Development of a balance, safe mobility and falls management programme for people with Multiple Sclerosis

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Abstract

Purpose

To utilise stakeholder input to inform the structure, format and approach of a multiple sclerosis balance, safe mobility and falls management programme

Materials and Methods

Using a three-round nominal group technique, participants individually rated their agreement with 20 trigger statements, followed by a facilitated group discussion and re-rating. Three mixed groups included service users (n=15) and providers (n=19). Quantitative analysis determined agreement, whilst qualitative responses were analysed thematically.

Results

Median scores for each of the 20 trigger statements did not change significantly over sequential rounds, however deviations around the medians indicated more agreement amongst participants over time.

Key recommendations were:

Aims and approach: The programme should be tailored to the needs of people with MS. Falls and participation-based outcomes are equally important.

Structure and format: The programme should balance expected burden and anticipated benefit, moving away from models requiring weekly attendance and promoting and supporting self-efficacy.

Optimising engagement: Support to maintain engagement and intensity of practice over the long term is essential.

Sustainability: Adequate funding is necessary. Staff should have multiple sclerosis specific knowledge and experience.

Conclusions

Participants collaboratively identified critical components of a multiple sclerosis balance, safe mobility and falls management programme. They also highlighted the importance of a collaborative, user-centred, multiple sclerosis-specific approach.

206 words

Keywords:

Self-management, Multiple Sclerosis, Accidental Falls, Balance, Rehabilitation, Nominal Group Technique

Introduction

Multiple Sclerosis (MS) is a chronic, degenerative neurological condition characterised by variable motor, sensory, visual and cognitive symptoms [1]. People with MS frequently experience problems with balance and mobility, and often report falls [2]. These may lead to injury, activity curtailment and further deterioration in mobility levels [3,4], with a consequent impact on quality of life [5].

The current evidence-base to guide the development of MS falls prevention programmes is limited, although reviews suggest that programmes of gait, balance and functional training alongside safe mobility education have potential [6]. In line with studies in older people [7], evidence indicates that exercise dose and duration, and long-term adoption of safe-mobility strategies are important in achieving a positive outcome [6,8]. To succeed, it is recognised that people usually require support to develop the skills and confidence to self-manage their mobility and falls-risk effectively [9]; with studies suggesting that this support may be key to promoting uptake and adherence with programmes of this type [10,11].

Defining programme content is only one aspect of developing an intervention [12]. Optimising programme utility is also important as adherence to rehabilitation packages can be poor [13,14], particularly in interventions which include preventative and educational components [15]. Experience in older people's falls prevention services suggests a range of factors are likely to impact on the eventual programme utility [16,17]. Alongside an evaluation of the evidence base to inform content, stakeholder input is therefore critical to ensure the programme structure and format is feasible and acceptable to service users and providers.

Aims and objectives

This study aimed to explore service users' and providers' views of the most suitable methods and formats of delivery for a balance, safe mobility and falls guided self-management programme for people with MS. The specific study objectives were to determine:

1. Programme aims, outcomes and approach
2. Programme structure, format and delivery methods
3. Factors affecting participant engagement with and adherence to the programme, both over the short-term and longer term
4. Factors affecting sustainability and integration of the programme within existing service provision

Materials and Methods

The study used a consensus development approach, employing a nominal group technique (NGT) [18]. This approach uses expert input to explore opinions and evaluate consensus through sequential rating, discussion and debate focussed around a series of trigger statements [19]. Individual and group activities are employed within a structured and facilitated process [20], aiming to stimulate discussion and sharing of ideas whilst ensuring that all participants have equal representation [21]. The process generates both quantitative and qualitative data: Quantitative analysis allows the ranking to be presented back to the group after each round, so that they can consider their own response in the context of the group consensus. Qualitative analysis provides a more comprehensive explanatory account of the rationale underpinning participant responses [22]. These analyses are a central tenet of consensus development techniques [23].

Participants

Purposive sampling was used to recruit a range of people with relevant expertise, including:

- People with MS who had/ had not fallen, and who were representative of the range of disease types and severity
- Rehabilitation professionals from varied backgrounds and service delivery settings
- Service commissioners, and

- Other individuals likely to be able to contribute expertise to the group (e.g. staff running falls groups for older people).

Participants were excluded if they did not have the capacity to give informed consent, or had severe communication difficulties preventing full participation in the nominal group sessions. Participants were recruited via advertisement and targeted visits to local networks, support groups and existing services. Permission for the study to proceed was obtained following ethical review by the South West (2) NHS Research Ethics Committee (Ref 13/SW/0309).

Formation of nominal groups and sample size

Three nominal group panels were convened covering the main geographical localities of the study area (South West peninsula, United Kingdom). With a recommended group size of no more than 12 members per nominal group [24], this represented a total maximum sample size of 36 individuals.

Nominal Group Plan

The stages of the nominal group process are summarised in figure 1. Prior to the meeting all participants received briefing and training; service providers received a mailed briefing paper, whilst MS service users were invited to attend a half-day training session led by the project team alongside a facilitator from the South West Peninsula Collaboration for Leadership in Applied Health Research and Care (PenCLAHRC) Public Involvement Group.

