

# NIHR PPI Newsletter July 2018

INVOLVE – NIHR Newsletter July 2018 – Focus on I Am Research/NHS 70

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## Working together to deliver training on patient and public involvement in research

Abstract: For organisations that want to involve patients and the public in research, it can be difficult to find the time and the resources to provide training and support, particularly given the recent uncertain economic climate.

Since 2009, Asthma UK and Alzheimer's Society have taken a collaborative approach to delivering training to their supporters, focusing on the basics of research and why it's important to get involved. In previous years, MS Society,

Epilepsy Action and Parkinson's UK have also co-delivered the training. Almost 300 patients or carers have completed the training.

Participants in the training are equipped with the knowledge and confidence to perform different roles in research. By gaining an awareness of the challenges researchers face participants are also skilled to make constructive contributions to research projects.

Feedback from participants is used to directly inform and improve the training. Creativity, efficiency of resources, interlinking diverse networks and sharing experiences are just some of the benefits of collaboration, and the results of the sessions have been extremely positive for all involved.

This poster aims to outline the benefits of taking a collaborative approach to training patients and the public to make an effective and impactful contribution to research as well as providing an honest insight into some of the challenges that we faced. It also aims to elicit discussion on how this approach might be taken forward by other organisations.

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## **Mystery shop exercise**

**Abstract:** The poster provides a summary of the results and recommendations of a 'mystery shopper' survey carried out at North Bristol NHS Trust (NBT) to find out how easy it was for patients to find out about clinical research opportunities. This replicated a national survey undertaken by the National Institute for Health Research (NIHR) of 40 NHS Trusts.

The mystery shoppers were five volunteers from the NBT research patient and public involvement panel.

What people will learn:

- How the survey was carried out and issues the mystery shoppers faced
- Our key findings
- Recommendations for improvement made by the mystery shoppers
- What we have been able to introduce immediately following their recommendations.

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## The Involvement Portfolio

**Abstract:** The Involvement Portfolio has been developed by the NHS R&D Forum Service User and Carer Working Group. It is a tool for those using health and social care services who are involved in voluntary or involvement activities such as consultation, committee membership, research and development, to record and provide evidence of their activities.

Many people using health and social care services are involved in a range of involvement and voluntary activities such as research, teaching and training. Much of this involvement goes unrecognised although the participants are gaining valuable skills and experience as well as contributing their experience and expertise. This tool allows people to record the skills and experience gained through involvement and voluntary activity as this can help with applications to undertake new activity, for educational or vocational courses, or to find employment.

In the portfolio, the portfolio holder has the opportunity to record their employment or other experiences including those gained through voluntary activity, or life experience such as being a carer or a parent, training events and experience of leading or facilitating training, 'involvement activity' and experience including taking part in committees, in consultation events, in NHS or social care research and development, or in curriculum development for educational courses. The portfolio holder has the opportunity to record the involvement activity they have taken part in, the type and level of involvement, the skills learnt, and any qualifications gained.

The portfolio was successfully launched some years ago and has now been refreshed and re-launched taking into account the lessons learnt and experience of its use.

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## **The Citizen Scientist Concept: Building a research active community**

**Abstract:** Public understanding of health research and access to information about local involvement opportunities is a widely recognised problem yet no simple solution seems to meet the public need.

As the Citizen Scientist Project Public Advisory Group, our goal was to help people find out about health research in our local area and opportunities where they can take part in research studies. The project aims to put the choice with the patient which we believe is a concept that is long overdue in clinical research. The Citizen Scientist Project is pushing a

cultural change of encouraging members of the public to enquire about research rather than being approached by a clinician. This is important as the vast majority of patients whose health, care and treatment we are trying to improve live in our communities not in our clinics. We believe that by making research more accessible in this way we can increase awareness, understanding and acceptance of the research.

The practical implications for the Citizen Scientist project are how we best communicate local research to local people. Improving access to opportunities and understanding of what research is and isn't are key objectives. We helped to determine the design and feel of the project and work closely with the management team to provide sense checks and oversight from a public perspective. We are proud to have helped drive this unique and innovative project forward. This poster is designed and presented by the Citizen Scientist Public Advisory Group (CSAG).

The Citizen Scientist Advisory Group supports the management team for the Citizen Scientist Project. They formed in early 2012 and consist of members of the local population of Salford. They have provided a means to sense check and support decision making for the project from early setup to its current plans for wider roll out.

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# **Patient involvement in the development of a patient**

# safety intervention

Abstract: Health service researchers are realising that patients can be an important source of knowledge in reducing avoidable harm and improving care, however, patients rarely have the means to share this information and may feel uncertain in doing so. Patients with kidney failure regularly require complex care in a range of environments but little is known about giving them the option to report on quality and safety and whether this is beneficial. Renal patient view (RPV) is a web-based electronic patient record that gives information to patients with kidney disease about their diagnosis, treatment, and latest blood tests – accessible from any networked computer. During this study, kidney patients have co-designed a system for patients to feedback both their positive experiences and concerns about quality and safety during the care they receive. As part of this study a patient-led steering group was set up to oversee and actively steer the study. This group consisted of kidney patients from the various stages of the disease, researchers and health care professionals.

In this presentation, we will present:

- The ways in which members of the patient-led steering group worked together to co-design the patient feedback system
- How the involvement of patients was evaluated
- What worked well
- What didn't work well and the lessons that can be learnt.

We will present examples of how the patient-led steering group was involved in the study and the design of the patient feedback system, as well as discussing the challenges of undertaking meaningful public involvement.

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# **Patient and public involvement in translational research: Experiences in a UK Biomedical Research Centre**

Abstract: Translational research aims to speed up the process of moving scientific research findings into clinical care for patients. The UK's 11 Biomedical Research Centres have been funded to conduct translational research and are required to collaborate with patients and members of the public in this process. This presentation will discuss:

- What kinds of patient/public involvement are practised in translational research?
- How can involvement in translational research make a difference?

We will report on the strategy and experiences of involvement in one UK Biomedical Research Centre, focusing on the successes achieved and challenges encountered over one year. Our strategy seeks to engage local communities in the Centre's research activities and encourage basic and clinical scientists to involve the potential beneficiaries of their research and improve recruitment to studies.

Successes include establishing a stable patient and public advisory group; increasing the number of lay panels to advise specific research groups; lay led studies of research participant experience; and lay led strategies to promote participation in research. Challenges include dealing with complex bureaucratic hospital and university structures; establishing and sustaining methods of on-going dialogue

between scientists and lay people; ensuring representation of diverse communities; and influencing rather than just approving. Not all of these challenges have yet been overcome.

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# **Establishing a committee to advance patient and public involvement within university departmental research and teaching activities**

**Abstract:** The Department of Health Sciences, University of York is a large, multi-disciplinary and multi-professional department with an international reputation for research that improves health and healthcare. Involving members of the public is vital for designing and conducting effective research studies and teaching activities at the Department.

We recently set up a committee of patient/public members, researchers and administrative staff to advise, co-ordinate and embed patient and public involvement (PPI) across the department and to link with PPI activity in other departments at the University.

We will discuss:

- How we set up the committee
- Its role, membership and how we have established equality between members



- Challenges faced
- Progress and effectiveness
- Aims for the future.

Our experiences may assist others who are trying to make PPI a fundamental part of the research and teaching process within an academic environment.

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