



National Institute for
Health Research

Great Ormond Street Hospital
Biomedical Research Centre and Clinical Research Facility

**A strategy for
Patient and Public Involvement and
Engagement (PPI E) and Patient
Experience in Research 2018-2022**

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“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well.”

- Professor Dame Sally Davies, Chief Medical Officer (CMO) for England

1.0 Our Vision

We want to deliver world-class Patient and Public Involvement and Engagement (PPI E) and patient experience in research by routinely embedding the perspectives of patients and their families and the public in all aspects of the research process and in the organization as a whole. It is only by cultivating active and sustained partnerships between researchers, patients and the public that we can guarantee research addresses what matters most to them.

Our vision is to lead the way in involving children and young people, patients and families in research design, delivery and strategy and continue to develop creative ways to ensure equitable involvement and engagement. PPI E will be an integral part of all aspects of the research process across our organisation.

Children and young people, patients, their families and carers will be included in our research decision making and structures to guide and influence this strategy and support its delivery, ensuring our research results in maximum patient benefit.

Annex A. P8 sets out a definition of Patient and Public involvement and engagement (PPI E) and Patient experience in research.

2.0 What we will do to achieve our vision

Current position and the future

Patient and Public involvement and engagement in research forms part of the wider PPI E agenda across the trust. The experience of patients and their families is collected and evaluated regularly to improve services throughout the trust including some areas of research such as the NIHR GOSH Clinical Research Facility (CRF).

Much progress has been made since the 2012-2017 Patient and Public Involvement and Engagement (PPIE) and Patient Experience in Research strategy was developed with a number of excellent examples of how patients and the public have been involved with research at GOSH and overall the PPI E strategy has been strengthening understanding and application of our PPI E in research.

We recognise that this refreshed strategy offers the opportunity to progress on some key work streams and develop new ones.

The previous PPI E strategy and activities have been driven forward by the UCL GOSH BRC; however the expectation is that this refreshed strategy will apply to all research at GOSH, the UCL Great Ormond Street BRC and the ICH and that further good PPI E practice developed could be used across UCL Partners.

The 2018-2022 strategy for Patient and Public Involvement and Engagement (PPI E) and Patient Experience in Research will:

be informed by:

- key learnings and outcomes from our Patient and Public Involvement and Engagement (PPI E) in Research strategy 2013-2017;
- Feedback, input and ongoing monitoring from our Advisory groups - Young Person's Advisory Group (YPAG) and Parent Carer Advisory Group.

align with:

- *Going the Extra Mile*, a strategic review of public involvement - National Institute for Health Research;
- the Six core national PPI standards for research;
- the PPI E section of our NIHR Biomedical Research Centre Competition application;
- the PPI E section of our NIHR CRF award;
- GOSH Research Communications Strategy.

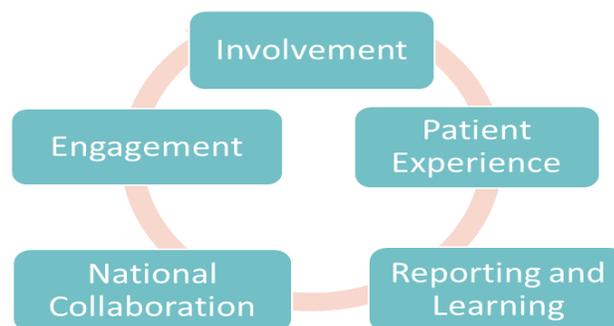
complement the:

- Trust's Strategy;
- Trust's Patient and Public Involvement (PPI) and Patient Experience Strategy;
- Trust's Research Hospital Business Plan 2015-2020.

Annex B. P9 sets out the NIHR six core national PPI standards for research.

3.0 Our five key objectives

In order to achieve our vision, and support the UCL GOSH Biomedical Research Centre (BRC) and Clinical Research Facility (CRF) strategies we have identified five key objectives:



1

Involvement

We will actively consult, listen to and involve patients, their families and members of the public about their views and perspectives on the research carried out across GOSH/ICH. To achieve this objective we will develop involvement opportunities for patients and the public in different specialities and at every level.

