlighted the benefits participants ascribed to their involvement in the ARNI programme, which included both physical benefits and others within the social sphere. The second theme, ‘it challenges you’, explores how participants believed these benefits were achieved and highlighted the specific ethos of challenge within ARNI and the role of peer support in meeting this. The final theme, ‘whatever you do don’t medicalise it’, suggests that the specific location and perceived de-medicalisation of ARNI was central to its success.

Each of these themes will be presented and critically discussed with illustrative quotes from the transcripts. These are presented as individualised quotes or conversations depending on the context. Pseudonyms are used throughout.

‘I never thought I’d be able to do that again’

The positive nature of participating in the course was the densest theme, with over 60 references to ascribed benefits across the four FGs. A key component of those benefits was subjective improvements in everyday activities, such as walking, shopping and household activities,
as well as those with more personal or spiritual meaning. For example:

‘Before, I either shook hands with my left hand or I did it very shakily like this, with my right hand, and it was very hesitant. Now I shake with my right arm and, because I am a churchgoer, I can even cross myself now, which is absolutely amazing. I honestly never thought I could do that again’ (FG2, 52-year-old female).

Progress in these activities was mirrored by reported changes in muscle strength, balance, mobility and fitness. Participants commented, for example, on their increase in energy and physical capacity to complete activities such as vacuuming and gardening. However, particular emphasis was given to an increase in confidence deemed critical to the ability to resume activities and roles that had been limited since their stroke. The following excerpt comes from an interaction in the third FG between two participants (49-year-old female [Participant 1], 76-year-old male [Participant 2]), the first of whom had communication difficulties. For participant one, the increased confidence she had developed through the training programme had resulted in her returning to a loved social activity — going to the pub. Similarly, Participant 2 relates his increased confidence to his capacity to go outdoors:

Participant 1: ‘Because I got um… confidence, yeah, and everybody here.’
Facilitator: ‘You’ve gained more confidence in yourself?’
Participant 1: ‘Yeah yeah. I want to… go out you see. Right. Then I loved the pub, but I can’t go. And then right, yes you can.’
Facilitator: ‘So are you going to the pub again now?’
Participant 1: ‘Yeah.’
Participant 2: ‘Well for me, I’ve got the confidence now to walk without a stick or any support at home or in the garden, which I couldn’t do before.’
Facilitator: ‘Oh great, great.’
Participant 2: ‘That’s what I mean by creating confidence.’
Facilitator: ‘Just feel like you can go out and do it?’
Participant 1: ‘Yeah I can, I do.’

During the FGs, the participants were asked to explain how they believed the programme had influenced their confidence. The sense of being able to achieve more than they had previously believed possible was common, and was directly verbalised by seven participants and generally agreed across the groups. In FG2, for example, one participant (54-year-old female) described how she felt the ‘cap had been removed’. In FG4, the experience that the course had ‘prevented them from putting up a glass wall and ceiling’ (43-year-old female) illustrated a similar 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. Detailing how the training programme had influenced this, participants explicitly drew on the concept of challenge, which is explored in the next section.

‘It challenges you’
The sense of the challenging nature of the training programme was consistent and strongly expressed, and also broad in its influence. The training was described as a physical challenge both in its intensity but also the activities undertaken within the programme. The mix of group and one-to-one training was also deemed central to the challenge. Finally, the training programme also implicitly encouraged the participants to challenge their own long-term commitment to activity and role resumption. Each of these three themes will be explored in more detail.

Physical challenge
The 12-week training programme was described as the opposite to ‘half-baked physiotherapy’ (FG2, 52-year-old female), with sessions long enough and intense enough to create an ‘environment of work’ (FG1, 63-year-old male). One participant (FG1, 32-year-old male) described how he was ‘sweating his bottom off’ during sessions and in general this level of hard work was appreciated and deemed essential to progress. Indeed, a number of participants suggested that the sessions, while a good length, should be offered more than once a week to increase the intensity. It should be noted that three participants across two focus groups (80-year-old male, 81-year-old female, 76-year-old male) also commented that the difficulty and intensity of the activities were sometimes overwhelming. However, this had not put them off attending as they described how activities were modified to suit their individual requirements.

