



Outcomes and Recommendations from VIOLET Stakeholder Panel Focus Groups.

Visually Impaired OLder people's Exercise programme for
falls prevenTion: a feasibility study

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1.

2. Introduction.

To maximise the feasibility and acceptability of adapting the FaME (Falls Management Exercise) intervention for older people with visual impairment (OPVI) we conducted focus groups at both intervention sites. The rationale for doing this has been rehearsed at length in our study protocol so we will only briefly summarise it here. FaME is a group based exercise programme which has shown benefit in decreasing falls and increasing confidence and ability to handle falls. To date the intervention has not been systematically tested in OPVIs and as such we have no clear idea of if and how it would need to be adapted to allow OPVIs to benefit from it. Therefore prior to conducting a multi-site randomised trial of this intervention in OPVIs, we sought the opinion of this group on what adaptations, if any, would maximize the chances of their enrolment and adherence to the FaME programme.

3. Procedure

Participants

We conducted groups at both Newcastle and Glasgow sites. Participants were accessed through Visibility in Glasgow and through Newcastle Society for Blind People (NSBP). They were informed about the project through advertising internal to both organisations. In Glasgow 9 participants took part in the first group and 8 of the same participants attended the second group. In Newcastle 5 people attended the first group with 4 of the same participants attending the second in addition to 1 new person. Groups were co-facilitated by Vincent Deary and Dawn Skelton with the presence of other members of the VIOLET team: Cathy Bailey and Dot Coe at the Newcastle meetings and Dot Coe at both the Newcastle and Glasgow meetings. Bill Norman, from NSBP attended the Newcastle meetings and Shelagh Palmer from Visibility attended the Glasgow meetings.

Structure and Focus Prompts

We ran two successive groups at both sites and attempted to keep the same participants for both groups. The overall focus of the first group was *how should the FaME protocol be adapted so that OPVIs might best be enabled to participate*. The overall focus of the second group was *How do the outcome measures and trial participation/data collection procedures need to be adapted to maximise participation/minimise participant burden for OPVIs*.

Both groups opened with a statement of the aims and purposes of the group by Vincent Deary, and verbal consent for participation and recording of the session was elicited, with all members agreeing to take part and be recorded. The structure of the groups was the same for both sites. Groups lasted for approximately two hours with a tea and sandwich break for about 15 minutes in the middle.

The first group, on adapting the intervention, opened with a general discussion in which participants were invited to talk about their experience of, and opinions around, falls and falling. This was facilitated by Vincent Deary. Dawn Skelton then introduced the FaME intervention and verbally described the protocol, piece by piece, in some detail. There were large print excerpts from FaME materials available, though most people were happy with the verbal descriptions. Next Dawn and Vincent facilitated a discussion of how it could be adapted. Finally Dawn invited participants to try some of the exercises and sought feedback on acceptability and potential adaptations.

The second group was focussed on the outcome measures and trial data collection procedures. Consent was sought and given as in Group 1. The one new participant in Newcastle was filled in on the background to the study and consented to take part. We began by describing the purpose of the outcome measures and then worked through the proposed measures pack, reading the introductions to questionnaires and sample questions. We also sought feedback on the ideal mode of presentation and collection of data. Next we asked if there were any significant aspects of meaningful outcomes that we were missing. We ended the groups by thanking the participants.

4. Outcome of Groups

Overall the groups were lively, interactive and every participant was given a chance to have their say. Facilitators needed to do little more than present the focus prompts and discussion ensued. We encouraged a “one at a time” convention, and on every major topic did a “group round” to make sure everybody’s voice was heard. Similar issues emerged in both groups and below we will summarise the main themes taken from notes made by Vincent Deary, Dawn Skelton and Dot Coe during and after both Newcastle and Glasgow meetings, and from Bill Norman during and after the Newcastle meetings.

