

## **NIHR Children and Young People Health Research Centre (NIHR HRC-PCH)**

### **Children, Young People and Family Involvement and Engagement Strategy 2024-2029**

#### **Introduction**

The National Institute for Health and Care Research (NIHR) Healthtech Research Centre in Paediatrics and Child Health (HRC-PCH) is dedicated to developing health technology for Children and Young People (CYP), from early life through to young adulthood. We are a national network, providing a comprehensive offer to the NHS and industry, combining expertise from world leading NHS Children's Hospitals and Units, and Universities.

The **vision** for HRC-PCH is to develop the best and most advanced technology-driven healthcare for and with CYP and families. Our aim is to publicise, encourage, support and facilitate appropriate, innovative and meaningful CYP and family involvement in all HRC-PCH activities and ensure diverse communities of underrepresented groups are at the heart of everything we do.

#### **Definitions**

We use the following definitions from the [NIHR](#) for '**involvement**', '**engagement**', and '**participation**'.

**Involvement:** research being carried out 'with' or 'by' patients or members of the public rather than 'to', 'about' or 'for' them. It is an active partnership between patients, families, and members of the public with researchers that influences and shapes research.

**Engagement:** where information and knowledge about research is provided and disseminated.

**Participation:** taking part in a research study, for example being recruited to take part in a clinical trial or another kind of research study, joining in a focus group or completing a questionnaire.

For CYP's involvement in decision-making we adopt a child-centred, rights-based approach informed by the United Nations Convention on the Rights of the Child (UNCRC).

**CYP’s involvement in decision-making:** we define this as “**the process by which CYP have active involvement and real influence in decision-making on matters affecting their lives, both directly and indirectly**”. This definition is consistent with Article 12 of the UN Convention on the Rights of the Child (UNCRC), which underlies this strategy (see Table 1).

Table 1: Article 12 of the UNCRC

1. State Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
2. For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law.

\*For the purpose of this strategy we align our approach to point 1.

### **How this strategy was developed**

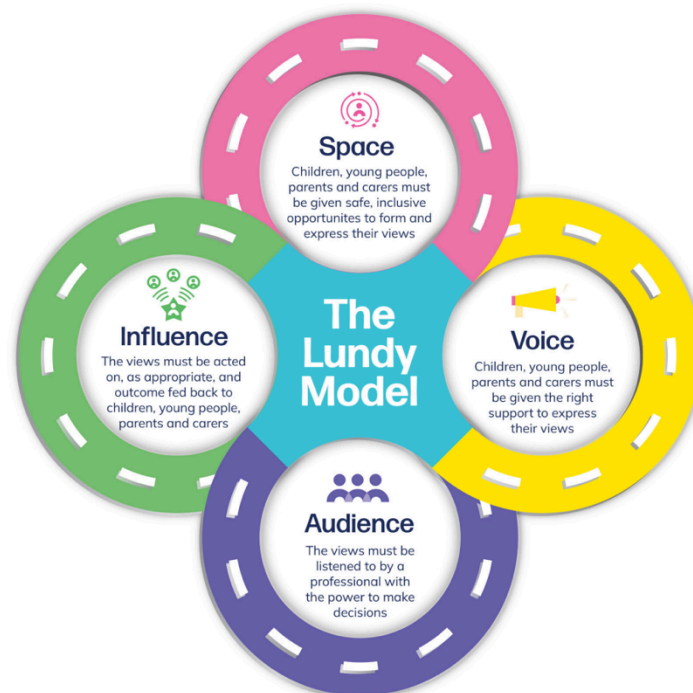
This strategy is built on the extensive experience of working in partnership with CYP and families within the National Child Health Technology Network – TITCH (Technology, Innovation Transforming Child Health), and the NIHR Children and Young People MedTech Cooperative. More importantly the strategy was developed in consultation with CYP.

The strategy is aligned to national NIHR strategies ([Going the Extra Mile](#); NIHR [Strategic Commitments for Public Partnerships](#)) and is underpinned by the [UK Standards for Public Involvement](#). More crucially, our work with CYP aligns to a child-centred, rights-based approach<sup>1</sup> that ensures the right for CYP to express their views, and the right for their views to be given due weight. This means that CYP and family involvement and engagement is everyone’s responsibility. So to embed it across the HRC-PCH, we have adopted a practice model: [The Lundy Model](#). The model uses four domains (see Figure 1) of Space, Voice, Audience and Influence as a framework to ensure that those we work with play an active role in what we do.