A key aspect highlighted by the participants was the challenging nature of the activities included in the training programme: things they may have never done before, would not have tried by themselves, or would not even have thought of doing:
'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 and then we had to get down and do things straight away, and I felt that was really challenging… but also encouraging… to find that I could do more than I thought I could' (FG2, 54-year-old female).

Overcoming these challenges was deemed key to the increase in confidence described in theme one. Participants who could now achieve the activity described how it ‘makes you more aware of what you can do’ (FG1, 63-year-old male), and gives you ‘a great sense of what can be achieved’ (FG1, 73-year-old female). Even those who were not yet successful at the activity commented on their shift from, ‘I can’t do that and then I think, well, I can do a bit of it’ (FG4, 76-year-old male).

This shift was not only encouraged through the activities themselves but also as a consequence of the structure of the training sessions.

**Structure of sessions**
The training programme was designed to include both group activities and a one-to-one focus on individual needs. The combination of this mix appeared to be critical to the capacity to develop a challenging environment. Participants who received individual attention, which was facilitated by having more than one trainer, described how their personal needs were addressed through specifically-targeted activities. This included adaptations to the group-based activities, as well as higher-level balance or specific strengthening needs. Despite this planned design, one-to-one attention was occasionally not possible due to a shortage in exercise trainer personnel. Its loss and consequent lack of specificity for individualised concerns was noted, further emphasising its importance.

However, notwithstanding the expressed desire and need for some individual attention, all the FGs were unanimous that the group itself was critical to promoting challenge in the training. Particular individuals were identified as encouraging other members to push themselves harder. Equally, observing how other members were progressing was motivating, as the following quote from FG2 illustrates:

(AQ: in the following quotes, Participant 1 and 2 are used again but for different people than these titles represented on the opposite page. To save confusion, it would be worth numbering each participant with their own number)

**Participant 1: ‘I think a group is an important part of that, because certainly we can see each other and encourage one another, which is actually what has been happening over the past 12 weeks… So I think peer group… itself I think is a good concept’ (FG2, 54-year-old female).**

**Participant 2: ‘Yeah I’ve been amazed at how much the group effort has, you know, shown me… well if they can do it, I can do it too. I would have never expected to do as much as I have’ (FG2, 52-year-old female).**

This positive impact of the group was raised by both the most physically-able members of the group but also those with higher levels of physical impairments.

**Continuing challenge of self**
A final aspect of this theme was the sense that the training programme encouraged the participants to challenge themselves outside and beyond the training programme itself. Few participants reflected on any formal process within the programme; however, all described current or planned changes in their behaviour they perceived to be a consequence of the training. The most frequently referred to was the observation that the benefits were lost if activity was not maintained. Consequently, and linked with their increase in confidence, nine of the participants had added regular physical activity sessions to their daily life. These included joining the gym, going swimming, or participating in other activity classes.

Another aspect of this theme was the addition of new, challenging goals in their lives, many of which demonstrated a return to activities and roles ceased since their stroke. Examples include one participant who was planning to go skiing for the first time since her stroke (46-year-old female). Another (32-year-old male), following the completion of the training programme, planned to volunteer in a day centre, his first job since his stroke; another (52-year-old female) had decided to train as an ARNI instructor; the youngest participant (19-year-old female), who had been living with carers since her stroke, was seeking independent accommodation; and another (73-year-old female) had recently managed to cook Christmas dinner for ten people and now independently participated in many household activities, enabling her husband’s return to work.

Despite the positivity of these participants, it is appropriate to acknowledge that other participants considered that the training programme had not been long enough for them to yet progress...
to independent activity and role resumption. Consequently, the majority of the participants recommended that the training programme had some form of continuation; examples given included a drop-in group or access to an ARNI trainer within a standard gym to ‘top-up’ when needed.

