

Involving older people in a multi-centre randomised controlled trial of a complex intervention in pre-hospital emergency care

This case study has been developed by **Alun Toghill**, Involving People Network Member, and **Marina Koniotou**, Swansea University. It describes Alun's experience of public involvement in the SAFER 2 study.

The SAFER 2 trial will measure the costs and benefits of a protocol for use by emergency ambulance paramedics in the care of older people who have fallen, allowing the paramedic to assess and refer appropriate patients to a community based falls service.

The randomised controlled trial involves ambulance stations in three participating services (London, Wales, East Midlands) which are randomly allocated to 1) implement the new protocol (intervention group) or 2) continue to provide care according to their standard practice (control group). www.saferproject.org

My SAFER 2 journey began when I answered a request from Involving People to be involved in a research project.

Starting out

I was immediately drawn towards the project because it was about a falls prevention programme and it ignited my passion to help others.

It wasn't long before the ball was firmly rolling, when the trial researcher contacted me to explain what my role would involve. I vividly recall being warmly welcomed by the group as I explained to them my background and what skills I possessed; allowing them to decide where I would best be placed to help.

My background is diverse; I've worked in hospitals and in the elderly care private sector as a nurse, and I've also had wide experience in the community and voluntary sector, including setting up projects for the care and support of the elderly and at risk.

These experiences led me to be involved in a number of tasks, which would include working with the study team to assist in designing the project methodology i.e. developing the patient questionnaire.

Attending Meetings

I attended Task and Finish Group and Task Management Group meetings in Swansea and Bristol, by teleconference and in person. When I was unable to attend meetings, the trial researcher would arrange meetings at my home, as this was better for me. The flexibility of this approach was an example to all and is a model to be replicated.

As the study progressed I was able to participate fully in meetings, to monitor and review progress not only in Wales, but also at both London and East Midlands participating sites. Attendance at joint meetings and through teleconferencing meant that I was fully integrated within the research network and was included in writing days to help input into the final report.

Making a difference

Together with other members of the research team I took part in evaluating patient transcripts to ensure that any identifiable information was omitted appropriately. My work helped to ensure there was no breach of confidentiality, for example, I identified one lady from one of the trial sites because the transcript noted

her first name and the road of the accident.

I also helped with the design and formatting of the patient questionnaire. From a lay person's point of view, I could ensure ease of completion by looking at the questionnaire's clarity, use of English and the order of questions.

I advised on how to improve the low completion rate of the patient questionnaire and consent form by suggesting changing the colour of the forms from white to cream. This was based on previous projects I worked on where it was identified that changing the colour of the paper helps it not get lost in an avalanche of other papers. It is more likely to be completed and returned if it stands out from the crowd!

Role-play

Along with the Welsh-based researcher, I undertook a role-play activity as part of a process to refine the patient interview schedule. I played the patient, whilst they posed the interview questions.

This novel way of working allowed me to refine how the interview flowed and offer advice on where the schedule failed to articulate itself in a language and order the patient would understand and be comfortable with.

I was able to identify any duplication in the questions and advise how to pitch questions to this vulnerable group of patients. It is important that the patients in the target group have enough time to answer; young people are quicker at responding.

I emphasised the importance of building a relationship of mutual trust with the patient interviewee. When you ask for their name and, for arguments sake, they say Elizabeth Rose Taylor, you should ideally respond by asking them what they would like to be called. If, for example, this person is known as Lizzie, addressing them in a familiar way rather than a formal way helps put them at ease. If the interviewer cares about the interviewee it can show that they are serious about hearing their views and a more open response is likely.

Reflections

My involvement with the project has been an enjoyable and valuable learning experience. I have found that my varied life experiences have been used by the project to enhance the final outcome. I do feel proud that my contribution has had a marked effect on this activity and that shared participation has been of value to all parties.

I was always listened to and, as a result, I gave everything I could and I got a lot out of it. I felt the other researchers had a similar attitude; they gave what they could and were open, honest and friendly. There were no barriers and this encouraged trust and mutual respect between everyone.

I brought a different insight to the study and my drive and passion grew when I could see an end product that was going to make a difference. I know I have made a difference as my suggestions have more than been acknowledged; many have actually been adopted.

I've talked to other studies about the SAFER 2 model; too many service users feel let down by the process as they have not been given a defined role and they have not been appropriately involved enough.

A final message

This has been a positive experience of feeling as though I am working together with the team. I hope my positive experience will have a ripple effect, as I will continue to promote this excellent model of service user involvement.