

Public Co-Applicants in Research – guidance on roles and responsibilities

This guidance is intended to help:

- Researchers wanting to include a public co-applicant in a study
- Public contributors wanting to become a co-applicant
- Research staff who coordinate public involvement activities or advise on funding applications
- Those working in or with research organisations to review or process research applications.

This guidance was developed jointly by the NHS R&D Forum, the Health Research Authority and INVOLVE.

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Pages: 24

Notes of INVOLVE Executive Group Meeting September 2017

Notes of INVOLVE Executive Group Meeting September 2016

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INVOLVE policy on payments and expenses for members of the public

This document lays out our internal policy and procedures for payments and expenses for members of the public involved with our work, including INVOLVE Group members. The policy explains when and how payments will be made and expenses covered. These procedures are specific to INVOLVE and our organisation. Others may find the information in the policy useful in order to develop a policy relevant to their organisation.

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Stronger together: Collective endeavours of a cleft and research organisation to promote the role of young people affected by a cleft in research

Abstract: The Cleft Lip and Palate Association (CLAPA) is a national charity that supports families and individuals affected by a cleft. It has been working closely with the Cleft Collective over the past two years to promote the active involvement of its members in research. The Cleft Collective is the world's largest cleft lip and palate research programme, with teams based in Bristol and Manchester. One group that has played an on-going role in this developing work is the charity's Children and Young People's Council (CYPC).

We are in the process of carrying out a consultation of young people's views and attitudes in shaping research on cleft. This will involve a focused discussion with members of the CYPC about what has happened so far and ways to improve this process in the future. We will explore what research means to this group, barriers and enablers to involving young people as patient and public involvement (PPI) partners and what these individuals might want to realise personally and more globally from undertaking such a role. We will report on results of this consultation, which we hope will prove useful for fellow delegates at the conference striving to engage young people in a PPI capacity. We anticipate it will raise issues that others have faced or considered when working with this age group in study development, production and dissemination.

Developing mobile applications for and with young people with long-term conditions learning to share their health-care with professionals: A young person and family-led approach

Abstract: Although young people are frequent users of mobile devices in day-to-day life, there is little reliable research that actually involves young people with long-term conditions as partners in the development and testing of mobile technology applications to support their health needs. However, the transition from child to adult health services means that young people need to develop their own clinical skills and knowledge so that they can manage their condition in a confident and competent manner. Therefore this area of research is ripe for development.

A group involving a patient with juvenile idiopathic arthritis (JIA), a parent, doctors, nurses, researchers and technologists have established a Manchester-based research and development programme on mobile technologies for young people with long term conditions. We have fostered strong partnerships with other national groups to help us agree on research priorities in this important area, and a plan of work

to help us achieve these.

First we obtained valuable suggestions from a national group of children and young people with JIA on the types of information and tools they would like to see included in a JIA specific mobile application. Next we are reviewing the research evidence to help us in our future work, and working with young people, parents and health professionals to produce a detailed software specification for a prototype application to test with young people. This poster will explore and discuss the progress we have made, with a focus on the central role of young people and their families living with JIA in the project.

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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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