The group meetings were convened in accessible local community venues; and scheduled to last a maximum of five hours (including two breaks). Each session was co-facilitated by the project researchers (HG or JF) and a research team member with extensive training and experience in running consensus groups (RE). A third team member acted as an observer, to make a non-attributable record of the process and dynamics relating to the consensus discussions, which were used as a reference source during analysis.

Insert figure 1 about here

Data analyses

Quantitative data analyses

1. Statement rating scores

Participants were asked to rate their response to each trigger statement (Figure 1) using a 9-point Likert scale (1=strong disagreement, 5=neutral, 9=strong agreement), with summary data of the responses presented to participants at each stage. On completion of the process, the median, inter-quartile range (IQR) and absolute range for each statement for each round was calculated.

2. Evaluation of the level of agreement between participants

For each statement, agreement between the participants was evaluated at each stage by determining the mean deviation from the median (MDM) [25,26], calculated as:

$$\frac{Sum\ of\ individual\ deviations\ from\ the\ median}{Number\ of\ participants}$$

The MDM was subsequently categorised to indicate strong, moderate or weak agreement by calculating the round one absolute MDM, which is then split into thirds [25,26].

3. Evaluation of rating scores

Wilcoxon signed-rank tests were undertaken to evaluate change in the rating scores and the MDM for each statement between the rounds. Mann-Whitney U tests were undertaken to investigate differences between the service user and provider scores at each round. Bonferroni corrections for multiple analyses were undertaken throughout, resulting in an adjusted *p* value of 0.017 [27].

Qualitative data analysis

The NGT process generated two types of qualitative data: written responses to the trigger statement questionnaires and audio transcriptions from the NGT meetings. Written responses were recorded on an excel spreadsheet at each stage, whilst group

meetings were audio recorded and fully transcribed. The two sources were checked for similarity and subsequently combined for analytical purposes in NVIVO [28,29]. Thematic analysis was undertaken using a pragmatic process of data immersion, coding and generation of categories which were developed with reference to the original aims of the study [30]. To assure that the codes were derived reliably, initial coding of the transcript from one nominal group meeting was undertaken by two independent members of the research team (HG, JF). To ensure the robustness of decisions made, as analysis continued, the inductive development of categories was discussed regularly by the team.

Development of position statement

On completion of the data analyses, results were synthesised into a position statement summarising the key recommendations. This statement was circulated to all participants, 13 of whom provided feedback (7 service users, 6 providers), which was incorporated into the final position statement. This document is available from the corresponding author on request.

Results

Participant characteristics

Thirty-nine people volunteered for the study, however five were unable to attend the nominal group meetings, leaving a total of 34 participants (Figure 2). Of these, 15 were service users and 19 service providers (Table 1).

Insert figure 2 and table 1 about here

Quantitative analyses

Statement rating scores

A summary of the results of the rating analyses for all participants is shown in Table 2. Overall, there was minimal change in the median and IQR for any of the individual

statements, with no significant difference in the scores between rounds one and three (p>0.05).

Insert table 2 about here

Analysis of agreement

There was a significant difference in the MDM between each of the rounds, with decreasing MDM values indicating an increase in the level of agreement between participants with each round of discussion and re-rating. According to the Vella [26] method of classification, final rating agreement was rated as low for 16 statements and moderate for four statements; none of the statements were ranked as having high agreement.

Scoring between participants

On average, the MS service users scored more highly (indicating a higher level of agreement with each statement) than the service providers, however, the differences in the final scores between the two types of participant were only statistically significant for two statements (statements 10 and 14). These related to the provision of exercise supervision and service funding respectively.

Qualitative analysis

The findings of the qualitative analyses are grouped according to the main aims of the study and presented below, with the collated round 3 ratings scores presented alongside where appropriate. Quotations are referenced by participant number with an accompanying brief participant description to add context.

1. *Programme aims, outcome and approach*

There was moderate agreement that the balance, safe mobility and falls programme should include both exercise and educational content (educational elements, final median 9, MDM 0.58; exercise elements final median 8, MDM 0.52). Participants recognised that these elements are included within the majority of existing falls services,

but considered that the content of a falls programme for people with MS should be different.

> People with MS have very separate needs to 'average' users of falls services (e.g. over 65's) *Falls prevention specialist physiotherapist, female (SP17)*

Service users highlighted limited availability of falls rehabilitation services for people with MS; even amongst those who described themselves as falling regularly. This experience was validated by the service providers, who commented that few people with MS were referred to existing falls programmes. There was a belief amongst service users that these generic (typically oriented towards older people) falls services did not meet their needs.

> By the nature of it it will tend to be older people who go [to the falls service], and then if you're someone young with say progressive MS, you may be grieving for your former self anyway without having it thrust in your face that you are falling around like your Gran. *Female, 35 years old, relapsing remitting MS, previously referred to a falls service (did not attend) (SU16)*

The group rating scores indicated agreement that reducing falls should be a primary goal of the programme (final median 8, MDM 0.91). However, the importance of functional outcomes was emphasised (final median 7, MDM 1.06), with discussions highlighting the need to decrease falls without compromising levels of activities and participation.

