

Impact of public involvement on the ethical aspects of research

Reward and recognition for children and young people involved in research – things to consider

Children and young people involved in research should receive appropriate reward and recognition for their contributions. This demonstrates the value that you place on their time, commitment and expertise when involved in your research activities. Many of the things to consider when involving adults also apply when involving children and young people; however there are other specific issues that you should think about when planning involvement that includes young people.

Involving children and young people in research: top tips

and essential key issues for researchers

This is a short overview of the key issues on involving children and young people in NHS, public health and social care research. These have been developed by INVOLVE in response to requests from researchers for practical information on what they need to consider when involving children and young people in research.

The purpose of this document is to highlight:

- top tips for researchers ranked by children and young people
- practical and essential information on how to plan to involve children and young people in research
- where to go for more detailed guidance and other resources.

The information was developed by reviewing existing information and guidance on involving children and young people in research. It is not intended as a comprehensive handbook or manual. The top tips were developed by selecting those that focused on the practicalities and asking children and people involved in research to identify which ones they thought were most important and if anything was missing.

Involving children and young

people in research: top tips for researchers

Many researchers understand the value of involving children and young people in NHS, public health and social care research, but are unsure how to go about it.

These tips were developed by:

- reviewing existing information and guidance on involving children and young people in research
- selecting those that were relevant to 'how' you involve children and young people
- asking children and young people involved in research to identify which ones they thought were most important and if anything was missing.

More detailed practical guidance including essential requirements for good practice such as safeguarding, legal and ethical requirements, alongside further reading and resources can be found in a related document [Involving children and young people in research: top tips and essential key issues for researchers 2016](#)

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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Sheffield Motor Neurone Disease Research Advisory Group

Abstract: The presentation will be in the form of a poster and it aims to educate people about the group that is now supporting Motor Neurone Disorders (MND) researchers through Yorkshire and Humber to:

- Enable patient and carer perspectives to be included in research proposals
- Identify and prioritise research topics important to patients and their families
- Improve recruitment to research studies
- Aid researchers to write clear lay summaries and study information sheets
- Help share research findings with a wider audience
- Raise awareness of MND research.

The group has increased its activity substantially since its development in 2009 and would like to share its experiences and ideas with other individuals involved in patient and public involvement work to encourage the innovative methods they have used.

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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