



Alder Hey Children's **NHS**  
NHS Foundation Trust



**NHS**  
*National Institute for  
Health Research*

# GenerationR & Patient Involvement in Research

UK Paediatric Rheumatology Trainee Day– 15<sup>th</sup> January 2016

**Jenny Preston**, Patient and Public Involvement Manager, NIHR CRN:  
Alder Hey Clinical Research Facility

**Phoebe Rushe**, Patient

# Learning Objectives


- Understand patient and public involvement (PPI)
- Model of involving young people – GenerationR
- Young people's stories
- How to do PPI – practical support



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## Young people and research



Flash dance for Psoriasis

We have gained an international reputation for our long-term commitment, and innovative approach to, involving young people in the design and delivery of clinical research in the UK.

**“The NIHR is committed to involving young people in relevant research, whether as participants or advisors, or in reviewing research studies and proposals. High quality research involving children and young people depends on listening to their voices, as well as their families and carers, taking account of their experiences, priorities and perspectives. The NIHR believes that children can make real contributions to decision making in these areas.”**

# Patient & Public Involvement in Research

- Involving patients, carers and the public, who have personal experience of or an interest in a health condition(s), in research or research related activities



- An active partnership between patients and the public and researchers, doctors and other NHS staff



# “When we talk about ‘involvement’ in research, we mean actively getting involved in the research process, rather than being participants of the research” HRA

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☒ Design of the research
- ☐ Management of the research
- ☒ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☐ None of the above

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☒ Design of the research
- ☒ Management of the research
- ☒ Undertaking the research
- ☒ Analysis of results
- ☒ Dissemination of findings
- ☐ None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

In order to establish a randomised clinical trial within a population of children with suspected infected eczema, we have service users (parents of children with eczema) as part of our Trial Management Group and Trial Steering Committee. The service user on our Trial Management Group also runs an eczema support group, and has sought advice and views from parents within the support group on the CREAM Study design and materials. During trial set-up, advice and review from our service users has been vital in ensuring ethical considerations regarding consent, developing participant information and data collection tools. Furthermore they have provided a non-expert overview of the study procedures and logistics to ensure they are understandable and workable.

NHS R&D Form

*Give details of involvement, or if none please justify the absence of involvement.*  
This study and the study documents have incorporated feedback from service users, which was coordinated by the Oxford Vaccine Group.

The Oxford Vaccine Group asks all participants or their families to provide feedback to help us improve. We will inform the design and conduct of future studies. In addition, participants will be asked to provide feedback during visits.

How?



A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☒ Design of the research
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**West Midlands**



**Nottingham**

# GenerationR YPAG



**South West**



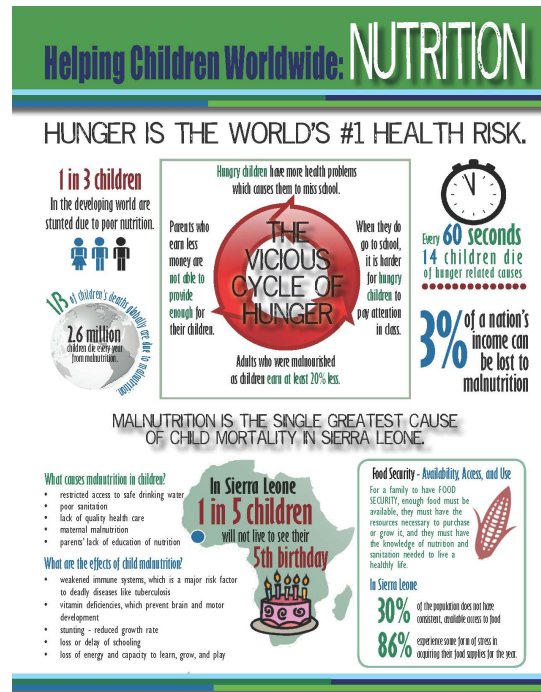
**Liverpool**



**London**



# How the group helps researchers



**KEEP  
CALM  
AND  
BE  
REASSURED**

# What's important to young people





**GenerationR**  
young people improving Research

HELP

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GAMES,  
QUIZZES & MORE

# Young people improving health through research

# Patient Perspective of Research

Phoebe Rushe



- ★ Phoebe Rushe
- ★ 2nd year Medical Student @ University of Liverpool
- ★ Juvenile Dermatomyositis patient
- ★ Currently treated at Centre for Adolescent Rheumatology, UCLH and Broadgreen Hospital.

