

# Co-production in action number two

This booklet is the second in a series of publications highlighting co-production in action. It builds on our earlier work, [Guidance on co-producing a research project](#) by showing how the key principles and features identified are expressed in practice.

40 pages

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# Co-production in action number one

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28 pages

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# NIHR PPI Newsletter February

# 2018

[INVOLVE – NIHR Newsletter Feb 2018](#)

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## **Developing patient and public involvement (PPI) at the Bristol Nutrition Biomedical Research Unit: The challenges of tailoring PPI**

Abstract: The National Institute for Health Research (NIHR) Biomedical Research Unit in Nutrition, Diet and Lifestyle at the University of Bristol and the University Hospitals Bristol NHS Foundation Trust was launched in April 2012 and specialises in a diverse range of research areas including:

nutrition, physical activity and lifestyle in men with prostate cancer; optimising nutrition in children with chronic disease; pre and post-surgical feeding; and sedentary behaviour in people with diabetes. The Unit aims to carry out research that is translational – directly translating research findings to benefit clinical populations – and involving patients and the public is an integral part of achieving its aims. Nevertheless the diversity of research areas presented challenges for researchers who were keen to involve patients and the public in their research.

This poster explores the ways that researchers, who had varying levels of experience with patient and public involvement (PPI), went about developing involvement across the Unit's key research themes. The presentation will explore how researchers developed PPI policies and associated documentation, adapted recruitment processes to suit patient groups, and tailored induction and training to meet the requirements of PPI involvement across related, yet distinct, research areas. The difficulties encountered and attempts to overcome these are discussed, and examples of successful PPI contributions into research projects are presented.

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**Research agenda setting from  
the perspective of a highly  
diverse patient population**

# with visual impairments or ophthalmological diseases

Abstract:

**Background:** Patient involvement in research agenda setting has been studied in various initiatives. However, little insight is available on effective involvement strategies for both vulnerable, and for highly diverse and divided patient populations.

**Objective:** To develop a research agenda for people with visual impairments or ophthalmological diseases, taking into account their specific needs for optimal involvement and the heterogenic nature of the patient population.

**Methods:** The Dialogue Model was used, comprising the following four phases: exploration, consultation, prioritization and implementation. Eight homogenous focus groups were organized and several additional interviews were conducted during the consultation phase. During the prioritization phase, medical research topics and societal and rehabilitation research topics were ranked in two questionnaires. Several strategies were applied to optimize the involvement of visually impaired participants.

**Results:** To unify the diverse patient population, the topics of the research agendas were categorized under general themes (eg regenerative medicine, cause and mechanism of disease, and orientation and mobility). Some topics were formulated for specific ophthalmological diseases; however, during the consultation phase a substantive overlap in research topics was identified between the different patient groups. Additionally, by correlating the results of the data to the ophthalmological disease and severity of the impairment justice was done to the diversity of the needs of the patient

groups.

**Discussion:** This research will provide insight in strategies to set up a shared research agenda from the perspective of a highly diverse and divided patient population.

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# Reflections on carrying out research on the impact of PPI in cancer research

**Abstract:** This poster offers reflexive insights into conducting research about public and patient involvement (PPI) in research. It is based on the experience of conducting an interpretivist, qualitative social science research study, which aimed to explore perceptions of the impact of service user involvement on the usability of cancer research findings amongst researchers, service users and other stakeholders. The study had two phases: phase one involved semi-structured interviews with these three groups of participants to explore their perceptions about whether or not user involvement improves the translation of research findings into service development and policy change. Phase two used the Delphi technique to help develop further insights about the findings from phase one amongst those working in health policy and healthcare improvement sectors.

Being reflexive in research is about ensuring that everyday surroundings, identities and contexts are acknowledged as contributing to the shaping of the research process. In this study this includes growing knowledge and research in the

field of PPI in research, and the researcher's own identity and role as regional PPI lead for the National Institute for Health Research (NIHR) Research Design Service East Midlands (RDS EM). Within this context the study was designed to include PPI at key stages to enhance quality, and to ensure trustworthiness and credibility in order to address issues of 'bias'. Drawing on ideas about reflexivity as well as Lincoln and Guba's (1985) four categories of: 'credibility', 'transferability', 'dependability' and 'confirmability', the poster describes how aspects of PPI were developed in order to address these criteria. The poster contributes to debates about reflexivity, researcher identity and the associated advantages and challenges of involvement in research.

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## **Lay involvement in reviewing scientific research bids: Untangling three perspectives; the academic, the bureaucratic and the lay**

Abstract: All National Institute for Health Research (NIHR) funding streams expect to see patient and public involvement (PPI) in every application they fund. Research Design Services (RDSs) are funded by the NIHR to help researchers develop their applications for national peer reviewed funding competitions. A service RDSs offer to researchers applying to nationally peer reviewed funding competitions is help and

support with developing thoughtful and meaningful PPI at pre protocol stage. The 10 RDSs across England do this in a variety of ways but for the RDS East Midlands (EM), one of the ways we do this is via a lay review service for the Scientific Committee (SC). The SC aims to mimic a genuine funding committee.

The RDS EM SC has been running for the last four years but since October 2013, a remote 'lay review' service was set up. The aim was to offer additional perspectives into the research being planned, such as providing comments on ethical issues, recruitment issues and whether the planned PPI seems appropriate and relevant. Since the lay involvement started in the SC, many academic, bureaucratic and lay issues have required careful thought and understanding. This poster highlights these issues and shares insights into what we did to overcome them.

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# **Engaging professional practitioners in patient and public involvement (PPI) in research**

**Abstract:** As professional practitioners we aim to support patients with physical, social and spiritual needs. We found that staff knowledge about patient and public involvement (PPI) in research is variable. Staff who are research active are involving patients in their research projects, whereas others find it hard to put the concept into practice.

We made a short video with members of the North Trent Cancer

Research Network Consumer Research Group (NTRN CRG) to reach a large and diverse group of staff working with patients. The aims were to:

- Raise staff awareness of the importance of involving the public in clinical research
- Improve the visibility of the patient as a research partner
- Help staff think about the different ways patients and the public can be involved in the research process.

We asked a single team to watch the video and think carefully about how to involve patients in research. We then evaluated the impact of the video as a learning tool using a staff survey. We want to know if the video helped to achieve staff understanding and engage patients with the desire to incorporate PPI into the research, and the knowledge and ability to make it happen.

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