1.1	Continue to engage our Research Advisory Groups: Young Person's Advisory Group and Parent carer Advisory Group to keep them informed and identify opportunities for involvement in:
1.1.1	Research Hospital plan;
1.1.2	Biomedical Research Centre;
1.1.3	Clinical Research Facility.
1.2	Develop our Research Advisory Groups: the Young Person's Advisory Group (YPAG) and the Parent/Carer Advisory Group
1.2.1	Promote groups among patients and researchers;
1.2.2	Expand and diversify group membership and opportunities for YPAG members to develop their skill sets;
1.2.3	Consider and implement new ways of engaging with group members including methods for virtual consultation;
1.2.4	Explore methods to provide training, learning and support e.g. training courses potentially delivered in partnership with other London BRCs; Generation R resources, mentoring by another patient, member of the public or researcher;
1.2.5	Offer involvement with the NIHR Patient Research Ambassador Initiative (PRAI) – advertise PRAI opportunities to all interested people and further develop our links with the NIHR Clinical Research Network PRAI Lead to signpost people, develop a GOSH PRAI cohort, training and facilitation of activities.
1.3	Support researchers to actively involve patients and the public in their research
1.3.1	Promote resources and local support available;
1.3.2	Provide bespoke advice to researchers on involving patients/public in individual research projects and programmes of research, including advice/input on grant applications;
1.3.3	Design and deliver PPI training for local researchers, and/or signpost to training opportunities;
1.3.4	Support the active involvement of children and young people and patients to help and improve studies so patients want to participate; helping to link them to studies where they can get actively involved in the design (i.e. information leaflets) so they are fully accessible.
1.4	Working in partnership with other PPI groups (internal/ external) to increase diversity of involvement
1.4.1	Continue to make links with GOSH Young Persons Forum and map out current PPI E research groups across GOSH/ICH. Ensure active involvement with the Generation R alliance and its future development.
1.5	Ensure adequate funding is available for PPIE activities.
1.6	Through Generation R and NIHR-led project, explore and develop further links with industry.
1.7	Explore, and support other opportunities for patients/public to be actively involved in research at GOSH e.g. Clinical Research Adoptions Committee (CRAC); GOSH generic consent project, Access Committee.

Engagement

2

We will share information about the research activity at GOSH and encourage conversations between patients, the public, researchers and GOSH staff.

2.1 Hold Engagement events for external audiences (public) e.g. BRC annual family fun day to inform and educate the public about the work of the ICH, BRC and GOSH researchers, GOSH Annual General Meeting.

2.2. Hold Engagement events for internal audiences (patients, families, staff) e.g. Research Awareness week and International Clinical Trials day, Rare Disease Day; Open House Strategy Days, Children's Commissioner Takeover week and Listening events.

2.3. Support researchers' engagement with students from schools/colleges e.g. BRC Family Fun Day, lessons in GOSH School and GOSH Activity Centre.

2.4 Collaborate with GOSH Arts and other creative arts based organisations to deliver creative - based activities to engage with internal/external audiences.

2.5 Refresh of all PPI E communications materials for our advisory groups in line with the GOSH research communications strategy.

Patient Experience

3

We will develop our aims in collaboration with the Trust Patient Experience team, the Clinical Research Facility (CRF) and PPI groups to deliver an excellent patient experience in research.

3.1 Improve our structures for capturing feedback; monitor the outcomes of Friends and Family test results and annual UKCRF/CRN surveys on research patient experience. Ensure these experiences are reflected in CRF and R&I management systems.

3.2 Identify new and innovative approaches of enabling participation and involvement; improve our digital reach to key stakeholders, develop new involvement opportunities.

3.3 Engage with Play Specialist in the CRF as critical partners in hearing of patients' experience and as ambassadors for patient involvement.

National Collaboration

4

We will develop our work within Generation R and other national groups to improve the design and delivery of research for children. We will ensure that our work fits within national initiatives for PPI.

4.1 Develop new opportunities for London YPAG to contribute to the Generation R Alliance.

4.2 Link in with Royal College of Paediatrics and Child Health young person's group '& us'.

4.3 Continue to develop our work with national bodies such as the Nuffield Council on Bioethics to inform public policy about the conduct of research with children.

