

Participatory video as a method for enhancing involvement for people with dementia

Abstract: This paper presents the findings of a study funded by the National Institute for Health Research's School for Social Care Research. It involved 15 people with dementia aged between 76 and 99 years of age who live in residential care. Because it is very easy for people in this situation to be left out of service user consultation, we wanted to find out whether a film-making approach called Participatory Video could help. Each of the participants could decide individually what they wanted their film to be about and who is allowed to see it. They chose the images to include, and can be heard in the films talking about things that are of importance to them. In this way we have tried to shift the power imbalance that can often arise between professionals, researchers and people with dementia.

Ten out of 15 participants completed short films, and our findings suggest that Participatory Video (PV) is a good way of helping people with dementia to have a voice. We assessed the impact of PV on well-being, social participation, and range of activity. We believe that the unique character of each participant comes through in their films. The films may also be useful to raise public awareness and to include in staff training. This paper will discuss the main findings from the study and its implication for service user involvement for people with dementia and other seldom heard groups.

Do you have an idea for research? How to develop a research priority

Abstract: This interactive workshop aims to equip members of the public with the tools to develop their own research ideas and priorities into potentially researchable questions, enabling them to more confidently discuss them with academic and clinical colleagues.

Delegates will be allocated a health or social care topic to consider, with the aim of developing it into a researchable question and mini 'research proposal'. The session will be divided into a series of exercises which participants will undertake in small groups. Activities will include a brief facilitated review of relevant research papers on the topic, considering what evidence already exists and what research might improve our understanding of the issue. Groups will then develop their own research question on the topic, considering what is feasible, practical, useful and ethical. Appropriate research methods for answering the question will be considered, along with how participants might be recruited and what ethical considerations need to be taken into account. If time allows, groups will present their research ideas and a 'winner' will be decided through a mock funding allocation.

By working through this process, delegates will gain an understanding of the issues they need to consider when presenting their own ideas for research. The workshop will be facilitated by staff and service users from the Richard Wells Research Centre based on our experience of working collaboratively to identify research priorities and develop them into research projects.

VOICE: Science for advocates – Quality advocacy needs quality education

Abstract: Independent Cancer Patients' Voice (ICPV) is a patient advocate group led by patients for patients. We bring the views and experience of cancer patients, their families and carers to the cancer research community. Our mission statement is that clinical research is improved by patients being partners with clinicians and healthcare professionals, rather than passive recipients of healthcare.

Members of ICPV are actively involved in many areas of research. To facilitate and enhance our role in these activities, members aim to understand the fundamentals of cancer, study design and current areas of controversy and research.

Working with the internationally renowned Barts Cancer Institute (BCI) we have developed a tailor-made course which provides a week-long intensive training in basic cancer biology, introduction to research terminology and study design, and critical evaluation of research proposals and scientific papers. This course VOICE (Vision On Information, Confidence and Engagement) Science for patient advocates is unique, the only course of this type in the UK.

To date, patients have had very little involvement or experience of laboratory based research which can cause challenges for patients and carers, who often have a limited understanding of cancer biology.

Researchers at BCI and members of ICPV therefore worked in

partnership to develop a 5 day training course for cancer patient advocates which aims to lead patients through the research process beginning with basic biology, through to experiments in the lab and on to discussing clinical trials.

In addition to attending lectures and performing experiments participants were able to meet and speak with cancer scientists. We believe that this project is the first of its kind in the world to offer people affected by cancer an opportunity to spend time in laboratories in order to build a practical understanding of cancer biology.

The inaugural course took place from 9-13 September 2013. Early feedback suggests that participants are more confident about discussing laboratory based research in their roles as advocates having gained a better understanding of how work is done by laboratory-based researchers. An additional impact is that scientists who were involved in the course have been both motivated and inspired by their contact with participants.

We have done a six month follow up of participants to assess the longer term impact of the course, and will be repeating it in 2014.

