SERVICE USER INVOLVEMENT IN RESEARCH

A BRIEFING PAPER FROM THE PALLIATIVE CARE STUDIES ADVISORY GROUP

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This briefing paper describes the activities of the *Palliative Care Studies Advisory Group* based in Sheffield, U.K. The group aims to offer feedback and advice to research projects with a palliative care and/or end-of-life care focus.

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BACKGROUND TO THE GROUP

The Palliative Care Studies Advisory Group was set up in 2009 in order to give advice and guidance to a Department of Health project about 'Transitions to palliative care for older people in acute hospitals'. The aim in setting up the group was to harness the skills and perspectives of interested members of the public and service users in order to improve the design, implementation, and dissemination of the research. The group played an active role in ensuring that the research process was relevant and acceptable to users of services, both in terms of recruitment to the project and in terms of implementing findings.

In setting up the group, an initial User Consultation Day was arranged for June 2009. It was attended by seventeen service users, carers, and advocates all with an interest in palliative and end-of-life care. Attendees were drawn from a range of local, regional, and national organisations including the North Trent Cancer Research Panel, the Cancer Experiences Collaborative, The Alzheimer's Society, The Older Lesbian and Gay Association, Darnall Dementia, Sheffield and District Afro-Caribbean Community Association, and local care homes. Feedback from the day was excellent, and sixteen of the attendees expressed an interest in continuing their involvement in the project.

The intention was to make the group as inclusive as possible in order to have a broad range of views represented. Members were recruited who had certain key attributes: knowledge of consumer perspectives; good communication skills; and an ability to both listen to others and express one's own views and concerns in discussions. Additional members joined the group from an older carers research project at the University of Nottingham, and from the volunteer service at the Nightingale Macmillan Unit at the Royal Derby Hospital.

WHAT DOES INVOLVEMENT MEAN?

Involving patients, carers, and advocates in research is about doing research **with** the public rather than **to** or **about** the public. It is a way of allowing lay representatives to influence the research agenda. If research reflects the needs and views of the end user, it is more likely to produce results that can be used to improve practice in health and social care. Public involvement means not only monitoring *what* is done during the life of the research project, but the *way* in which it is done.

Involvement can be:

CONSULTATIVE: This is where researchers consult members of the public to find out their views and then try to incorporate these views into the research.

COLLABORATIVE: This involves active, on-going partnerships between researchers and members of the public e.g. through collaboration in an advisory group, or on a steering committee.

USER CONTROLLED: Here, members of the public take the lead in directing the research and driving it forward, making key decisions about the project in the process[i].

An advisory group can have different levels of involvement in a project, depending on the nature of the research project, and the level of commitment group members want to make in terms of time. For example, it is possible that members could help to co-facilitate focus groups as part of the research, or help to recruit people to the project through their own networks.

Ultimately, involvement is about meaningful communication and information exchange between researchers and the advisory group. It is about building up lasting relationships for the duration of the research project and giving people the opportunity to contribute and to have those contributions valued and incorporated into the research study.

> "I would like to see any skills that people have in the group being used more. You know, if people have got skills sitting in front of the computer inputting data, I know you'd have to sign forms and so on, but I for one would be quite happy to do that. Or setting up spread sheets or filming stuff you know. Because at one time we were professional people and we had important jobs some of us (or jobs we like to think were important!) and we can bring all that."

Jacqui Gath, member of the advisory group

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[i] "Involving the public in NHS, public health, and social care research: Briefing notes for researchers" http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf

MOTIVATIONS FOR GETTING INVOLVED

"It was at the time my wife was in hospital for the umpteenth time because she was ill over thirteen years and I got talking to one of the sisters there and she sort of put my name down (laughing). I really don't know how it came about but she said would you be interested and ... I thought I'll have a go at it. But I've found it highly interesting, highly informative and I'm pleased I did."

John White, member of the advisory group

"As far as research is concerned, it doesn't matter what the subject is, if you don't have continual research into it you don't move forward, you just stand still. This is why I'm prepared to take part. My thoughts are based on my experiences of looking after my wife. If by influencing research I can help somebody in the future, that's all to the good. I can put something back into society in return for what I got out of it."

Ken Hall, member of the advisory group

The Palliative Care Studies Advisory Group met every six months throughout the three years of the 'Transitions to Palliative Care' project.

ROLE OF THE GROUP

The Palliative Care Studies Advisory Group met every six months throughout the three years of the 'Transitions to Palliative Care' project.

The group has contributed to various aspects of the project, including:

Commenting on whether research in this area is important
This prompted a discussion of the value and the merits the group members found in the proposed research. Members gave examples of both positive and negative experiences of end-of-life care. It was emphasised that a good death should be seen as a success in medical terms. The group feedback was incorporated into the research studies application for ethical approval, and facilitated the approval process.

