# NIHR CYP-MEDTECH

# Children, Young People (CYP) and Family Involvement Strategy.

### 1.    NIHR CYP-MEDTECH Vision

The National Institute for Health Research (NIHR) CYP-MEDTECH to become a world class organisation for the development of paediatric healthcare technology, driven by the views and opinions of children, young people (CYP) and family involvement. The national reach for identifying unmet needs amongst CYP and families and supporting paediatric technology acceleration is key to the success of CYP-TECH. The ethos of our paediatric medtech co-operative is to ensure that children and young people are involved at every step of the innovation pathway.

### 2.    Introduction

NIHR CYP-MEDTECH is dedicated to the development of healthcare technology specifically for CYP. Thus NIHR CYP-MEDTECH regards the involvement of CYP as a fundamental requirement. In addition, views of parents are vital in understanding the holistic needs of their children. Theme Leads involved in NIHR CYP-MEDTECH already have experience and access to specific patient groups through patient organisations, charities, Patient and Public Involvement & Engagement (PPIE) groups within institutions such as the Royal College of Paediatrics and Child Health

(RCPCH), and specialist networks, to ensure CYP and family involvement is central to CYP-MEDTECH activities.  Specialist PPIE support is imperative to the successful development and delivery of paediatric technologies as experienced by our Theme Leads and PPIE Executive Lead. The involvement of CYP and their families will ensure that technology is developed for and with the user, is adopted more rapidly and is better accepted into clinical practice.

### 3.    Our Vision

We will use transparent processes for working with CYP, families and members of the public, thus ensuring that paediatric healthcare technology development in CYP-TECH can flourish in an informed and inclusive environment.

### 4.    Strategic Priorities

We will achieve this by the following four strategic priorities:

**Strategic Priority 1:** Work in partnership with CYP, families, members of the public in the design and delivery of paediatric technologies
**Strategic Priority 2:** Continuous improvement through patient experience and public awareness
**Strategic Priority 3**: Widen participation and involvement of CYP and families in NIHR CYP-MEDTECH activities
**Strategic Priority 4:** Grow the evidence base of the impact of CYP and family involvement and engagement in the design and delivery of paediatric technologies

### 5.    Implementation Plan

Key objectives in these four areas are listed below.

**Strategic Priority 1:** Work in partnership with CYP, families, members of the public in the design and delivery of paediatric technologies

To achieve this, CYP-TECH will:

| 1.1 | Equip theme leads and researchers with the necessary skills to undertake |
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| | effective CYP, family and public involvement activities |
| 1.2 | CYP and family representatives will be invited to attend the six Theme workshops. Themes will be expected to set up Project Advisory Groups (PAGs) that will include two patient/family representatives. PAGs will meet 3-4 times per year. |
| 1.3 | Increase the quality of CYP-MEDTECH projects by embedding CYP and family involvement in the earliest stages of project design, including identifying specific unmet needs in CYP; work with CYP and families to develop ideas relating to targeted unmet needs to ensure the patient and family view drives development; ensure that CYP and families are involved in the collaborative development of paediatric technology from proof-of-concept to product development and clinical evaluation. |
| 1.4 | CYP-TECH will ensure specific projects include CYP and family representation and that all projects are reviewed by young person's advisory groups via the GenerationR Alliance http://generationr.org.uk led by the PPIE Executive Lead. |
| 1.5 | Continue to partner with key stakeholders (Regulators; Industry, Charities, Academia) to co-develop innovative projects that empower CYP and their families to participate in CYP-TECH projects. |
| 1.6 | CYP-MEDTECH will ensure that CYP are directly involved in the development of technology to support transition from paediatric to adult care (Cross-cutting Theme: Transition) in accordance with the NICE Guidance (Transition from children's' to adults' services for young people using health or social care services). This will involve focus groups and team development that will involve young people as members of the team. |

**Strategic Priority 2:** Continuous improvement through patient experience and public awareness

To achieve this, CYP-TECH will:

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| 2.1 | Systematically undertake user experience surveys with CYP and families who use CYP-MEDTECH technologies and devices, using CYP age-appropriate and co-produced questionnaires. |

| 2.2 | Share learning both locally and nationally about CYP and family activities via NIHR and wider (e.g. I Am Research Campaign; International Clinical Trials Day etc.) |
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| 2.3 | Engage with young people and their families at relaevant events to showcase technologies and gain feedback |
| 2.4 | Ensure that CYP and families are kept up to date with the latest CYP health technologies though relevant forums and patient user groups |

