

NIHR HealthTech Research Centre in Paediatrics and Child Health

Research Inclusion Strategy

1. **Governance:** Please outline where the Research Inclusion work sits in the governance structure and arrangements for the strategy

The Research Inclusion Strategy operates within the established NIHR HRC PCH governance framework, with clear reporting lines through to the Executive Committee and Steering Committee.

Jennifer Preston, as PPIE Executive Lead, has primary responsibility for strategy delivery, ensuring alignment between equality, diversity and inclusion approaches and the broader PPIE strategy. This work directly supports the HRC's commitment to creating the world's most comprehensive approach to involving patients and families through innovative methodologies.

The operational delivery is integrated into the HRC's management structure:

- The Head of Operations and National Programme Coordinator provide strategic oversight, ensuring Research Inclusion objectives align with the HRC's core themes and overall mission. They facilitate regular reporting on inclusion metrics as part of the established Executive Committee meetings.
- Theme Project Managers take responsibility for implementation within their respective themes (Early Life, Long Term Conditions in Childhood, Transition, Mind Body Integration, and Child Health AI Network). They work closely with Theme Leads to ensure inclusion objectives are embedded in project design and delivery, particularly focusing on engaging underserved communities relevant to each theme's focus area.
- The PPIE Board, meeting quarterly, includes PPIE Theme representatives and patient and family representatives who provide input into HRC strategy and operations, reporting to the Executive Committee and Steering Committees, including on issues of Research Inclusion.
- Progress against Research Inclusion objectives forms part of our formal annual reporting to NIHR, enabling regular review and refinement of our approach.

2. **Vision:** In the context of the objectives of your overarching award, please clearly state your vision for equality, diversity and inclusion and how it supports the delivery of the NIHR [Research Inclusion Strategy 2022-27](#).

The 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 organisation, providing a comprehensive offer to the NHS, academic experts, and industry partners, combining expertise from world leading NHS children's hospitals and universities.

The vision for the 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 meaningful efforts to enhance equality, diversity and inclusion (EDI) within the HRC-PCH and across the portfolio of work that we support.

We hope to achieve this with six key objectives, detailed further below:

1. Ensure that the HRC-PCH culture is inclusive and fair
2. Improve under-representation within HRC-PCH staffing where possible
3. Embed EDI awareness as part of our investment in the next generation of child health technology researchers and innovators
4. Widen and enrich our networks and collaborations to include representation from different communities across England
5. Actively promote EDI within all HRC-PCH collaborations and projects
6. Embed a culture of inclusive and diverse PPIE approaches in all HRC-PCH activities

How this strategy was developed

This strategy is built on the extensive experience of working in partnership with CYP and families within the national Technology Innovation Transforming Child Health (TITCH) Network, as well as CYP and families who were involved in the work of NIHR Children and Young People MedTech Co-operative (now known as HRC-PCH).

Early drafts of this strategy were shared and discussed with the EDI leads at the HRC-PCH host institution (Sheffield Children's NHS Foundation Trust).

The strategy is aligned to the national NIHR Research Inclusion Strategy 2022-27, with particular synergy in the following areas:

- Developing our knowledge, skills and capacity to both reduce inequalities and maximise inclusion within the HRC-PCH and the projects it supports;
- Consideration of protected characteristics, as informed by the Equality Act 2010, such as age, disability, gender reassignment, marriage or civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. In addition, the risk of inequality in relation to socio-economic status, geographic location and access to health and care will be considered;
- A recognition of, and efforts to enhance our staff's understanding of, the impact of intersectionality (described in the NIHR Research Inclusion Strategy 2022-27 as "a framework that acknowledges that all people have unique experiences of discrimination and disadvantage exacerbated by the overlap of multiple social identities");
- Several objectives highlighted in the NIHR Research Inclusion Strategy 2022-27 resonate with those of the HRC-PCH strategy, including: a focus on improving the evidence base of diversity data collected via patient and public involvement and engagement (PPIE) work and research projects (including the systematic tracking, reporting and evaluation of diversity data); improving the diversity of research participants in the research studies we support; developing and implementing a standardised EDI training plan for the HRC-PCH workforce; developing inclusive communications strategies; and investing in the "talent pipeline" through early career researcher support and engagement with schools.
- In particular, we share the intention of taking an approach of "learning as we go," embedding regular opportunities to review and reflect on the EDI work completed so far, in order to inform next steps and adaptations to our EDI / PPIE strategies accordingly.

Definitions

The HRC-PCH aligns with the following definitions set out in the NIHR Research Inclusion Strategy 2022-27:

- **Equality:** Ensuring that everyone is given equal access to resources and opportunities to utilise their skills and talents.
- **Equity:** Trying to understand and give people what they need to achieve their potential, and promoting notions of fairness, justice, entitlements and rights.
- **Diversity:** Being reflective of the wider community, including people from a broad range of backgrounds represented in all areas and at all levels.
- **Inclusion:** An approach where groups or individuals with different backgrounds are welcomed, culturally and socially accepted, and treated equally, ensuring a sense of belonging that is respectful of people for who they are.
- **Research inclusion:** Taking a whole systems approach to what we do and how we do it; identifying and removing long standing, structural barriers to success across our people, policies, processes and practices.
- **Intersectionality:** A framework that acknowledges that all people have unique experiences of discrimination and disadvantage exacerbated by the overlap of multiple social identities.
- **Under-served groups in research:** The NIHR INCLUDE project identified the term 'under-served' as the most appropriate term through a consensus workshop with diverse stakeholder groups that included patients and the public. The term has subsequently been adopted by the NIHR and more widely. The term reflects the perspective that the research community needs to provide a better service for people in these groups, and that the lack of inclusion is not due to any fault of the members of these groups.