Developing project information leaflets for distribution to the public, and assisting with distribution
The group designed and agreed content for a project information leaflet. Members encouraged a more positive style of language, and pointed out areas where more explanation about the research was needed. The group identified places where the leaflet could usefully be distributed (for example: day centres; local council offices; Age UK) and many members were involved in distribution.

Identifying ethical problems or concerns with the study
One of the most important contributions of the advisory group has been in negotiating the ethical challenges of the study. All ethically contentious issues were discussed with the group in order to inform the study design and to assist with applications submitted to Research Ethics Committees. The most ethically challenging issue related to gaining approval from a specialist ethics committee to undertake a retrospective medical case note review of patients who had died. An initial application made by the project researchers was rejected on the grounds of the contentious ethical issues. A dedicated meeting of the Advisory Group was held to gain detailed feedback on the issues raised; feedback which was then incorporated into a revised application. After this and written support from one member of the group, a second application to the ethics committee was approved.
It is worth highlighting how crucial the input of the Advisory Group was in securing this ethical approval, without which it is extremely unlikely that a key component of the 'Transitions' project would have been able to go ahead.

Commenting and providing feedback on the project website, and suggesting content
The group agreed that a project website was a very good idea, as it would help to get information about the study to a wider audience, especially younger people. Suggestions for content included links to other related websites, and regular updates on the input of the Advisory Group.

Contributing to dissemination and distribution of the research findings
In order to see the results of the research being implemented, the group was keen to play a part in disseminating findings from the study in different forums. Some wanted to do so informally through face-to-face encounters with their peers and with people they came into contact with on a regular basis: "That's far more effective than reading it in a written report in the funder's office." The group also agreed it was important to see findings disseminated through the mainstream media.

ADVISING OTHER STUDIES

Other researchers have become aware of the *Palliative Care Studies Advisory Group* and have asked the group to consider providing advice to their projects. As a result, the group has been consulted on a wide range of palliative care research projects from a range of universities. Projects the group has offered advice to include: a study exploring palliative sedation; end-of-life care communication for patients with respiratory disease; and optimising hospital environments for palliative care. The group has also advised on a PhD research project and on a medical student's research project, directly contributing to the success of these projects and to the awarding of educational qualifications.

> "I consulted with the advisory group when designing my BMedSci project. I found the experiences of individuals within the group invaluable, specifically in relation to how I should approach patients in hospital and the phrasing and design of study materials. The group also gave me confidence in the importance of my research, given their first-hand experiences of inadequate palliative care".

Emilie Green, medical student, The University of Sheffield

> "The benefit of consulting the user group is priceless to the researcher. Presenting to the group makes you think through your research study and articulate it clearly and concisely, and they frequently raise issues that you had not previously considered at all. On the other hand when we have been, as it proved, overly concerned about some aspects of approaching participants about sensitive issues they have a down-to-earth common sense approach that has allowed us to reassure ethics committees and others. Working with the group is always a joy!"

Jayne Brown, researcher, The University of Nottingham

GETTING INVOLVED IN RESEARCH … WHAT’S IT REALLY LIKE?

“I think what’s interesting is that from my experience and a lot of people I’ve talked to in similar groups to this, we’ve become involved by accident, it hasn’t been an intention. And we’ve become more involved as we’ve attended the meetings and become more and more interested and found it more and more rewarding and by finding it rewarding I think we are also making a valuable contribution to the subject.”

