### Report on Involving Children and Young People in Research

This report presents the findings from both a mapping exercise and survey regarding the process of involving children and young people in research as advisers as opposed to research participants. Both these activities were undertaken by INVOLVE Coordinating Centre staff with guidance and advice from the Children and Young People's Working Group which consists of young people, public involvement leads and researchers.

## Children's Liver Disease Foundation

# 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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## NIHR Nottingham Biomedical Research Centre

## NIHR PPI Newsletter September 2018

INVOLVE - NIHR Newsletter September 2018

In this issue:

- Priorities for health research
- Keeping Co-production on the agenda
- Help shape medtech research on diagnosing flu
- Patients' experience of taking part in the INFORM study
- NIHR Annual Stats
- Hear about great PPI work being done
- Patient group shows power of working together
- People in Research survey

 Help guide future research about problematic knee replacements

#### Sophie Ainsworth



I stumbled into the world of research and healthcare, following a diagnosis of Lupus in 2014, when I was 14 years old. Since then I have become a passionate advocate for patient voice in healthcare, particularly for children and young people, who are often overlooked. Following my diagnosis, I became a participant

in research studies, both as a patient and being on advisory groups. I have sat on the advisory group for the TRECA Study, which develops multimedia interventions for patient information sheets. I have also worked closely with the Alder Hey Clinical Research Facility and Lupus UK on a variety of projects and have been an NIHR Patient Research Ambassador for two years.

Most of my work nowadays focuses on RAiISE, a charity I founded two years ago which stands for Raising Awareness of invisible Illnesses in Schools and Education. It is dedicated to supporting students who are living with 'invisible' illnesses to ensure they are given the support they need in school by equipping teachers with resources and information to do so.

## IN Bulletin 6 – Involving young people in research

Welcome to the sixth issue of our IN: Bulletin.

This bulletin focuses on young people in research. Sam Goold, INVOLVE's Public Involvement Officer, meets a researcher and young person from a healthy eating research project.

#### NIHR PPI Newsletter July 2018

INVOLVE - NIHR Newsletter July 2018 - Focus on I Am Research/NHS 70

In this issue:

- #IamResearch is a conversation opener for public involvement
- Simon Denegri recognised in Queens' Birthday Honours
- Celebrate NHS 70th Birthday
- The Great Untold Story of Research
- The public as our partners' highlights report
- Patient Experience Survey results
- Co-Producing research: How we do it? Event, London