3. Objectives: Please clearly state what your equality, diversity and inclusion objectives are for the term of the award. There should be a clear follow through from vision -> objectives -> actions. Please use the Excel sheet to provide further detail in the accompanying action plan.

1. Ensure that the HRC-PCH culture is inclusive and fair

- Ensure all HRC-PCH new starters complete EDI training
- Ensure all HRC-PCH core team members have regular, ongoing EDI training

2. Improve under-representation within HRC-PCH staffing where possible

- Improve the HRC-PCH team's awareness of EDI in our attraction and recruitment processes
- In line with NHS trust recruitment policies, ensure all HRC-PCH job applications promote EDI
- Establish, where possible and in line with NHS Trust recruitment policies, diverse and inclusive interview panels in recruitment processes
- Regularly review EDI within HRC-PCH staff meetings and annual performance reviews

3. Embed EDI awareness in our education and training programmes for the next generation of child health technology researchers and innovators

- Ensure our support of early career researchers includes signposting to EDI training and resources
- Engage with schools, particularly in under-served areas, to raise awareness and aspiration for careers in health and care research, particularly in the context of child health technologies
- Ensure the opportunities we provide to schools and youth groups are inclusive and open to diverse groups of children and young people

4. Widen and enrich our networks and collaborations to include representation from different communities across England

- Develop connections with community champions from under-served communities locally and nationally
- Establish partnerships with organisations representing and supporting under-served groups (for example, disability advocacy groups, LGBTQ+ organisations, ethnic minority associations)
- Develop capacity and competency within the HRC-PCH team on inclusive communications strategies

5. Actively promote equality, diversity, and inclusion within all HRC-PCH collaborations and projects

- Improve data capture of EDI across all HRC-PCH activities
- Signpost collaborators and project teams to resources on EDI
- Work in collaboration with academia, healthcare, industry and the community to identify health inequalities challenges and issues specific to the Child Health Technology space, ensuring the findings of this work guide the HRC-PCH portfolio and are shared nationally.
- Share resources, best practice, and case studies within the HRC-PCH online knowledge centre, as well as through our networks, social media channels, and website
- Identify and build links with existing communities of practice within EDI (for example, engaging with the NIHR Inclusion Forum once this is established, and the Children and Young People's Health Equity Collaborative (CHEC))
- Spotlight EDI best practice and guidance in our global Child Health Technology conferences

6. Embed a culture of inclusive and diverse PPIE approaches in all HRC-PCH activities

- Establish systems, procedures, and resources that ensure involvement and engagement opportunities are inclusive, safe, enjoyable and meaningful for CYP and families (based on the Lundy Model)
- Offer a range of inclusive opportunities for CYP and families to collaborate with the HRC-PCH, such as influencing the planning and delivery of HRC-PCH workshops, theme projects, and strategic decisions
- Launch and deliver the HRC-PCH's PPIE Development Methodologies and EDI (DeMEDI) programme
- Work in partnerships with CYP and family involvement networks (i.e., GenerationR Alliance, NHS youth forums, as well as the charitable and Voluntary sector, etc) to increase EDI within PPIE and research activities

4. Research Inclusion budget (if applicable): Please provide details of your equality, diversity and inclusion expenditure each year. Please separate out staffing and project costs.

Our approach to EDI is fundamentally integrated across all aspects of HRC-PCH operations and activities. EDI considerations are embedded within:

- Core staffing costs through dedicated time allocations for EDI activity where applicable within relevant roles
- Project planning and delivery costs across our portfolio
- Our comprehensive PPIE programme, particularly through our PPIE Development Methodologies and EDI Programme led by our PPIE Executive Lead
- Training and development activities for staff and research partners
- Communications and engagement initiatives

For specific research projects and grant applications, EDI costs are built into individual budgets based on project requirements and scope. We work collaboratively with partners to ensure appropriate resourcing for EDI activities within each funding application, which may include:

- Targeted engagement with underrepresented communities
- Accessible materials and communications
- Support for diverse participation in research activities
- Reasonable adjustments and accessibility requirements

This integrated approach ensures EDI remains a core consideration in all our activities while maintaining flexibility in resource allocation based on specific needs and opportunities.

5. Collaboration: Please give details of planned collaborative inclusion activities with other parts of NIHR Infrastructure, wider NIHR and other partners (including industry).

The HRC-PCH will further develop the following strategic partnerships in support of our work to enhance our equitable, diverse and inclusive practice:

Local to host organisation (Sheffield Children's NHS Foundation Trust)

- Sheffield Children's NHS Foundation Trust Health Inequalities Team
- Sheffield Children's NHS Foundation Trust EDI Leads

National

- NIHR GenerationR Alliance (co-ordinated by the HRC-PCH PPIE Executive Lead)
- NIHR HRC Network
- Royal College of Paediatric & Child Health (RCPCH)
- Royal College of Paediatric & Child Health & Us (RCPCH&Us)
- TITCH Network
- NIHR Methodology Incubator (HRC-PCH 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 (HRC-PCH PPIE Executive Lead provides specialist CYP support and advice)
- NIHR Great Ormond Street Hospital (GOSH) Biomedical Research Centre CYP PPIE National Collaboration (HRC-PCH 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 HRC-PCH PPIE Executive Lead)
- European Children's Rights Unit (University of Liverpool)