

# GenerationR Alliance

## Terms of Reference

### 1.0 Introduction

The GenerationR Alliance is a national community of practice dedicated to coordinating and advancing the involvement of children and young people (CYP) in health and social care research. Established in 2015 following a national meeting to strengthen collaboration in this area, it brings together organisations, researchers, and Patient and Public Involvement (PPI) practitioners to support meaningful involvement through shared learning, mutual support and collective leadership. The GenerationR Alliance is supported by the Hugh Greenwood Legacy for Children’s Health Research Fund and the Experimental Arthritis Treatment Centre for Children (EATC4Children).

### 2.0 Purpose

- Bringing together PPI practitioners, child-health researchers, healthcare professionals and partner organisations, the GenerationR Alliance provides shared leadership, promotes consistent practice, and strengthens collaboration across the sector.
- It also creates structured opportunities for feedback and shared learning, enabling members to reflect on effective practices, exchange practical insights, and collectively improve involvement approaches over time.
- Through this coordinated effort, the GenerationR Alliance contributes to building a robust UK and international evidence base on the impact of CYP involvement in research.

### 3.0 Objectives

#### The Alliance will:

- **Develop and implement an engagement strategy** that supports, signposts, and promotes collaboration within and between:
  - GenerationR affiliated Young People’s Advisory Groups (YPAGs)

- Outwardly to other CYP groups (including those linked to specific conditions or services)
  - To CYP more broadly who may not be part of an established YPAG.
  - To parents and carers.
- **Facilitate collaborative work** informed by the GenerationR Alliance recommendations and other agreed priorities identified by the community of practice.
  - **Act as a national forum and network** to gather, coordinate, and disseminate information about activities relevant to the GenerationR Alliance and CYP involvement across the research landscape.
  - **Build and strengthen the evidence base**, nationally and internationally, on the impact of involving CYP in health and social care research, both on research design, delivery, and outcomes, and on CYP's knowledge, confidence, and skills.

#### 4.0 Membership

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

- **Demonstrates a commitment to promoting CYP involvement** in health and social care research.
- **Actively collaborates and shares learning** with other members, including information about processes, activities, and outputs involving CYP.
- **Shows a willingness to involve CYP meaningfully** in their work or practices.
- **Endorses and supports the objectives** of the GenerationR Alliance.

#### 5.0 Coordination of the GenerationR Alliance

The GenerationR Alliance is coordinated by Jenny Preston, Senior Patient and Public Involvement Manager, and Jodie Jones, Youth and Family Participation Officer, employed by the Experimental Arthritis Treatment Centre for Children (EATC4Children).

They will oversee the activities of the GenerationR Alliance to:

- **Monitor and ensure adherence to the GenerationR Alliance's aims, objectives, and agreed ways of working.**
- **Approve membership** applications from interested organisations, groups, or individuals.
- **Coordinate national activities** that support CYP involvement and shared learning.
- **Organise regular meetings** for Alliance members to connect, plan, update and collaborate.

- **Provide training and support** for maintaining and updating GenerationR website pages and producing blog content.
- **Promote and share good practice** across the community of practice.
- **Review the ToR on a yearly basis.**

## 6.0 Communication and Dissemination

The GenerationR website (<http://generationr.org.uk/>) will serve as the primary platform for communication, information sharing, and dissemination of Alliance activities. It will include:

- **Information on the structure, purpose, and activities** of the GenerationR Alliance.
- **A directory of affiliated members**, including dedicated pages or links to their respective websites.
- **Outputs and resources produced by GenerationR YPAGs**, including reports, case studies, and project summaries.
- **A blog and interactive space** for sharing updates and inviting comments, reflections, and suggestions.

Members are encouraged to share updates, news items or examples of good practice by submitting a short contribution through the Alliance's new 2026 Google Form, which also supports newsletter content planning and helps ensure that shared learning is circulated across the network.

## 7.0 How to get involved

Organisations, groups, or individuals interested in joining the Alliance can express their interest by completing the online registration form on the GenerationR [website](#). This will begin a conversation about potential involvement and contributions to the Alliance.