1. Focus Group One: Adapting FaME

5. 1.1 *Experience of Falls*

As one participant put it, daily life “is a pilgrimage into the unknown” for people with visual impairment. There was a general agreement that falls and fear of falling were significant issues for this group. Fear of falling was particularly an issue when people were outside their home and in unfamiliar environments. Main areas of concern were street furniture; the state of repair of roads and pavements; steps (on and off, up and down) and unclear or confusing signposting of step edges (leading edges demarcated, last/first step identified). Public transport was a significant issue for all participants, particularly getting on and off and the wheelchair/pushchair friendly, but OPVI “unfriendly”, expanded atriums of newer buses (too large an open space with fewer handholds). People also remarked upon the often unhelpful behaviour of drivers (accelerating before OPVIs seated, not informing them of stops). It was also remarked that being visually impaired was for many an “invisible” impairment for those who are not identifiable by members of the public as visually impaired (i.e. if they don’t have a cane or guide dog) and that other pedestrian/pavement users can cause problems. Pain, distraction, over-caution, and poor lighting were other issues people mentioned as increasing the likelihood of falls, trips and fear of same.

Most participants when directly questioned had fallen. One important theme to emerge from this was the “near miss”. If we define fall (as we did for these groups) as an involuntary ending-up-on-the-ground then whilst full on falls were relatively rare, slips and trips, where OPVIs had come close to ending up on the ground but had corrected themselves, or been prevented from falling by another person, were quite common. These were thought to affect confidence and curtail activity just as much as a fall might. We therefore revisited this theme when we discussed Falls Diaries (see Group 2 below). So common were trip/slips that the groups talked about them as if they were to be expected, as were minor injuries, bruises and grazes. Most, falls, trips and slips had occurred outside of the home, though one participant had a significant fall in their own bathroom.

Several participants suggested that the degree of visual impairment would affect both the fear of falling and falling, and the reflection of both the participants and members of the research team was that this may a complex phenomenon to do with personal confidence (“the nature of the person” as one participant put it), length of time of visual impairment, personal coping strategies, street-wise knowledge, desire to be independent and other factors.

6. 1.2 *The Intervention*

Dawn Skelton took participants through the FaME intervention. Overall, there was almost universal enthusiasm for it and for its potential to increase strength, balance and confidence.

Participants readily related to the idea of not just falls prevention but also “falling better” as relayed by Dawn, and liked the idea, particularly in Glasgow, of being trained to “get off the floor”. There was more expressed anxiety about learning to do this, by “getting down on the floor” during FaME classes, in the Newcastle group, as it was their perception that once you were down it was hard to get up. When it was explained to them that this was precisely why floor exercises were practiced, and how this was done in a graded manner at their own pace, their anxieties were mollified. More specific points are described below.

Group Size and Structure. Most people wanted smaller groups, of 8 max, with 6-8 being the commonest expressed preference. This was mostly to do with feeling confident that the instructor was able to keep an eye on them and in order to get to know everyone well, by voice if necessary.

Music/Lighting. Most felt no music. There was some discussion about lighting and glare, but no consensus, with some preferring dim, others good/strong lighting. There was discussion of “glare” glasses being available and it was emphasised that instructors needed to ensure that people were asked about the lighting on the day and whether people need to be in a different part of the room and/or needed use of aids.

Carer/friend/family member. Participants wanted choice as to whether they brought someone else along to the sessions, particularly at first.

Social Element. There was a strong and universal preference for a social element to be part of the group and for people to have time to get to know each other (and the instructor). In Newcastle, participants thought this could happen both before and after the group. In Glasgow there was a preference to get “business” out of the way first and to socialise after the FaME class. There was a suggestion of running the session twice a week at first to get bonding going. People were also keen that there was some ongoing structure after the groups were finished, by way of a peer support group.

Venue. There was a strong and universal preference that the venue should be somewhere familiar or at the very least that participants had a chance to familiarize themselves with a new beforehand, and that the venue needed to be fully accessible. There was a strong preference for the groups to be based in the NSBP and Visibility premises, as both premises and the routes to them were familiar.

