

A series of five examples of public involvement in research developed by the NIHR Evaluation, Trials and Studies Coordinating Centre.

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## **Example 2: Transitions to palliative care for older people in acute hospitals**

### **About the research**

**Lead researcher:** Professor Christine Ingleton, The School of Nursing and Midwifery, University of Sheffield.

**Funder:** National Institute for Health Research Health Services and Delivery Research Programme.

**Project aim:** To explore how older patients make transitions from curative care to palliative care in hospital: when and where this occurs, how it is managed by professionals and how it is perceived by patients and carers. The overall goal was to improve these transitions, encouraging professionals and policymakers to change policy and practice to be more in line with patients' needs.

**Type of research:** Mixed methods - qualitative and quantitative research.

**Duration:** 3.5 years, January 2009 – June 2012.

### **Who we spoke to**

We interviewed the post-doctoral researcher who worked on this study, Dr Clare Gardiner, now at the University of Auckland, New Zealand. Her comments are written in blue text below.

### **About the involvement**

#### **How patients and carers were involved in the study**

Early on in the project, the research team set up a Patient and Public Involvement (PPI) Advisory Group that worked with them throughout the course of the project and into the dissemination phase. The Group met 2-3 times a year and was formed of a core membership of 10-12 service users and carers. There was some turnover, but overall it was very cohesive.

*"We chose this model of involvement because we wanted to make sure that everything that we were doing fitted with what service users want and need – they are the group that the research was aiming to help." Clare*

#### **How were patients and carers recruited to the Advisory Group**

The team ran a one-day workshop in a community centre inviting service users and carers linked to local organisations, including charities, advocacy organisations and nursing homes. The researchers talked about the project and what they wanted from involvement, but also asked what the service users and carers thought would be important to find out. The participants were invited to join the Advisory Group and about 15 people expressed an interest.

“Most people on the group had experienced caring for a loved one who had died – but there were also people with long-term conditions using palliative care services themselves. We were worried about upsetting people, constantly asking questions about death and dying, but we never once had people visibly upset or distressed in the meetings. They were an incredible group – very willing to share their experiences to help others.” **Clare**

### **Impact of the involvement**

The Group had an impact at all stages of the project, including influencing the research design and methods used, as well as what research questions to answer. They were very involved at a practical level developing consent forms and patient information sheets. This was particularly valuable in the context of palliative care research, where the researchers wanted to find sensitive ways to approach patients and relatives.

“The Group was especially helpful with ethical issues. One phase of the project was initially turned down by the ethics committee. We went back to the Advisory Group and discussed the issue and they came up with some guidance for us. The ethics committee then approved it second time round. Without that input, we wouldn’t have been able to have done that work – and importantly it was then done in an ethical way.” **Clare**

At the dissemination stage, the Group helped to identify which groups and individuals it would be important to influence as well as helping to develop briefing papers and study reports for different audiences.

“The reports were much more effective at engaging service users, policymakers and other stakeholders than if we’d just written a paper for a fusty academic journal!” **Clare**

### **The challenges of involvement**

The researchers had some concerns that it might be difficult to find a group of people who would be willing to contribute to palliative care research, but this proved not to be the case. However, the majority of group members were older people, which presented some practical challenges.

“We had to make sure that meeting venues were accessible and to provide funding for taxis to and from meetings – so that the older members of our group were properly supported. Our project was well resourced so we were able to do that.”

**Clare**

At the end of the project, the team were faced with the challenge of not wanting to lose the valuable skills and experience of the Group, even though the funding had run out.

They therefore decided to find ways to support the Group to continue. During the course of the project, the Group had already been receiving requests for advice from other palliative care researchers. This work has continued, for example the Group has advised a current EU-funded study working across six countries. The researchers who consult the Group are asked to provide a small amount of funding for travel and refreshments for meetings.

“After so much investment, we didn’t feel we could turn round and say ‘Thanks very much and goodbye’. It was too much of a valuable resource for us to lose. The group members had developed their own knowledge and skills, particularly ways to get their points across – they had become more and more effective in doing that... Luckily, without any effort on our part, the Group had started advising on other projects more widely, other researchers had started to contact us. It was good for us to hear about these projects – and also good for the Group. As a result, the Group has been able to continue in its own right and two years later the members continue to provide advice to other projects.” **Clare**

### **Lessons learnt**

“Make sure that you have adequate resources for involvement so you can meet people’s needs. Don’t underestimate the costs.

Be clear about what you want to achieve with involvement – don’t see it as a tick box exercise. There was some cynicism at the beginning of our project, but our work has shown how important it can be. There’s a lot of guidance out there on how best to engage service users – make use of that to help you make the most of the opportunity.

Think about the long term and how you might continue the involvement at the end of the project – so as not to lose valuable expertise.” **Clare**

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### **References:**

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Merryn Gott, Christine Ingleton, Clare Gardiner, Naomi Richards, Mark Cobb, Tony Ryan, Bill Noble, Mike Bennett, Jane Seymour, Sue Ward and Chris Parker.

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December 2014