> If I was commissioning a group and everyone in the group had fallen three times before they joined and no times afterwards, but they had spent six weeks being miserable, or living lesser lives because they were taking less risks as a result, then that's not an outcome I would be particularly interested in. *Service commissioner (long term conditions), female (SP14)*

Developing self-management strategies was suggested to be an important aim for the programme. This included increasing knowledge about falls risk factors and supporting the development of coping strategies.

> Giving people the tools to take control of their condition is really important. *Community physiotherapist, female (SP16)*

2. *Programme structure and format*

The score for the statement relating to use of group sessions in the programme was neutral (final median 6, MDM 1.12), with discussions in all three NGT meetings

identifying that a variety of formats could be effective. However, groups were felt to provide important positive benefits.

> With regard to exercise groups that I've been a participant in, somehow there is some kind of, um, 'group energy' that comes about. I don't know if its competition or what it is, but there definitely is something there in the group. *Male, primary progressive MS (30+ years) (SU15)*

However, there was recognition that a variety of personal factors may affect peoples' preference for group or individual activities.

> I've got patients who have MS who will not go to groups, so it's making sure that there is something available for them…… *Neurology specialist physiotherapist, female (SP8)*

The frequency and duration of attended sessions were identified as potential issues, with participants highlighting that MS specific issues may significantly impact on participants' ability to achieve this.

> It's not a question of motivation necessarily, it's a question of falling ill in between times or having hospital appointments that clash or just life -I don't think I could guarantee I'd be there every week at the same time for 20 weeks. *Female, secondary progressive MS (20+ years) (SU10)*

The feasibility and choice of setting for programme elements which might be held away from the participant's home was the subject of significant discussion. The logistical challenges of rurality were recognised, however participants felt that living in a remote location made access 'difficult' rather than 'impossible' (final group median 5, MDM 1.30).

> I suppose there's a variation between some people who will overcome all sorts of barriers to get there because they really want to come, and other people who down the road is too far *MS specialist nurse, female (SP7)*

The need to optimise convenience for participants was emphasised, with discussions highlighting the impact of travelling distance and time on MS specific issues such as fatigue. It was suggested that the number of essential face-to-face sessions in a programme was an important consideration.

> I think if they're coming for a one-off, that's something that you can work around, but if you're coming week after week I wonder how much convenience and accessibility has a part to play. *Neurology/ general community physiotherapist, female (SP12)*

Despite the positive perceptions of group-based activities, applying learning and undertaking exercise at home was deemed essential to the programme's success, regardless of whether group sessions were included or not. Participants highlighted the challenges associated with self-management, and the need for strategies to be included to provide support and maintain motivation for this aspect of a programme.

> I don't, I don't, I need to be in a group for things to happen properly. I've tried this lots of times to do things properly; I'm thinking this all needs a group. Singly I don't know if I would bother to do it. *Female, secondary progressive MS (16+ years), falls regularly (SU10)*….

> …. I agree: In our [older people's] falls and balance group I always say, "now who's done the exercises since last week"? And I'll get about two hands out of eight…. *Falls service lead, female (SP20).* Discussion excerpt

3. Optimising engagement

The importance of sustaining a high level of engagement over a long period was widely recognised. Personal choice was perceived to be an important factor affecting engagement and adherence, however there was widespread agreement that professional input was essential to guide and support activities.

> I would like my goals to be taken into consideration, but equally I need help to identify the exercises that can help me achieve those goals. It's all very well me saying that my balance sucks, but I need someone to say why my balance sucks and what they can do about it. *Female, relapsing remitting MS (<5 years), falls regularly (SU16)*

The need for exercises to be challenging in order to be effective was recognised by both professional group members and people with MS; however, striking a balance between challenge and achievability was highlighted as a key consideration.

> It's getting the balance between, it's got to be challenging enough to actually progress balance, if it's easy you're not going to progress the balance at all; but at the other end if they're too difficult then people give up. You've got to progress, to start something easy and then move up. *Therapy assistant, female (SP10)*

It was identified that programme participants were likely to need significant encouragement and support to develop the confidence to undertake highly challenging balance exercise. Lack of confidence was recognised as a barrier to exercise alongside physical ability.

> I think sometimes you have to push yourself to know what you can and can't do physically and mentally. *Male, secondary progressive MS (11-15 years) (SU20)*……

> …You might try those [difficult] exercises with a little 'prodding'... *Female, secondary progressive MS (<5 years) (SU18)*……

> …I think I might need a little bit more than 'prodding'… *Female, secondary progressive MS (11-15 years) (SU17).* Discussion excerpt

The need for frequency of practice of both behavioural and exercise elements of a balance, safe mobility and falls programme was recognised. It was suggested that supporting participants to identify their own needs and preferences would be beneficial, whilst also being more in keeping with an ethos of self-management.

> Daily, in the form of exercises at home-if you want me to do two hours of exercise you can forget it; I have better things to do even though it may help me self-manage my condition. *Female, relapsing remitting MS (<5 years), falls regularly (SU16)*

Panel members recognised the challenge of maintaining engagement in a programme over a long period. It was proposed that ongoing engagement is likely to be dependent upon the success of integrating the exercise and educational aspects of a programme into the participant's daily lifestyle.