Home exercise. Most felt they would *not* do 2 lots of one hour home exercise a week (as per FaME protocol). Some suggested they might reach that if instead it was pitched at 20 minutes a day, or two lots of 10 minutes; and everybody wanted a choice. Some people liked the idea of

some kind of prompt to remind them to exercise, either self-generated or from the FAME team. Some wanted the exercises to be integrated into their everyday tasks and some suggested having a home visit to work through where in their home some of the exercises could become habit. Some were concerned that too many home exercises would be hard to remember and liked the idea of just a few to concentrate on each week. There was also a preference for changing some exercises from week to week (as long as they were familiar with them from a class session) as they thought this might help motivation. Some thought they would remember the exercises, some wanted large print booklets, some wanted audio, or DVD, some thought better to record the group session (with the voice of the instructor) so as to replay at home. Overall people wanted personal choice.

Transport to sessions. If familiar with the place they felt that they might not need additional help with transport, but if unfamiliar, they felt that they might have to be supported for a few visits to get to know a new route. Paid for taxis was a popular idea.

Instructors. When we did some “sample exercises” as the end of the group it became very clear that some of the participants needed one to one support during exercise practice due to them either being totally blind and/or also being deaf. Even with less impairment, there was quite a lot of need for detailed guidance and additional reinforcement of the verbal instructions given, and all members of the research team had to “pitch in” at this point. As such there was a general feeling that more than one instructor, or additional volunteers, would be useful, and that lack of this could affect retention. Some of the OPVIs preferred to be given verbal instructions rather than being touched, others did not mind the latter. Again, they wanted to be asked. Participants thought that there had to be time and space for the instructor to really get to know the person and their particular needs (not necessarily just to do with VI), and to spend time at the start of each session re-engaging and building relationship with the participant and getting to know their current state/needs. Many have to rely purely on voice, so clear voice, good projection and a friendly manner were appreciated. It was considered vital that they had VI awareness training so they understood some of the VI specific issues, but also vital that they did not assume that everyone with the same VI issue had the same limitations. One of the group facilitators suggested a pre exercise class assessment visit by the exercise instructor. In this visit the exercise instructor would get a flavour of the capability of the participant and any adaptations (to venue, kit etc.) that would be required for that specific participant. The participants in the focus group felt this would be both useful and acceptable.

Overall the strongest recurring theme was that the instructor(s) had to spend time to get to know each individual and their functional and emotional needs, and that any programme would need to be tailored to individual requirements. Choice was the other key theme. No-one wanted to be told to exercise; rather they wanted a range of support options and the acknowledgment that these might change from week to week.

7. Focus Group 2: Outcomes and Trial Procedures

We discussed the outcome measure both with regard to their form and their content.

8. 2.1 Form

Again the key theme that emerged from how outcome measures (OMs) were presented filled in and returned was *choice*. There were a range of preferences expressed. Some wanted them to be read to them and then to reply (face to face or over the phone); others wanted large print; some could see large print but not their own writing; some were happy to receive things by email as they had screen readers on their computer, and so on. Whilst most thought OMs over the phone would be acceptable, the consensus was that people should be given choice and preference elicitation should form part of the initial VIOLET intake meeting.

A considerable amount of time in both groups was spent discussing how best to keep the Falls Diary and how to interpret its contents (see 2.2). This is the most “heavy” participant burden as it has to be filled every day and submitted, in some manner, every week. Whilst again there was no overall consensus, in discussion with the research team, most were happy to do this by way of a weekly telephone call from a member of the VIOLET team.

9. 2.2 Content

All the questionnaires were gone through in some detail. There were several issues identified. People found the introduction to the FES-I (Falls Efficacy Scale – International) confusing, particularly the Glasgow group. There were quite a few participants who felt that some of the quality of life questions around relationships and isolation were unnecessarily intrusive and would prefer not to answer them (this was more marked in the Glasgow group). There was also a feeling that a focus on limitation and reduced quality of life could adversely affect people’s mood and that this should be signalled to them in some way.