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<sup>1</sup> A rights-based approach is the application of human rights standards in practice. The right to participation is one of the underpinning principles of a rights-based approach and it also recognises the interdependence of all human rights, meaning the realisation of one right may depend on the realisation of others.

**Figure 1: The Lundy Model**

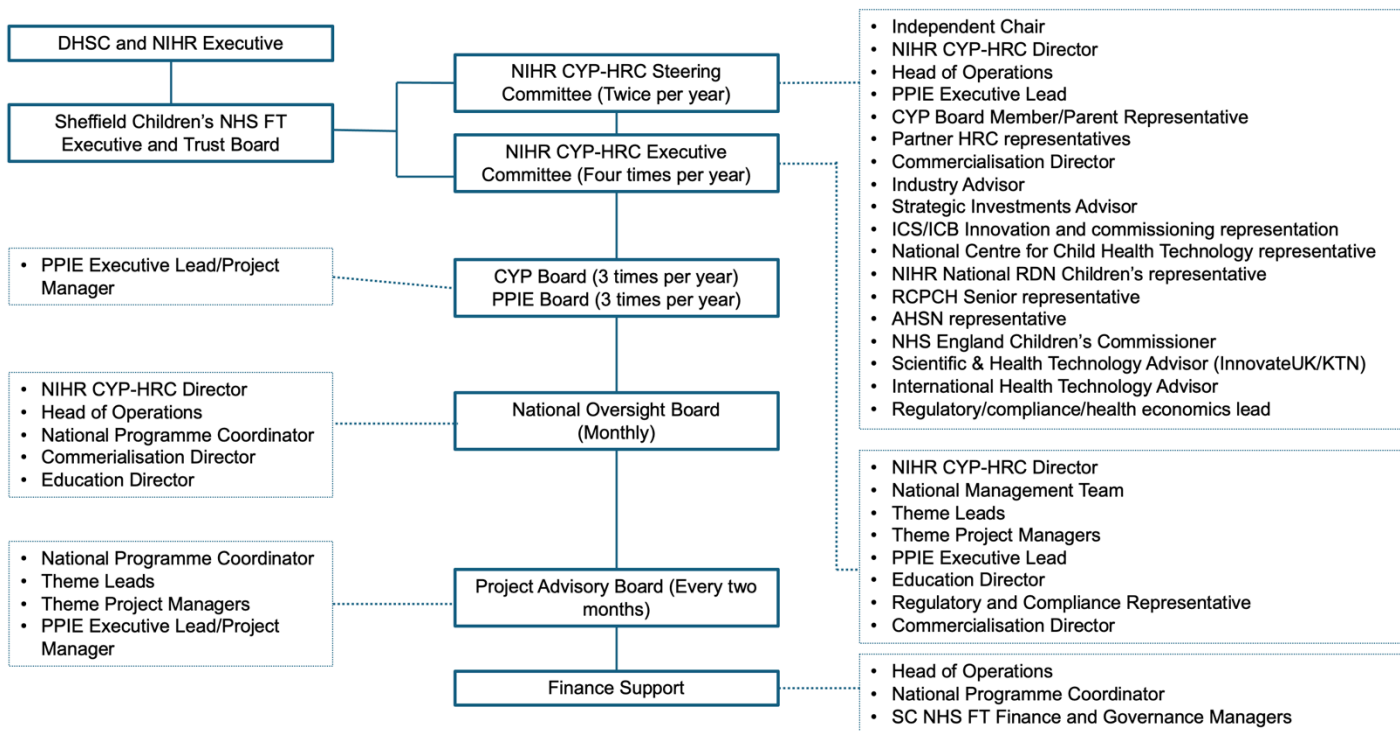


### **Leadership and Governance**

The PPIE Strategy was endorsed by the HRC-PCH Executive Committee. The HRC-PCH Patient and Public Involvement and Engagement (PPIE) Executive Lead has extensive expertise working in partnerships with CYP and families across the globe, and will lead ground-breaking work that is transferable to commercial and non-commercial organisations nationally and internationally. The PPIE Executive Lead will be responsible for the review and delivery of the strategy, supported by a Project Manager and the wider PPIE team (Project Managers and PhD students linked to HRC-PCH Themes). The PPIE Executive Lead is accountable to the HRC-PCH Director.

