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In this issue:

- Introduction from Zoe Gray, Director of INVOLVE
 - INVOLVE Coordinating Centre news
 - Benefits Advice Service
 - Understanding the research patient experience: results of a participant experience 'OK to ask' post card questionnaire undertaken by UK Clinical Research Facilities
 - Helping researchers to produce better patient information sheets
 - Noticeboard
-

Public involvement in research and research ethics committee review

This statement has been developed by the Health Research Authority (HRA) and INVOLVE for researchers who will be submitting applications for ethical review to provide clarity and guidance on public involvement in research and the requirements of Research Ethics Committee (REC) review.

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 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.

[Download poster](#)

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.