**Strategic Priority 3**: Widen participation and involvement of CYP and families in CYP-TECH activities

To achieve this, CYP-TECH will:

| 3.1 | Lead on strategies to widen participation by developing outreach activities and publicising opportunities for involvement and engagement amongst CYP and families. |
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| 3.2 | Build on strategic partnerships with Industry, Charities, Regulators, and Academia) and continue to set up joint projects to promote effectiveness of our CYP and Family Involvement Strategy. |
| 3.3 | Continue to coordinate, share and support the active involvement of CYP and families locally, nationally and across the Globe, through forums such as: GenerationR Alliance; European Young Person's Advisory Group Network (eYPAGnet), and via the International Children's Advisory Network (iCAN). |
| 3.4 | Develop the role of Young Patient Research Ambassadors in collaboration with the NIHR Clinical Research Network Patient Research Ambassador Initiative to ensure CYP and their families are aware of CYP-MEDTECH research. |

**Strategic Priority 4:** Grow the evidence base of the impact of CYP and family involvement and engagement in the design and delivery of paediatric technologies

To achieve this, CYP-TECH will:

| 4.1 | All CYP and family activities will be evaluated, reported and developed with specific objectives, methods, outputs and indicators for impact. |
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| 4.2 | Continue to share good practice, knowledge, skills and resources through our dedicated 'GenerationR' and CYP-MEDTECH websites. |
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| 4.3 | Where clinical evaluation of paediatric technology is being developed, CYP-MEDTECH will ensure that stakeholders are aware of the RCPCH Infants', Children's and Young People's Child Health Research Charter. http://www.rcpch.ac.uk/system/files/protected/page/RCPCH%20ResearchandUs%20A4%20Poster.pdf T |
| 4.4 | Learn from the work currently being undertaken by the NIHR Senior PPIE Team Impact Working Group to ensure our impact assessments are in line with the whole of the NIHR and wider. |
| 4.5 | Build in CYP and family involvement into CYP-TECH Quality Assurance Processes and Reporting to systematically collect and monitor data on all CYP and family activities. |

## 6.    Partners and Collaborations

We will continue to partner with key stakeholders (Regulators; Industry, Charities, Academia) to co-develop innovative projects that empower CYP and their families to participate in CYP-MEDTECH projects.  We will also continue to work with relevant Patient and Public Involvement and Engagement activities in other programmes, such as: UKCRF Network, INVOLVE, NIHR, EUPATI, MRC HTMR, EUPFI, Life Sciences Strategy etc. This will ensure that the CYP-MEDTECH is in a prime position to benefit from ongoing activity and maximise resources for new involvement/engagement activities.

## 7.    Leadership and Governance

Leadership is provided by Jenny Preston (NIHR CRN CC Patient and Public Involvement and Engagement Priority Lead; NIHR Alder Hey Clinical Research Facility, and Coordinator of the GenerationR Liverpool YPAG and GenerationR Alliance Lead) is PPI Executive Lead for CYP-MEDTECH.  Jenny will represent CYP and family involvement at the Executive Committee of CYP-MEDTECH and yearly stakeholder Paediatric MIC meeting to discuss paediatric technology collaborations. A summary of CYP and family activities and impact will be included in CYP-MEDTECH Annual Reports to NIHR.

### 8.    Resources

Named PPIE Lead is Jenny Preston, who will provide on-going support for CYP and family involvement with CYP-MEDTECH, primarily through GenerationR Alliance and YPAGs across the country and via theme leads and their links to patient organisations and charities.  Budget allocated for CYP and family activities has been secured within the CYP-MEDTECH infrastructure funding

### 9.    Monitoring, Reporting and Review Arrangements

Delivery of CYP-MEDTECH PPIE Objectives will be reviewed at CYP-MEDTECH Executive Committee meetings.  Outputs and impacts will be reported annually to NIHR.

### 10. Communication and Dissemination

NIHR CYP-MEDTECH will develop an effective communications/social media strategy and implementation plan with CYP and families to 'reach-out' to as many stakeholders as possible about CYP-MEDTECH activities. We will use Twitter and a web based platform as a means of informing patients and the public of specific events and technology development, and to harness information relating to unmet needs in paediatric healthcare relating to the proposed Themes.