The PPIE Executive Lead will establish a CYP Board and PPIE Board (members will include Theme representatives, and family representatives) to meet quarterly from Q3 (Year 1) to input into HRC-PCH strategy, operations, governance and project activities. Young members of the CYP Board and parent representatives will be members of the Executive Committee, supported by the PPIE team (see Figure 2).

**Figure 2: NIHR HRC-PCH Governance**



We have designated a considerable amount of resource to CYP and family involvement/engagement including staff time, and a consumable budget to deliver activities (including paying CYP and families for their time based on NIHR guidance). All CYP and family activities comply with ethical, safeguarding and GDPR principles.

**Strategic aims**

Our vision is underpinned by our networks and wide-ranging experience to involve CYP and families in research in meaningful and effective approaches, whilst valuing their contributions and building sustainable long-term relationships. We will achieve our vision through the following strategic aims and objectives, each with associated actions designed to improve the quality and consistency of CYP and family involvement and engagement:

- **Inclusive decision making:** To enable and support CYP and families to be involved in decision-making and governance throughout the HRC-PCH.
- **Diversity and inclusion in CYP and family involvement and engagement:** To embed a culture of inclusive and diverse involvement and engagement in all HRC-PCH activities.
- **Capacity, learning and leadership:** To enhance skills and confidence in HRC-PCH staff, researchers, partners, CYP and families in meaningful involvement and engagement.
- **High quality advice and support:** To provide high quality HRC-PCH advice and support to partners and research teams on embedding meaningful CYP and family involvement and engagement.
- **Knowledge exchange and impact:** To embed standards, reporting and a culture of feedback and evaluation to demonstrate the impact of CYP and family involvement in HRC-PCH activities.

**Strategic objectives**

G o v e r n a n c e	Strategic Aim	Objectives
	<p><b>Inclusive decision making:</b> To enable and support CYP and families to be involved in decision-making and governance throughout the HRC-PCH</p>	<ul style="list-style-type: none"> <li>● Involve CYP and families in HRC-PCH governance and research-facing activities</li> <li>● CYP and families regularly meet senior staff and HRC-PCH members and are included in decision-making.</li> <li>● Improve understanding of CYP and families experiences of involvement in research governance and decision-making committees.</li> <li>● Job descriptions for all HRC-PCH staff includes the promotion of CYP and family involvement and engagement and this is evaluated in core staff's annual performance appraisals.</li> </ul>

I n c l u s i v e o p p o r t u n i t i e s	<b>Strategic Aim</b>	<b>Objectives</b>
	<p><b>Diversity and inclusion in CYP and family involvement and engagement:</b> To embed a culture of inclusive and diverse involvement and engagement in all HRC-PCH activities.</p>	<ul style="list-style-type: none"> <li>● Put in place systems, procedures and resources that ensure involvement and engagement opportunities that are inclusive, safe, enjoyable and meaningful for CYP and families involved (based on the Lundy Model)</li> <li>● Offer a range of inclusive opportunities for CYP and families to become partners, to influence the planning and delivery of HRC-PCH theme projects and strategic decisions</li> <li>● Launch the PPIE Development Methodologies and EDI Programme (DeMEDI)</li> <li>● Create novel methodologies to direct the inclusion of hard to reach and seldom heard groups, through workshops and capacity building</li> <li>● Enhance established collaborations and outreach with underserved groups and regions</li> <li>● Work in partnerships to gather, maintain and use intelligence of CYP and family involvement networks (i.e., GenerationR Alliance, NHS Youth Forum, Charitable and Voluntary sector, etc) to increase reach and support researchers.</li> </ul>