The content of the Falls Diary was further discussed. It was felt that falls should be distinguished from trips (tripping on an obstacle) and slips (losing footing) and that all three should be recorded. The terminology of the Falls Diary was considered unclear. Most were not sure what a soft tissue injury was; they wanted to add “graze” and have a chance to tell someone rather than try to explain it on a form that they could not see well (or at all); they wanted a question on whether they were physically or psychologically impacted by a fall to reduce their activities or substantially changed their routine; they wanted to be able to record changing and limiting activity (as opposed to “immobilization” as currently on diary). Similarly the “costs” of a fall were unclear to people. Again, in discussion with the research team, people were happy for the Falls Diary to be a “daily yes or no” document and for all other details to be elicited with a weekly phone call.

For the Timed Up and Go tests, people wanted to know that they could use the standard aids (or dog) that they normally used to walk.

Overall, with the caveats listed above, people could see the reason behind the OMs and thought they were appropriate and necessary.

10. 2.3 Additional OM and Personal Data Suggestions

We ended this session by asking the groups to reflect on if we were missing measuring anything. There was a strong feeling amongst some members that we needed more VI specific demographics, such as: nature of VI; duration of VI (or lifelong); stable, progressive or changeable VI; recent change in VI; personal adaptation and confidence related to VI and impact of VI on daily activity.

One area that was discussed at some length was the specific impact the intervention could have on quality of life, confidence and daily activity *as determined by VI*. There were various suggestions for capturing this in the form of “before and after” data collection: asking additional specific questions such as “are you impaired in everyday activities as a result of your VI?”; using new questionnaires such as the CONFBal (a measure of balance confidence) or WASA (Work and Social Adjustment Scale) (suggestions from the research team); asking about confidence and ability to orientate in new environments; assessing amount of physical activity; assessing degree of general happiness and amount of pain; adapting existing questionnaires by adding Likert scales.

We discussed with the group the problem of changing validated questionnaires and the need to be able to compare their use in other groups. This issue was understood. Finally several members of the group suggested patient specific outcome measures, targets that were meaningful to them and that could be measured by degree of achievement before and after the groups.

11. Conclusion

These groups proved to be a rich source of serious and engaged thinking about the FaME programme, about research participation, about the impact of VI on daily life and about what enabled people to cope and adapt. The outputs from these groups have shaped the programme and we will continue to elicit input from some of the members who have signalled an interest to continue to be involved. We would like to end this report by thanking them once again for the time and work they put into improving the VIOLET study.

12. 3. Recommendations

The overall recommendation from the stakeholders is that personal choice and individual adaptation should be paramount across the study.

3.1 Adapting FaME

Fully accessible familiar venue or ability to get to know unfamiliar venue.

Taxi to venue/aid getting to and from venue

Size: Maximum 8

No music

Individual adaptation regarding lighting and glare

Choice to bring another person with them

Social element (tea and chat) post the exercise session

Potentially run more than one class (flexibility of time) at the beginning for group bonding

Home exercise: reduce length of home exercise session to 10-20 minutes. Give a variety of exercises. Provide prompts (large print format, DVD, audio). Integrate into activities of daily living.

PSI: training on impact of visual impairment and adaptations (aids) that could be used for specific visual impairment. Training communication (verbal clarity)

Potentially more than one instructor or additional person to help OPVI.

Potential for pre session visit

Information regarding the individual OPVI to be passed to PSI, time to fully understand the nature of the impairment and how this may affect the individual and how that may vary across timeframes.

Tailoring of content to individual (floor work)

3.2 Outcomes and trial procedures

Ability to choose how outcome measures are received and administered (email, post, verbal)

Reduce the content of the falls diary

Remove the resources/expenses form so that the researcher administers this.

Incorporate a weekly telephone call to capture data around nature of slip, trip fall and the impact of that slip, trip fall (to ensure capture of near miss).

Define slip, trip and fall.

Patient centred outcome measures (personal goals).

Use a tool to capture impact of visual impairment on person and their activities.