

Involving young people in the design and delivery of health research

By Jenny Preston and Sarah Moneypenny (member of the NIHR Young Persons' Advisory Group)

Thanks to the support of the National Institute for Health Research (NIHR) Clinical Research Network (CRN): Children (originally known as the NIHR, Medicines for Children Research Network) set up in 2005, more than 56,000 children have taken part in almost 300 trials, many concerning novel drugs and treatments. This has had an impact on the care that all children receive. This is driving more researchers to seek the input of patients and families in the development of their work, which is leading to a transformation of the cultural and regulatory environment for children's research. The Network has been at the forefront of patient and public involvement in research for some time. In 2006, it started its first Young Persons' Advisory Group (YPAG) based at the Network's coordinating centre in Liverpool. Since then, four more groups have been established in London ([see article about the London YPAG](#)), Nottingham, Birmingham and Bristol. Each group has approximately 15-20 members aged between 8 and 19 years old.

The remit of the group is to engage young people with research and to work in partnership with, and offer support to, researchers. The group provides a forum for young people to learn about, and comment on, various aspects of the research cycle from the identification of research questions to the dissemination of research findings. The group also works alongside national and European governing bodies, such as the National Research Ethics Service (NRES) and the European Medicines Agency (EMA) as well as organisations such as the Royal College of Paediatrics and Child Health (RCPCH), helping

to remodel guidance they provide to researchers to help them design and deliver ethically robust research for children, as well as support researchers in the design and deliverability of their studies.

With the paediatric research community increasingly focusing on the real-world relevance of research, the influence and impact of the Young Persons' Advisory Group is growing dramatically. This shift in culture is further evidenced by the number of researchers approaching the group for support and this includes life sciences organisations. In 2013-14 an evaluation carried out by the National Children's Bureau (NCB) Research Centre of the group's activities (www.crn.nihr.ac.uk/children/resources) highlighted their involvement in over 60 activities to support individual research projects. The majority of projects were medical studies (81%). Among these the most common study types were randomised control trials (28% of all recorded studies) and observation studies (27% of all recorded studies).

Also important is the need to engage researchers at the earliest stage possible in protocol development to ensure the outcomes and acceptability of the study suit the needs of patients and families. Several examples of this can be found in the highlighted evaluation report, but one particular example is of a company that approached the group to help develop informed consent documentation. The study involved investigating a therapy to help spasticity due to cerebral palsy in 8 to 18-year olds and, at a later date, 0 to 8-year olds. The company approached the group for advice and attended a group meeting not knowing what to expect. The company was pleased to leave the meeting with several different versions of informed consent/assent forms and other ideas, including the use of different technologies such as Apps. One concern of the company was discussing the delicate topic of cannabis, which is a component of the drug in the study, and was referred to as 'plant based' in the assent

forms. The level of understanding of the group was much higher than the company expected, which encouraged much more open and frank discussions. This led to some really good outcomes, including a clear definition of the drug being tested, a revised structure for the informed consent/assent forms for different age groups, a review of diaries to be used by patients and families, and some good ideas about keeping children motivated throughout the trial with stars and certificates. The ethics committee highlighted that the assent/consent form was very good and the study rapidly received ethical approval. Shortly after the study was approved it recruited its first patient worldwide from the Evelina Children's Hospital in London. The study is now on the way to achieving its recruitment targets.

Sarah Moneypenny, a member of the Liverpool Young Persons' Advisory Group, highlights the importance of working alongside researchers:

"To be able to work alongside researchers and be taken seriously is really motivating....it is great to see that industry is open to involving young people in their research to develop a more patient friendly end product."

We need to promote and develop similar collaborations and encourage as much involvement in the early stages of research development as possible.

CRN: Children has had a substantial amount of success in engaging with children and young people. The formation of the Young Persons' Advisory Group, topic specific focus groups, and engaging with young people in schools, has enabled young people to become more involved in the research process by giving them the confidence, information and opportunities to be able to contribute at all levels. An exciting initiative to expand our work with young people is working with Sir Iain Chalmers, Coordinator of the James Lind Initiative, in the development of a young persons' website that will sit within

Testing Treatments interactive (www.testingtreatments.org). The purpose is to improve young people's understanding of the reasons for doing fair tests of treatments, what fair tests look like, and how they and everyone else has some role to play in promoting better research for better health care. Members of the Young Persons' Advisory Group have been integral in developing and having editorial responsibility for one or more modules within the website, which will be launched in April 2015.

For further information about the group or to find out how to access the group to support your study please contact Jennifer.preston@liverpool.ac.uk or follow the links via www.crn.nihr.ac.uk/children/pcpie/young-persons-advisory-group/