For more information visit the [ICPV website](#)

Using an online survey to paint a picture of service user involvement in the field

of Healthcare Associated Infection Research

Abstract: This poster will present the results of an online questionnaire survey of researchers working in the field of Healthcare Associated Infections. The survey asks participants to provide data on: the level and types of patient and public involvement (PPI) included in current and recent research; researchers' experiences of PPI; perspectives on the benefits and challenges in involving the public; and views on what might be done to increase levels of PPI. For researchers indicating that they have not included patients or the public in their research, the survey aims to ascertain the perceived barriers and how these may be overcome.

The survey will be emailed in April 2012 to 150 researchers identified through existing contacts of the HCAI Research Network and those who have published research in the Journal of Infection Prevention and Journal of Hospital Infection. In addition, a link to the survey will be promoted via the Infectious Diseases Research Network and placed on the websites for the HCAI Research Network and its Service User Research Forum (SURF).

The poster will present the results from the survey using graphical representations and an accompanying interpretation of the findings from members of SURF.

The Service User Research Forum is a group of service users with an interest in reducing Healthcare Associated Infections through research. Members are actively involved in a variety of research activities from reviewing funding applications and patient information, to working as part of the research team as service user researchers.

Download poster

A model for sustainable and effective PPI in health research

Abstract:

The presentation will discuss the role of PPI in the health research world from the point of view of an emergency care, and cancer panel in South Yorkshire and North Trent. It will discuss how these panels are able to enhance research for patient benefit and improvements in patient outcomes, by providing trained and supported lay individuals for research projects. The panel provides a constituency for these lay individuals, and gives them a safe haven in which to discuss their ideas and input, and to give a broad response to health researchers. This kind of group working prevents lay researchers from working in isolation. It explains how patients who find committee working difficult can effectively have their voice heard in deliberations about health research. The two presenters have a combination of over twenty years experience, working in the field at local, national, and international levels. It will also explore the support needs of these groups, including the need for finance, time, space and academic and clinical expertise.

The role of INVOLVE for

developing the Framework for User Involvement in Research in Denmark

Abstract:

Denmark is on the top five list among nations for clinical research. It is documented that the Danish population has a very positive attitude towards participation in clinical research. In 2010 it was recognised that this attitude was just one aspect of an active user involvement in research.

This presentation will describe how and why the inspiration from INVOLVE has played a crucial role for the plans for implementation of a comprehensive user involvement in research in Denmark.

The Role of INVOLVE for developing the Framework for User Involvement in Research in Denmark

Performing an inquiry: An innovative model for involving people in the

interpretation of research data

Abstract:

This workshop will explore how service users are being involved in the interpretation of qualitative research data, as part of a study looking at why people develop severe pressure ulcers (SPU). One of this study's challenges has been keeping the patient voice strong when data is interpreted by professionals. We are keen to see if service users interpret the data in the same way as a largely clinical research team.

To do this we will be holding a public engagement event with members of the Pressure Ulcer Research Service User Network UK, in May 2012. During this event participants will be asked to interpret one of the case studies from the SPU project.

To make this event as engaging and accessible as possible, we will use a live simulation (a type of role play) and video clips to illustrate different perspectives within the data. Participants will then be asked to act as 'expert witnesses' and give their opinion on the case. The event will be evaluated using video.

During our interactive INVOLVE workshop we will take participants through part of the process described above and explore how performance-based approaches can facilitate involvement and create dialogue between service users and professionals.

Do you have an idea for research? How to develop a research priority

Abstract:

This workshop aims to equip service users with the tools to develop their own research ideas and priorities into researchable questions. We will use our experiences of developing a research question and a pilot study from the ideas and interests of a member of the Service User Research Forum. We will present the process we used to develop this collaborative study, which investigated the infection prevention and control education of undergraduate healthcare professionals, and use this as a template for the workshop.

Delegates will be asked to work in small groups to look at a given topic/issue with the aim of developing this into a researchable question/set of questions. We will facilitate the process by breaking the task down into a series of exercises, asking delegates to consider: what is feasible, practical, useful and ethical? Groups will think about how to develop research questions and will undertake a brief facilitated review of relevant literature – gaining an understanding of what evidence already exists and how we might build on that evidence/identify gaps in it. Finally, each group will be asked to explain their ‘mini’ research proposal/idea and, if time allows, a ‘winner’ will be decided through a mock funding allocation.