> I think it might be helpful if the programme incorporated [functional activities] rather than saying "try and do this certain programme at home for however long". Saying "actually, in the tasks you're undertaking at home every day, if you did it this way then actually you would be incorporating or helping to progress what you learnt". *General community physiotherapist, female (SP12)*

There was a recommendation that a balance, safe mobility and falls programme needed to include strategies to aid adherence and to help people get back on track after relapses or other issues.

> I think as well as along with the motivation… it's important to help people deal with the fact that some days and weeks they're just not going to be able to exercise, and sometimes they will have setbacks and not just giving up, but being able to come back and keep coming back. *MS specialist nurse, female (SP7)*

4. *Programme* sustainability

Long-term sustainability was considered critical. Participants identified the importance of "doing it properly or not at all" to optimise effectiveness and satisfaction for both staff and service users. Service providers consistently highlighted the difficulties associated with

current levels of service provision and funding, suggesting that meeting the demands of a new MS falls service within existing resources would be challenging

> It needs to have its own resources because you get fed up trying to run everything on a shoestring and rushing in and doing a group and then rushing off again to the next thing. *Neurology specialist physiotherapist, female (SP8)*

The leadership and facilitation role was seen as central to the long-term success of a programme. A large number of skills and attributes were identified as being necessary (figure 3), but, it was viewed as essential for the programme leader to have MS specific knowledge, regardless of professional discipline, or qualification.

Insert figure 3 about here

> It's not just that somebody is highly qualified that's important, it's that somebody has experience of and understands MS. I have had Physio from a non-neuro Physio and …it is not as effective or as enjoyable as having someone specialist looking at the way you're doing your exercises and responding to what you're doing. *Female, relapsing remitting MS (6-10 years), does not fall (SU4)*

In discussion, the participants explored the importance of leadership approach and the rapport between programme participants and the programme leader.

> I think the relationship between the therapist, the enabler, whatever we want to call this wonderful being who is leading this group, and the people of the programme is utterly paramount. Because unless that sense of trust, respect, friendliness is there, the opportunity isn't going to be exploited to the full. *Female, relapsing remitting MS (<5 years) (SU16)*

Supervision and feedback was seen as essential to encourage and maintain engagement with the programme. However, members identified that a collaborative, partnership approach was essential.

> It's a partnership, because the therapist needs to know…, then the people with MS also need to have an idea …so that they can tell the therapist when they're reaching that point. So, it's always a two-way conversation. *General community physiotherapist, female (SP19)*

Discussion

This study utilised a novel application of the nominal group technique to inform the structure, content and delivery method of a balance, safe mobility and falls guided self-

management programme for people with MS. The quantitative data indicated the strength of opinion and level of agreement relating to each of the statements, whilst the qualitative data added depth and detail. Both sources of data were valuable to inform the development of the final position statement and to identify ongoing uncertainties.

Programme aims and approach

The results indicate that reducing falls whilst maintaining or improving activity and participation in daily life should be primary aims of the programme. Work by Laybourne [31] previously highlighted the risk to activity and independence outcomes that a pure focus on falls reduction may present [32]. The findings of this study suggest that tailoring the programme to optimise balance and 'safe mobility' (as against 'falls prevention'), and integrating the content into the participants' daily lives from the outset may provide opportunities to improve engagement and adherence to the programme.

There was a recurring theme that individual responsibility and the successful utilisation of self-management approaches would impact on the success of all elements of the programme. However, the importance of providing targeted support and advice to progress activities and maintain motivation was recognised. As with other studies [33], there was widespread acknowledgement that input from programme leaders was crucial. The nature of the relationship between the programme leader and participant was felt to be critical to achieving the balance between 'expert' and 'participant'. The overall recommendation is for an approach which develops a "collaborative partnership". Other studies suggest that this approach can be challenging for the staff providing the programme, requiring a change of emphasis and approach [10].

Programme structure and format

The findings of this study are broadly in agreement with others [34], suggesting positive perceptions of group-based activities amongst many people with MS. However, studies also emphasise that there are challenges associated with solely group-based

rehabilitation programmes [35–37]. The NGT results align with this: Panel group members viewed frequent attendance as especially challenging, particularly in long-duration programmes and in rural areas. A programme with a relatively low number of group sessions, or where sessions are spread over time could be more attractive and feasible to people than a programme requiring attendance once or twice a week for a longer period. However, evaluation is essential to ensure that a balance is struck between optimising feasibility and maintaining effectiveness; this has yet to be explored empirically.

Optimising engagement

Maintaining engagement in falls programmes has been cited as a key factor influencing outcome, both in the short and long-term [38]. Alongside more general challenges, people with MS may experience a range of condition-specific issues negatively impacting on longer-term adoption of exercise interventions [39]. In this NGT study, the need to structure activities so that they became habitual and integrated into daily life was emphasised, as was the importance of supporting participants to get back on track after interruptions (for example due to health issues). Different behavioural approaches utilising a range of strategies to improve or maintain engagement with general physical activity programmes have been evaluated in people with MS [40–42]. In general, participant satisfaction with the value and utility of these interventions has been high [43,44], although physical activity outcomes to date are more mixed [41,43,45–47].

