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## **Nothing about us without us: the importance of involving young people in healthcare research, from the bench to the bedside.**

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There is a growing appreciation amongst the research community of the positive impact that young people and their families can make to healthcare research. No matter how experienced the researcher is, there are certain skills and experiences which can only be shared by individuals with lived experiences of ill health. Young people who have experienced ill health bring an important perspective to the table, which can enrich research for the better. However, researchers should be mindful that involving young people is not a 'one box fits all' approach (Buck et al., 2014). It is important to remember that involvement in research should be a personalised experience, tailored to the needs, wishes and abilities of each young person – building on their unique journey. For example, with recent diagnoses, some young people may feel angry, frustrated and in denial, as they come to terms with their condition. With time and support, individuals may begin to accept and adapt their lifestyle accordingly. Let's also not forget that young people with ill health are busy people! Studying, working, socialising and managing health conditions is no easy task. With this in mind, researchers should recognise and appreciate the time and energy young people with ill health offer to research, and must ensure that the necessary support and recognition is in place, from the offset.

The National Institute for Health Research (NIHR) has pioneered patient and public involvement in research, placing people at the heart of everything it does. Between 2013 and 2014, over 1000 members of the public were involved on NIHR advisory groups responsible for prioritising and funding research (NIHR, 2014). Ultimately, people who are affected by research have a right to be involved in choosing what research is undertaken, and the way in which it is conducted. By recognising and accepting the expertise of young people with lived experiences of ill health, we can raise the quality and relevance of research. The NIHR's Clinical Research Network has actively promoted and support the involvement of young people throughout the entire research cycle – from prioritisation through to dissemination and informing future research. Unfortunately, young people are not always involved in the earlier stages of research, and are often only consulted during the design phase, where aims and objectives are more or less defined. Involving young people in the prioritisation and early design stages will help the delivery of research that addresses the unmet needs of young people and their families (Kirby, 2004).

### **Involvement, engagement and participation – are they not the same thing?**

On the whole, there is a relatively poor understanding amongst researchers, and members of the public alike, as to what 'patient and public involvement' in research actually is, and how it can impact the quality of research. Therefore, it is helpful to contextualise the different research activities that young people may be associated

with, whether or not they have lived experiences of ill health, or are simply interested in healthcare.

**Participation:** This is where young people take part in a research study, as a 'participant'. For example, when young people are recruited to a randomised controlled trial, or are asked to complete a questionnaire. Young people may find out about research participation opportunities from their general practitioner, secondary care team, local hospital trust or the clinical trials gateway, for example.

**Engagement:** This is where information and knowledge about research is provided to young people who are not actually being invited to participate in research as defined above. Some examples of engagement activities include attendance at science festivals, open days at hospitals, and raising awareness via print, broadcast, and social media.

**Involvement:** This is where young people are actively involved in research projects as contributors and partners in research. Some examples of involvement activities include membership of young person advisory groups (YPAGs), conducting interviews with participants, co-authoring manuscripts, and presenting at conferences.

In the United Kingdom, the NIHR has established a YPAG network, called GenerationR (GenerationR, 2016). These dynamic groups of young people, aged between 8 and 19, meet on a monthly basis, to learn about healthcare research, as well as supporting and working in partnership with researchers and health professionals. Members include a combination of young people living with one or more health conditions and healthy young people with an interest in healthcare. GenerationR groups also provide input and support to a wide number of organisations, and are affiliated with the international children's advisory network (iCAN), a worldwide consortium of YPAGs working together to provide a voice for young people and families in healthcare research.

Researchers who have worked with young people have found it an enriching and rewarding experience. Their involvement is often instrumental in ensuring the validity and appropriateness of study outcomes for young people and their families (Preston et al., 2016). By involving young people in research, we can generate new research ideas, understand how best to approach young people, and find new ways to talk and communicate with them. Only by involving young people in research can we keep them and their families at the very heart of healthcare research and practice.

### **Useful resources for young person and family involvement in research**

- GenerationR: <http://generationr.org.uk/>
- International Children's Advisory Network (iCAN): <http://www.icanresearch.org/>
- INVOLVE: <http://www.invo.org.uk/>
- NIHR CRN: Children: <http://www.crn.nihr.ac.uk/children/about-children-research/clinical-studies-groups/>
- Patient Research Ambassador Initiative:
- People in Research: <http://www.peopleinresearch.org/>

- Royal College of Paediatrics and Child Health & Us:  
<http://www.rcpch.ac.uk/improving-child-health/us-voice-children-young-people-and-families/us-voice-children-young-people-an>

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