C a p a c i t y a n d	<b>Strategic Aim</b>	<b>Objectives</b>
	<p><b>Capacity, learning and leadership:</b> To enhance skills and confidence in HRC-PCH staff, researchers, partners, CYP and families in meaningful involvement and engagement.</p>	<ul style="list-style-type: none"> <li>● Training programmes are made available for all staff in relation to active and meaningful involvement and engagement of CYP and families, and they are actively involved in the design, delivery and evaluation of these programmes.</li> <li>● Develop an education package for public and private sector partners to direct meaningful CYP and family involvement.</li> <li>● Share knowledge and develop resources on involving and engaging diverse populations</li> <li>● Implement an induction and learning programme for CYP and families.</li> </ul>

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A d v i c e a n d S u p p o r t	<b>Strategic Aim</b>	<b>Objectives</b>
	<p><b>High quality advice and support:</b> To provide high quality HRC-PCH advice and support to partners and research teams on embedding meaningful CYP and family involvement and engagement.</p>	<ul style="list-style-type: none"> <li>• Develop a clear offer of support and advice for researchers to undertake meaningful CYP and family involvement and engagement</li> <li>• Develop and use guides to support high quality CYP involvement and engagement during project development and delivery</li> <li>• Provide feedback and share lessons learned to all stakeholders to continuously improve practice</li> <li>• Support the HRC-PCH PPIE team to develop and maintain best practice processes and systems for involving and engaging CYP and families in research activities and projects.</li> </ul>

I m p a	<b>Strategic Aim</b>	<b>Objectives</b>
	<p><b>Knowledge exchange and impact:</b> To embed standards, reporting and a culture of feedback and evaluation to</p>	<ul style="list-style-type: none"> <li>• Adopt and promote the UN Convention on the Rights of the Child, and UK Standards for Public Involvement.</li> <li>• Incorporate listening to and acting on the views of CYP and families as part of usual business.</li> </ul>

<b>c t</b>	<p>demonstrate the impact of CYP and family involvement in HRC-PCH activities.</p>	<ul style="list-style-type: none"> <li>● Regularly share best practice examples where involvement and engagement has affected positive change, via newsletters, publications and as a central feature of the Child Health Technology Conference.</li> <li>● Develop a toolkit for practitioners in collaboration with CYP and families, outlining the processes and activities needed for effective involvement and engagement.</li> <li>● In collaboration with CYP and families, establish agreements about the range of incentives that CYP and families will receive for their active involvement, and ensure these are consistently offered in HRC-PCH related projects.</li> <li>● Schedule wider consultation events and campaigns throughout the year alongside the overall planning timetable for the HRC-PCH Board to maximise their influence.</li> <li>● Develop robust online systems for monitoring CYP and family involvement and engagement, that track equality, diversity and inclusion, in collaboration with the CHAIN theme.</li> <li>● Develop systems by which CYP and families can self-reflect on their MedTech development involvement and engagement.</li> <li>● Collate the results of PPIE processes (both at an organisation and project level), analyse them, and feed them back to CYP, families, internal and external personnel linked to the HRC-PCH and key decision makers (i.e., funders and sponsors).</li> <li>● Ensure that methodologies, frameworks and/or models that are developed are transferable and/or disseminated across the HRC-PCH themes to local PPIE Leads and to National NIHR research delivery and infrastructure.</li> <li>● Create an impact assessment framework to demonstrate the 'valued' involvement, impact and change from PPIE.</li> </ul>
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### Partnerships

HRC-PCH will build on the extensive PPIE, co-design and co-development capabilities of NIHR CYPMedTech and the following strategic partnerships:

#### National

- NIHR GenerationR Alliance (<https://generationr.org.uk>) (Coordinated by the PPIE Executive Lead)
- Royal College of Paediatric & Child Health (RCPCH&Us)
- NIHR Methodology Incubator (PPIE Executive Lead co-chairs the Paediatric Incubator PPIE Working Group)
- NIHR Research Support Service (RSS) and Specialist Centre for Social Care: Lancaster University and Partners (PPIE Executive Lead provides specialist CYP support and advice)
- NIHR Great Ormond Street Hospital (GOSH) Biomedical Research Centre CYP PPIE National Collaboration (PPIE Executive Lead is a member of the Working Group).



International

- International Children's Advisory Network (iCAN)
- European Young Person's Advisory Group Network (eYPAGnet) (Co-founded by the PPIE Executive Lead)
- European Children's Rights Unit (University of Liverpool)