Programme sustainability

These results emphasise the importance of developing an MS specific balance, safe mobility and falls guided self-management programme which is appropriately funded and yet sustainable within current models of service delivery. The qualitative findings highlight the lack of utilisation of existing falls services by participants in this study, despite over half of them reporting having fallen in the past year. Participants described a general ‘normalisation’ of falling and a lack of focus on falls during healthcare

interactions, despite recommendations that falls and balance issues should be assessed as part of the regular MS review process [48,49]. This, coupled with the perception that existing (typicaly older people's) falls services are not suitable to their needs, is likely to influence service use. In order to make the case for funding of MS specific falls services, research will be required to demonstrate the need for and value of any intervention, alongside the provision of evidence that referral into existing falls services is less effective. This has yet to be determined.

Strengths and weaknesses of this study

This study aimed to determine the most appropriate format, structure and delivery methods for balance, safe mobility and falls programme for people with MS, considering issues of sustainability, feasibility and fit with existing services. We believe the use of nominal group methodology, complemented by our approach to training users and actively supporting them throughout the process, optimised their participation, although we are not aware as to whether this has been formally evaluated in other studies. Importantly it provided a robust, reproducible process which enabled discussion and exchange of ideas between service users and providers in contrast to other studies, wherein service users and providers contributed in separate sessions [50]. Analysis of the scoring between the participants did reveal small differences between the two groups, suggesting that each has different perspective to offer.

There are limitations to this study: Despite purposive sampling, only one service commissioner and one therapy assistant were recruited, and no representatives from the voluntary sector attended the NGT meetings. We appreciate that attendance at an all-day meeting can be a challenge for many people. Use of an alternative methodology (such as a Delphi technique) could have reduced the time commitment required for participants, allowing them to make their contributions at a time and place suitable for them. In the second NGT meeting there was an imbalance between service user and

provider representation, with only two service user participants attending the session. However, the scores and recommendations from this group were not significantly different to the other two meetings where there was a more balanced spread of service users and providers. Given the nature of MS, it is likely that issues affecting attendance are highly likely to occur; therefore, in future studies we would recommend that researchers aim to recruit *at least* equal numbers of professional and service user participants to allow for such issues to arise without overly affecting group dynamics.

Of the 15 MS service users, 10 had previously been involved in falls prevention research, suggesting they had a particularly keen interest in the topic. This recruitment bias may have limited the range of viewpoints expressed which may have impacted on the discussions and resultant recommendations. Thus, it is important that the experiences of staff and service users involved in any interventions informed by this research are thoroughly evaluated to confirm the acceptability and utility of the recommendations. Caregivers/spouses were not invited to participate in this study. Given their potential role in program adoption and adherence, their views are an important perspective, however we wished to provide service users with an opportunity to express views that they may not have felt free to do should caregivers / spouses be present. Further research to explore this would be beneficial. Although the final position statement was developed in response to the data generated in the group meetings, a less than 50% response rate to the member checks could limit credibility of these recommendations. Owing to limited time, the position statement was circulated electronically, with a single reminder email sent to encourage comments. Alternative methods of communication (for example telephone follow up) could have enhanced the response rate. Finally, all the NGT meetings were undertaken in one geographical area of the United Kingdom. Future work to canvas a wider range of views and ideas, including a range of stakeholders from varied locations both within and out of the UK (for example through a Delphi study) could enhance transferability of these findings.

This study builds on previous work indicating that an MS specific programme to address balance, safe mobility and falls is required [2,6]. The findings suggest that activity and participation measures should be included as key outcomes alongside evaluation of falls rate. We have also identified potentially important elements of programme structure likely to influence the feasibility and acceptability of a programme. These include balancing expected burden and anticipated benefit for participants in the planning, delivery and format of the programme. The need for participant choice, control and independence is highlighted; however, the importance of ongoing tailored support should not be underestimated. Participants recommended that development of the programme should be done 'right or not at all', including securing appropriate funding, ensuring a fit with existing services and recognising the key role and high-level attributes required by staff providing and supporting the programme.

4656 words

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Tables

Service providers (attendees)			
	Profession	**Specialism**	**Number**
	Therapy assistant	Rehabilitation (general)	1
	Service Commissioner	Long term conditions	1*
	Specialist Nurse	MS	2
	Occupational Therapist	Community rehabilitation (general)	1
		Neuro rehabilitation	1
		Falls Service lead	2*
	Physiotherapist	Community (general)	5
		Community (neurology)	1*, 2
		Consultant neurology	1*
		Falls specialist	1
		Private (neurology)	1
MS service users (attendees)			
	Self- reported MS Classification		
		Relapsing remitting	6
		Primary progressive	2
		Secondary progressive	5
		Other/ Unknown	2
	Gender		
		Female	11
		Male	4
	Years since diagnosis		
		0-5	2
		6-10	5
		11-15	3
		16+	5
	Mobility		
		Walking unaided	7
		Walking with stick(s)/ crutches	7
		Walking with frame/ wheelchair	1
	Falls status[1]		
		⩾2 falls in past year	7
		1 fall in the past year	2
		No falls reported	6
	Previous involvement in fall prevention research[1]		
		Yes	10
		No	5
	Previous access to a fall prevention programme[1]		
		Yes	1[2]
		No	14
Non- attendees			
	Nominal Group One		
		Community physiotherapist	1
		MS service user	1
	Nominal Group Two		
		MS service users	2
	Nominal Group Three		
		Occupational therapist (falls lead)	1