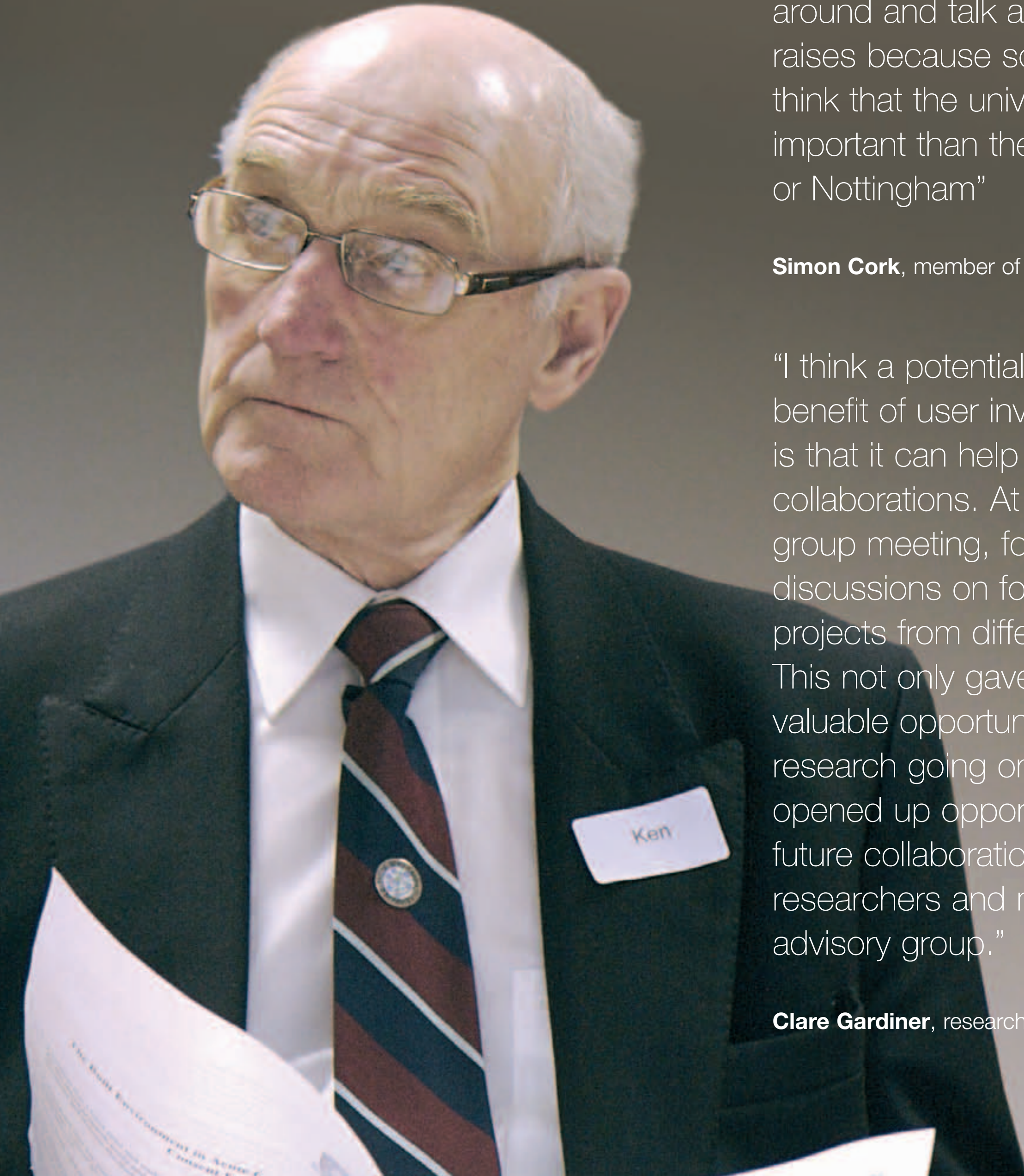
Don Thompson, member of the advisory group

“Funnily enough, the more I get involved in [the group] the more I’m able to contribute back. I can think about things from a broader perspective. Now I can think about research and make positive suggestions. It’s important to be able to make positive suggestions about how things could be or should be.”

Jacqui Gath, member of the advisory group

VALUABLE FEEDBACK FOR RESEARCHERS

People who use services are able to offer different perspectives on research to those of professional researchers. They can help to ensure that the issues that are identified and prioritised are important to them and therefore to health care, public health and social care services as a whole. For researchers, it is easy to get preoccupied with the more technical aspects of conducting research. The palliative care studies advisory group was able to remind the professionals of the overall purpose of the research - the “nuts and bolts”, as one member called it - and why it matters.



The group acts as an invaluable ‘sounding board’ for ideas.

“I think research groups like this serve a very useful purpose because, the way I see it, you’ve got to have the academic input to know how the nuts and bolts work because some of the ethical issues are so important now you’ve got to have the academics who have got the experience and know how to do it. But then eventually you’ve also got to have a group of people to sit around and talk about the issues it raises because sometimes you might think that the university of life is more important than the University of Sheffield or Nottingham”

Simon Cork, member of the advisory group

“I think a potentially unrecognised benefit of user involvement in research is that it can help foster research collaborations. At a recent advisory group meeting, for example, we had discussions on four very different projects from different research teams. This not only gave researchers a valuable opportunity to hear about other research going on in their area, but also opened up opportunities for current and future collaborations involving the researchers and members of the advisory group.”

Clare Gardiner, researcher, The University of Sheffield

FUTURE ROLE FOR THE ADVISORY GROUP

The group intends to continue its involvement in research, giving invaluable feedback, and acting as a ‘critical friend’ to upcoming research projects in the region.

There are a number of researchers working on palliative and end-of-life care in Sheffield, Nottingham and even as far away as New Zealand. This includes large and small scale projects, PhD projects, and projects funded by universities, government departments, and the voluntary sector. Our project has benefitted greatly from the involvement of the group, and we hope that other projects too can consult the group and benefit from their feedback.

GETTING IN TOUCH

The group is always keen to attract new members. If you are a patient, carer, or advocate and are interested in joining, or know of someone who is interested in joining the group, then we would like to hear from you.

If you are a researcher who is working on a palliative care and/or end-of-life care project and would like to consult the group, then we would also like to hear from you.

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