



Generation R Alliance: Terms of reference

1. Introduction

Building on the success of the first GenerationR meeting in September 2013, a meeting on 31st October 2015 brought together people and organisations with an interest in children and young people's (CYP) involvement in health research. The purpose of the meeting was to highlight progress with the eleven recommendations set out in the [GenerationR report](#), and to discuss what needed to be done to ensure CYP's involvement in the design and delivery of health research, which remains a key priority in the UK.

Over 30 delegates, including young people and representatives of the National Institute for Health Research (NIHR), charities, the Nuffield Council on Bioethics, the Royal College of Paediatrics and Child Health, the James Lind Initiative, industry, and the Health Research Authority shared their experiences and discussed both challenges and priorities for future work. There was overwhelming consensus on the need for:

- interested groups to collaborate,
- national oversight of CYP's involvement,
- adequate resources to support CYP's involvement in research.

Delegates agreed to name such collaboration 'The GenerationR Alliance' and suggested it be responsible for developing an engagement strategy to support, signpost and promote collaboration.

2. Objectives

The Alliance will:

- Be responsible for developing an engagement strategy to support, signpost and promote collaboration both within and among existing Generation R young people's advisory groups (YPAGs) and more widely, for example, looking outward to other CYP groups, for example those linked with experience of specific conditions or services, and to CYP in general as well as parents and carers.
- Facilitate work based initially on the GenerationR recommendations and on other agreed priorities
- Act as a forum and network to collate and disseminate information about activities relevant to GenerationR Alliance
- Work together to build an evidence base, in UK and internationally, on the impact of

the involvement of CYP in health research, both on the research and on the knowledge of CYP.

3. Membership

The Alliance will offer open membership to any organisation, group or individual able to:

- demonstrate an interest in promoting CYP's involvement in health research
- collaborate and share with other members information about relevant processes and outputs of CYP activities
- demonstrate willingness to include CYP in their work
- share the GenerationR Alliance's objectives (section 2,above)

4. Coordination of the Alliance

The Alliance will be led by Jenny Preston, Patient and Public Involvement Manager at the NIHR Alder Hey Clinical Research Network, Dr William van't Hoff, Director of the GOSH Clinical Research Facility and Dr Pamela Dicks, ScotCRN Manager. We will oversee the activities of the Alliance to:

- monitor and ensure it meets and adheres to its objectives (see section 2 above)
- approve membership of interested organisations, groups or individuals
- coordinate national activities
- organise regular meetings with Alliance members
- Provide training & support in maintaining pages on the GenerationR website and blog writing
- Share good practice

5. Communication and Dissemination

The GenerationR website <http://generationr.org.uk/> will be the main portal of communication and dissemination, listing:

- Structure, purpose and activities of the GenerationR Alliance
- List of affiliated members, with a specific page (or link) to their respective websites
- All outputs and work of the GenerationR YPAGs
- Blog/Interactive section for comments/suggestions

6. How to get involved

Interested organisations, groups or individuals should register their interest using the online registration form on the GenerationR website to initiate discussion of possible involvement in and contributions to the Alliance.

7. GenerationR Recommendations

Recommendation 1: Work with key stakeholders including parents and young people to identify solutions on tackling the major challenges. This could be achieved in collaboration with organisations such as the Nuffield Council for Bioethics and the Royal College of Paediatrics and Child Health (RCPCH)

Recommendation 2: Summary level results should be made publicly (open access) available for all clinical trials

Recommendation 3: A patient specific (confidential) results feedback sheet mandatory part of the research process (as is the Patient Information Leaflet)

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Recommendation 5: Researchers and sponsors should ensure provision for the on-going supply of a treatment shown to be successful in a clinical trial to the study participant

Recommendation 6: To explore alternative and innovative ways of engaging with more young people and families, building our links with charitable organisations and parent/young people's groups

Recommendation 7: NIHR CRN: Children, PPI work-stream to work closely with the CRN Children's Research Industry Group (CRIG) to explore how models of closer collaboration with industry partners can be implemented

Recommendation 8: Build on collaborations with NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) to encourage involvement of young people and families in the identifying and prioritising of research studies

Recommendation 9: Develop an effective communications strategy that showcases involvement activities and sustains the objectives highlighted at GenerationR. This will require the use of innovation communication tools, such as; a dedicated GenerationR website, E-Magazine and the use of social media

Recommendation 10: To develop a systematic way to measure the impact of involvement activities

Recommendation 11: Work with the education sector to promote clinical research in schools, sharing resources such as Testing Treatments Interactive, resources developed by

NHS England, and the Centre of the Cell.