[1]: Self-report; [2]: 1 person had previously been referred to a falls prevention programme but chose not to attend; * denotes service provider with managerial responsibility

Table1: Participant characteristics

Statement Number	Statement	Median scores (Interquartile range)				Absolute range				Mean deviation from the median (MDM)		
		R1	R2	R3		R1	R2	R3		R1	R2 p= 0.001[a]	R3 p= 0.01[b]
Programme outcome statements												
1	Reducing falls should be a primary goal of the programme	8 (2)	8 (2)	8 (1)		5-9	3-9	3-9		1.00	0.97	0.91**
17	Being able to see improvements in function is more important than measures of balance or falls	7 (2)	6 (2)	7 (2)		3-9	3-9	4-9		1.32	1.33	1.06
18	Daily diaries are essential to check that exercises are carried out	6 (2)	5 (2)	5 (2)		2-9	1-9	2-9		1.36	1.64	1.52
19	Programme leaders should regularly discuss progress with individual participants	8 (2)	8.5 (1)	8 (1)		5-9	5-9	5-9		0.94	0.76	0.76**
Programme structure and format statements												
2	People with MS should be given specific exercises to carry out to improve balance	8 (1)	8 (1)	8 (0)		4-9	6-9	6-9		0.85	0.62	0.52**
3	Advice to help people cope with falls should be a key part of any falls programme	9 (1)	9 (1)	9 (1)		6-9	7-9	7-9		0.47	0.50	0.58**
4	Exercise is more effective when carried out in a group	6.5 (3)	6 (2.75)	6 (2)		3-9	3-9	4-9		1.50	1.44	1.12
8	People should be able to access the falls programme without having to be referred	8 (2)	8 (2)	8 (2)		4-9	5-9	3-9		1.19	0.94	1.06
9	Any sessions outside the home should be organised in a hospital setting	2 (2)	2 (2.75)	2 (2)		1-9	1-9	1-9		1.42	1.35	1.36
10	Exercise should always be supervised	5 (3)	5 (3)	5 (3)		1-9	1-9	1-9		1.79	1.79	1.67

Statement Number	Statement	Median scores (Interquartile range)				Absolute range				Mean deviation from the median (MDM)		
		R1	R2	R3		R1	R2	R3		R1	R2 p= 0.001[a]	R3 p= 0.01[b]
16	Living in a remote location means that taking part in a programme away from home is impossible	5 (3)	5 (2)	5 (2)		1-8	1-9	2-9		1.56	1.41	1.30
Optimising engagement statements												
5	Exercises should be done on a daily basis	7.5 (2.75)	7 (2)	7 (2)		2-9	2-9	2-9		1.53	1.32	1.24
6	Exercising for an hour at a time is unrealistic	6.5 (3)	6 (3)	6 (2)		1-9	2-9	2-9		1.68	1.55	1.33
7	Participants should be able to choose the types of exercise in their falls programme	7 (2)	5 (2)	6 (2)		2-9	3-8	2-9		1.50	1.15	1.24
11	It is unreasonable to expect people with MS to do balance exercises that are difficult for them	4 (4)	4 (2.75)	4 (2)		1-9	1-8	1-8		1.97	1.56	1.48
20	It is unrealistic to expect people to undertake a falls programme for 3-6 months	3 (2)	3 (2)	3 (2)		1-9	1-9	1-9		1.53	1.38	1.30
Programme sustainability statements												
12	The role of the programme leader should be to push participants to their limits	5 (3)	5 (1)	6 (2)		1-8	1-7	2-8		1.55	1.38	1.12
13	Programme leaders must have formal qualifications	7.5 (3)	8 (3)	7 (3)		3-9	3-9	4-9		1.56	1.41	1.21
14	A falls programme should be provided within existing resources	5 (3)	5 (3)	5 (3)		1-9	1-9	1-9		1.88	1.82	1.70
15	It is reasonable to ask participants to pay a contribution to the cost of any attended sessions	5 (1.75)	5 (1)	5 (2)		1-8	1-8	2-8		1.00	0.91	1.00

R1: round 1; R2: round 2; R3: round 3.