- ★ My involvement in research
- ★ What do patients think of research?
- ★ Effect of involving young people in research
- ★ How can we encourage patient participation in research?

# My involvement in research





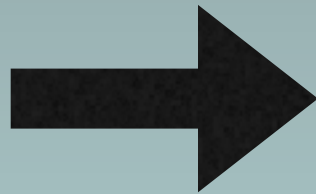
What do patients think of  
research?

How can being  
involved in research  
benefit patients?

How can we involve  
more patients in  
research?

How can we involve  
more patients in  
research?

# Thank you!



[phoeberushe@gmail.com](mailto:phoeberushe@gmail.com)

# Living with JIA & contributing to research



<http://www.arthritisresearchuk.org/arthritis-information/your-stories/juvenile-idiopathic-arthritis/simon-stones.aspx>

# Planning Involvement



# Top tips!

- **Plan** involvement as early as possible
- Be clear about what patients or families **will be able** to do
- Be clear about what patients or families will **not be able** to do
- Ensure all staff **understand** the reasons for involving patients
- Support patients and families with **training** and **information**
- Identify a **key person** within the research team for patients to contact
- As a minimum reimburse users **travel expenses**
- Where possible offer **childcare** or **carer expenses**
- **Acknowledge** patient input and be sure to feedback on the research and what you feel their contribution meant

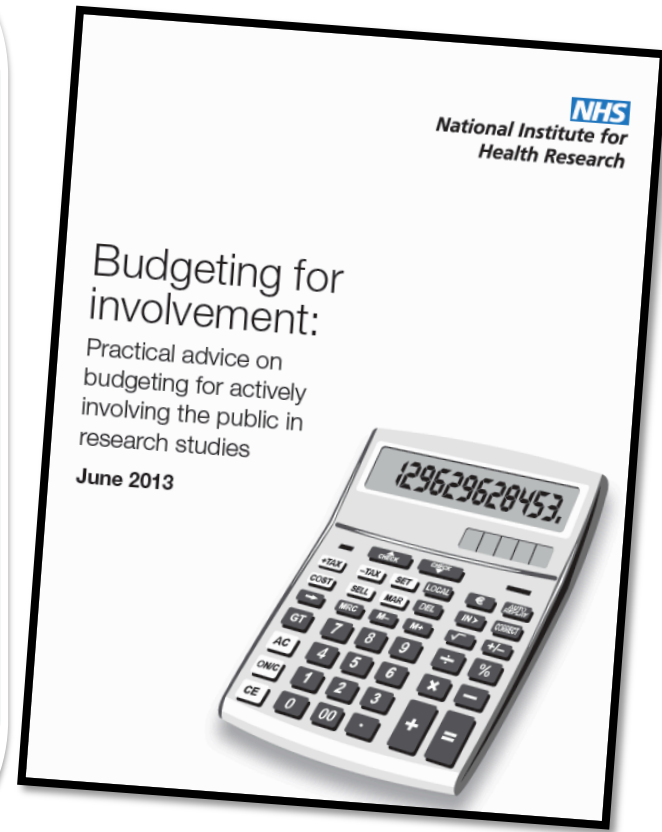


# Budget considerations

- **How many** patients you involve
- What you expect the patients **to do** and **how often**
- **Where** they travel from
- Childcare and carer **support**

*Other considerations include:*

- Room hire
- Refreshments
- Training
- Stationery
- Payment (if you feel this is appropriate and budget allows?)





**Learn  
More**

# Additional resources

[Home](#) > [Find out more](#) > [Involving children and young people](#)

## Find out more

- ▶ [What is public involvement in research?](#)
- ▶ [Public involvement in research](#)
- ▶ [Interested in getting involved?](#)
- ▶ [Information for researchers](#)

## ▶ [Involving children and young people](#)

- ▶ [Resources for involving children and young people in research](#)
- ▶ [References on involving children and young people](#)

## Involving children and young people

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### Involving children and young people will help you:

- find out about research questions that are important to them
- learn new ideas for your research that you might not have thought of
- understand how best to approach young people to



## See also

-  [Resources for involving children and young people](#)
-  [Articles about involving children and young people](#)



Contact details:

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GenerationR website

[www.generationr.ac.uk](http://www.generationr.ac.uk)



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@EATC4Kids