

The evolving role of children and young people in Research





INVOLVE at 21 Conference, 28 November 2017

GOSH Young Person's Advisory Group (YPAG)



We are part of





a national Young Persons' Advisory Group made up of six groups around England

NIHR Great Ormond Street Hospital Biomedical Research Centre (GOSH BRC)

- aged between 8-21 years old, some of us have health conditions and experience of participating in clinical trials, currently we have 24
- all interested in medicine, research and science;

members;

- meet 6 times a year at GOSH on Saturdays;
- get actively involved in the **design** and **delivery** of clinical research to make sure that it is relevant to young people;
- researchers planning to undertake health research with children and young people visit YPAG to get input and advice on any element of their project- we learn about their clinical research and discuss how to make it work better for young people;
- attend events and conferences like today's to speak about our work and to encourage researchers to engage with us!



NIHR Great Ormond Street Hospital Biomedical Research Centre (GOSH BRC)

NHS National Institute for Health Research

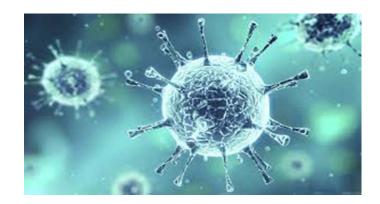
How I've been involved – my first meeting

- reviewed Patient Information
 Sheets for different age groups for a project on Vitamin D in children
- gave my views on a study to compare the long-term outcomes after two different anaesthetics





 gave feedback on a clinical trial of gene therapy for children with a genetic liver disease





Children and young people as **partners** from the early stages of research;

Involving more children and young people as **Research Ambassadors**!

ensuring future research is more **relevant** to children and young people and establishing an ongoing dialogue with them.





Running a research project and want our input? Email: research.ppi@gosh.nhs.uk

Want to meet the other Generation R groups? Website: <u>www.generationr.org.uk</u>

Training for Researchers Website: <u>http://www.uclhospitals.brc.nihr.ac.uk/investigators/ppi-training</u>