‘Whatever you do don’t medicalise it…’
In discussing the resumption of physical activities within general health-promoting centres (e.g. joining the gym and swimming), participants identified that a key benefit of the training programme had been its location outside of the medical, therapeutic and, specifically, hospital environments. This included not only the physical location, but also the de-medicalisation of both the training and the trainers.

A frequent comment across all four FGs related to the location of the programme. In the first FG, participants commented that the leisure centre environment was ‘free’, ‘open’ and ‘friendly’, but also that the environment itself was a place of physical work. This was contrasted with their experience of hospital, where they felt ‘molly-coddled’, i.e. overprotected. Likewise, FG3 participants made it clear they no longer wanted to be around ill people and that a hospital environment was inappropriate for positive thinking. FG4 participants also raised this point but extended the benefits of the community-based facility, indicating how the training programme acted as a bridge to other facilities.

Participant 1: ‘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. There is a gym just around the corner, there is a pool at the other end, and it brings you to a place where, suddenly…’ (36-year-old female).
Participant 2: ‘…It’s encouraged you to do stuff’ (81-year-old female).
Participant 1: ‘It has…’
Participant 3: ‘It has made this facility accessible to me. And it’s important that it’s in the community because it brings people that perhaps are stuck out of the community into the whole community’ (56-year-old male).

The accessibility of the facility went beyond its location and link with community health in general to very practical aspects. It was well connected by public transport, there was a large car park that was free to users, and it had a coffee area where participants would meet or carers would read and chat. Although these aspects are peripheral to the actual training, they were an integral part of the participants’ desire to regularly attend, a habit all wanted to continue at the end of the programme.

A significant factor related to this was quality of the class facilitators and their specific histories, which all FGs discussed in some detail. All of the instructors were fitness professionals and three involved in the training were also stroke survivors themselves. For some, the fact an instructor was a stroke survivor was critical. Watching them and what they had achieved acted as a motivator for participants and increased the belief that they themselves could ‘do it’ and furthered the challenge described previously. But the other trainers, despite not being stroke survivors were equally praised. As one participant described in FG2 (52-year-old female), ‘even though he hasn’t had a stroke, it’s almost as if he did’. This point was picked up by another participant (54-year-old female) who added that it is ‘more the system (ARNI) rather than the individual’, referring to the fact that the training programme was designed by a stroke survivor. As a consequence, people perceived the training to be less focused on abstract exercises and more on real-life problems they encountered. For example, one activity focused on the ability to divert people in the street effectively while maintaining balance. A participant described how her inability to divert people previously had resulted in a significant injury, others how their fear of both being knocked over and unable to get up without making a scene had led to them to avoid crowded areas. With their increased ability and confidence to manage such situations, participants described how they participate more in community life by using public transport, going to the dentist and theatre in the city, and walking the dog.

DISCUSSION
Prior to a discussion of these results, it is acknowledged that the participants in the FGs volunteered and, therefore, may not be a true reflection of all the group members. However, volunteering occurred before the start of the programme and, indeed, three participants who initially had not volunteered chose to do so as a result of their experience. It is also accepted that these are the views of a limited, albeit diverse, number of stroke survivors in a specific geographical location. Furthermore, the timing of the FG directly after the completion of the programme may have influenced the participants’ responses. Consequently, the following discussion is written with these limitations in mind.
The results of these FGs indicate that participation in the ARNI programme was a predominantly positive experience for a very diverse group of stroke survivors, including those with communication difficulties. The sessions, as described by the participants, were not just exercises undertaken in a group, with the expected and previously well-recognised benefits of improved communication, shared experience and physical improvements (Brazzelli et al, 2011), although these were all evident. Rather, additional qualities can be drawn from these accounts, which illustrate both the multimodal complexity of the intervention and the central importance of its method of delivery. Figure 1 conceptualises the relationship between the benefits that the participants both directly and indirectly ascribe to their participation, highlighted in theme one. Figure 1 also highlights the contextual aspects of the training, which were deemed to support these benefits drawn from themes two and three. The contextual factors specifically focus on the impact of peer involvement in the process as well as the subsequent de-medicalisation through the environment and the content of the programme. The benefits focus less on the specific physical improvements noted, but on their ascribed wider impact on life. Increased confidence and the promotion of personal and ambitious goals reflect the desire to take more control of future recovery, summarised here as encouraging self-management. And finally, the promotion of active citizenship reflects the wider impact on social activities and possibilities, as well as the opening of the social spaces that should be accessible to all.