Likert scoring ranges: Scores of 1-3: Disagree; Scores of 4-6: Neutral; Scores of 7-9: Agree;

MDM scoring: lower MDM indicates greater agreement *p*= significance using Wilcoxon signed-rank test*; a:* comparison between R1 and R2*; b:* comparison between R2 and R3; Classification (Vella et al)[26]: Low agreement: MDM ≥0.93; Moderate agreement: MDM 0.47-0.92**; High agreement: MDM ≤0.46

Table 2: Nominal group rating results (all participants)

1

STATEMENT	1	2	3	4	5	6	7	8	9	10
All participants median (IQR)	8 (1)	8 (0)	9 (1)	6 (2)	7 (2)	6 (2)	6 (2)	8 (2)	2 (2)	5 (3)
Service Provider Median (IQR)	7.5 (1)	8 (1)	9 (1)	6 (2)	6 (1.75)	5.5 (2)	6 (2)	9 (2)	2 (2)	4 (2.75)
MS service user Median (IQR)	8 (2)	8 (1)	9 (1)	7 (1.75)	7 (2)	6 (2)	6 (1)	8 (2)	2 (2.5)	6 (3)
p	0.25	0.07	0.97	0.40	0.10	0.38	0.69	0.76	0.37	0.01*

STATEMENT	11	12	13	14	15	16	17	18	19	20
All participants median (IQR)	4 (2)	6 (2)	7 (3)	5 (3)	5 (2)	5 (2)	7 (2)	5 (2)	8 (1)	3 (2)
Service Provider Median (IQR)	4 (2.5)	6 (1.75)	7.5 (2.75)	3.5 (2.75)	5 (1)	4.5 (2.75)	7 (1.75)	5 (2.5)	8 (1)	3 (1.75)
MS service user Median (IQR)	4 (3.5)	6 (2)	7 (1.5)	5 (2)	5 (2)	5 (2.5)	7 (2)	6 (2.5)	8 (1.5)	3 (2)
p	0.33	0.88	0.56	0.01*	0.83	0.12	0.28	0.11	0.81	0.86

IQR: inter-quartile range; *= *p*=>0.017 using Mann-Whitney U test;

Table 3: Comparison of final round scoring between service providers and MS service users