A number of the contextual influences identified from the data have previously been raised in related stroke literature. For example, much has been written regarding motivation and its link with relevant or ambitious goals (Barron and Harackiewicz, 2001). Debates continue and both the efficacy and best method for goal-setting remain unclear (Sugavanam et al, 2013). However, it was apparent from these FGs that the individuals, who had all completed their formal rehabilitation, desired a focus on goals that pushed them beyond what they initially believed was achievable. While they may not have arrived at the class expect-
ing or wishing for that, all articulated the central importance of this at the end of 12 weeks and a continuation of those expectations of themselves at the end. This desire for challenge in activities post-stroke has been articulated elsewhere (Reed et al, 2010) and, on the whole, this programme appeared to deliver it, although it is noted that the balance between group and individualised training is essential.

Associated with this was the value that was perceived from both the peer leadership of the training as well as the peer support within it. The potential of both of these factors has been emphasised previously in programmes such as the Chronic Disease Self-Management Programme (Lorig et al, 1999) and also beneficial aspects of group membership (Reed et al, 2010). However, ARNI arguably takes peer support a step further as the evidence base that underpins this approach has been directly interpreted by a stroke survivor. Hence activities promoting strength, flexibility and balance have been connected with challenges faced in the real world of the stroke survivor. This experiential component, complemented by the group members and the trainers, was important in both the motivational and challenging aspects of the course, but also was attributed to expanding the potential of participation of the individual stroke survivors and problem solving in their own specific life circumstances. Pound (2011: 97) discusses the desire for interactions ‘uncluttered by the hierarchical power relationships inherent in therapy’ and the ‘fertile atmosphere’ that can be created by shared experience. Both appeared to be evident in these groups and central to promoting engagement with activities both within the programme and outside. Through re-accessing community facilities and removing the glass walls and ceilings, a bridge had been created to access resources that could support a more integrated life. Stroke survivors need and want to be enabled to be part of their community and ‘lead more autonomous lives and move on after stroke’ (Department of Health 2007: 8).

Subjectively, these classes appear to have acted as a catalyst in this process.

Previous studies on exercise referral schemes post-stroke have highlighted a similar range of ascribed benefits to those described here, such as increased confidence and the re-introduction to physical activity factors, such as peer support, have been illustrated as catalysts (Sharma et al, 2012).

The data presented in this study mirror these findings but in a more physically diverse stroke group. This study concurs that future studies should examine aspects, such as self-management and participation. However, this study further emphasises the need to explore the influence of contextual factors, such as: location; the influence of the specific trainers; and the balance between individual and group influences on training.

CONCLUSION

The results of the qualitative arm of this mixed-methods study indicate that participants perceived the ARNI approach, when delivered in a group setting, to have an important influence on life post-stroke. This includes a suitably supported level of personal challenge, which acts as a bridge when successful to encourage a return to life as an active citizen. These findings strengthen the call for community-based, user-developed/informed training programmes to support the long-term needs of stroke survivors.

However, some questions remain around the ideal delivery method, programme length, and the longevity of its impact. Additionally, accepting the subjective nature of these reported benefits, further study is warranted to understand both the intrinsic qualities of the training programme and its measurable impact on participants’ lives.

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