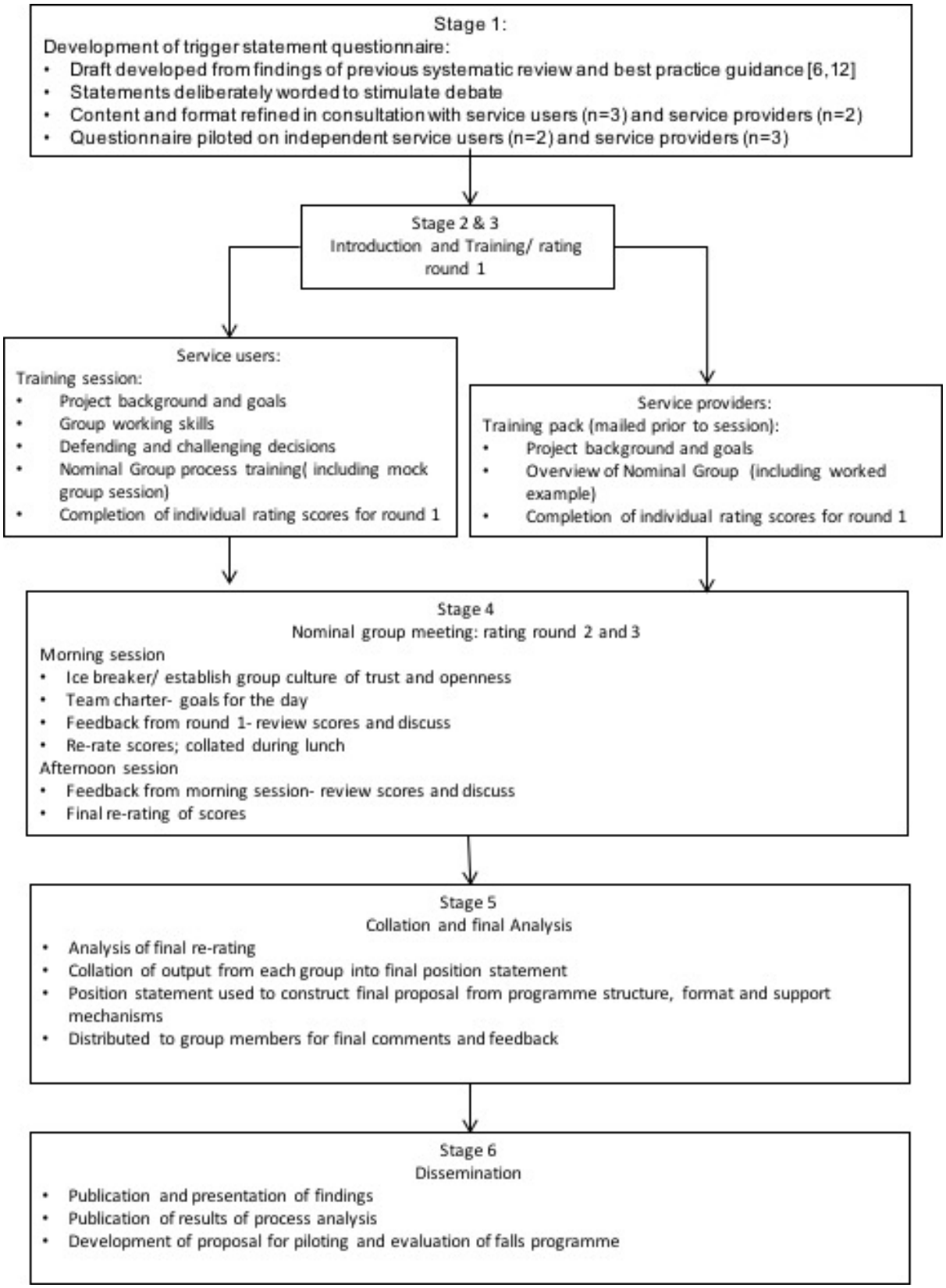
Figure Legends

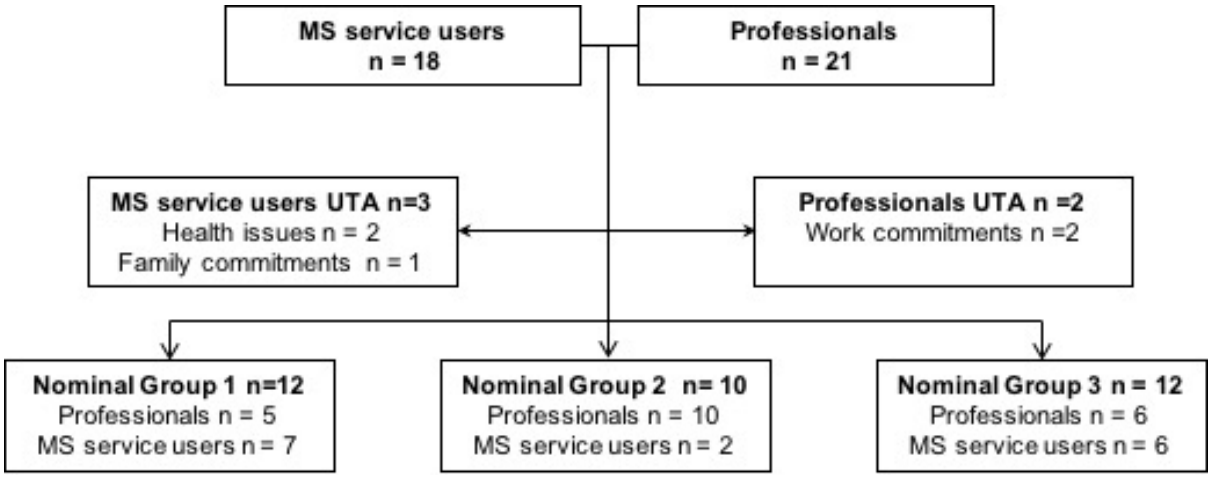
Figure 1: Nominal Group stages

UTA: unable to attend

Figure 2: Participant flow chart

Figure 3: Summary of leadership skills and attributes identified within the NGT meetings


Stage 1:
Development of trigger statement questionnaire:
• Draft developed from findings of previous systematic review and best practice guidance [6,12]
• Statements deliberately worded to stimulate debate
• Content and format refined in consultation with service users (n=3) and service providers (n=2)
• Questionnaire piloted on independent service users (n=2) and service providers (n=3)
Stage 2 & 3
Introduction and Training/ rating round 1
Service users:
Training session:
• Project background and goals
• Group working skills
• Defending and challenging decisions
• Nominal Group process training(including mock group session)
• Completion of individual rating scores for round 1
Service providers:
Training pack (mailed prior to session):
• Project background and goals
• Overview of Nominal Group (including worked example)
• Completion of individual rating scores for round 1
Stage 4
Nominal group meeting: rating round 2 and 3
Morning session
• Ice breaker/ establish group culture of trust and openness
• Team charter- goals for the day
• Feedback from round 1- review scores and discuss
• Re-rate scores; collated during lunch
Afternoon session
• Feedback from morning session- review scores and discuss
• Final re-rating of scores
Stage 5
Collation and final Analysis
• Analysis of final re-rating
• Collation of output from each group into final position statement
• Position statement used to construct final proposal from programme structure, format and support mechanisms
• Distributed to group members for final comments and feedback
Stage 6
Dissemination
• Publication and presentation of findings
• Publication of results of process analysis
• Development of proposal for piloting and evaluation of falls programme


MS service users
n = 18
Professionals
n = 21
MS service users UTA n=3
Health issues n = 2
Family commitments n = 1
Professionals UTA n =2
Work commitments n =2
Nominal Group 1 n=12
Professionals n = 5
MS service users n = 7
Nominal Group 2 n= 10
Professionals n = 10
MS service users n = 2
Nominal Group 3 n = 12
Professionals n = 6
MS service users n = 6


Make sessions enjoyable
Facilitating Not instructing
Professionalism
Aspirational
Attributes
Motivation & Challenge
Empathy & Understanding
Encouraging
Ability to manage complexity


Verbal & non-verbal communication
Risk assessment/ management
Assessment
First Aid & Basic Life Support
Knowledge & Skills
MS specific Knowledge & Experience
Group work
Exercise Prescription & Progression
Listening