We will develop processes to: report on, learn from, evaluate the impact of, and share good practice in Patient and Public Involvement and Engagement (PPI E) in research.

5.1 Reflect on previous year's activities to develop an annual Operational Plan to outline priorities and support the delivery of the strategy.
5.2 Build/extend networks for learning, development and support with other PPIE research leads e.g. attend/present/ share good practice at local/national meetings.
5.3 Explore methods and implement approaches to evaluate the impact of PPI E e.g. 'case studies' that demonstrate the value and impact of PPI E in funded research studies, develop further our processes for monitoring PPI E activities including formal evaluation for both those participating and researchers, collect feedback from participants and researchers at engagement events.
5.4 Ensure a visible GOSH presence and contribution at local, national and international PPI E events and conferences.

4.0 Operational Plan

Update on Operational Plan April 2017-March 2018

The 2018-2022 strategy builds on the progress of our 2013-2017 strategy. We recognize that there has also been development in the period up until the launch of the 2018-2022 strategy.

Moving forward - Operational Plan April 2018- March 2019

We believe that the 2018-2022 strategy will evolve over its lifetime therefore an Operational Plan for the March 2018 - April 2019 period has been drawn up. This will be refreshed and updated annually in consultation with our Advisory Groups, setting out our focus for PPI E activities as opportunities develop and grow.

5.0 Resources

To properly embed PPI E in research across the BRC, ICH and GOSH, staff labour and financing will be necessary, both for individual research projects, and across the BRC, ICH and GOSH.

- **Costs for PPI E in each research project** should be factored and grant application. INVOLVE has recently developed an Involvement Cost Calculator, for researchers to budget PPI E in a research project (<http://www.invo.org.uk/resource-centre/involvement-cost-calculator/>). The Research Design Service London also offers advice and funds for PPIE activities (<http://www.rdslondon.co.uk/Patient---Public-Involvement/Enabling-Involvement-Fund.aspx>). In addition, researcher time should be taken in to account to run PPI E activities and events. This information will be provided to researchers as part of the grant application process.
- **Staff to support PPI E strategy:** In order to develop a culture of PPI E for research, commitment to core resources is required. To fulfill the objectives within the strategy, a 1.0 WTE PPI E Lead

role will be appointed as part of the Division of Research and Innovation. This post holder will provide PPI E support for researchers in the BRC, ICH and across GOSH. Equally, the BRC, ICH and GOSH will support this individual with promoting PPI E. This individual will be the point of contact for researchers to liaise with the research advisory groups and may signpost to families and charities for PPI E, and vice versa. The individual will also oversee the delivery of all PPI E engagement events, and in-house training for research staff and will be supported by administration.

- **Funds for PPI E activates:** In addition, funds should be set aside in the annual budget for PPI E activities. These funds could be put towards items such as refreshments and remuneration for participants (e.g. vouchers, or money paid at the INVOLVE rate), and directly incurred costs for running PPI E activities.
- **Research Involvement/ Engagement Communications:** The PPI E Lead will work closely with the Research Communications Manager to communicate PPI E events and activities internally and externally and to ensure PPI E communication materials are updated as necessary.
- **Other resources:** Easy access to an iPad and/or camera will be provided to document and share PPI E events and activities.

6.0 Annex A. Defining Patient and Public involvement and engagement and Patient experience in research

This strategy is about patient and public involvement and engagement in research as well as the experience of patients and their families taking part in research.

For the purposes of this document, the INVOLVE definition of Patient and Public Involvement and Engagement will be used:

- Public involvement in research will be used, which is, “research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.” INVOLVE goes on to describe ‘public’ as, “patients, potential patients, carers and people who use health and social care services”. Therefore, in the context of GOSH and the UCL BRC this refers mostly to children, parents, and families.
- Patient and public engagement can be defined as, “where people are given information about research and can discuss it with researchers and research organisations.”

For Patient Experience the following definition will be used as referred to by the GOSH Patient Experience team:

- Patient experience is generally defined as ‘feedback from patients on what actually happened in the course of receiving care or treatment, both the objective facts and their subjective view of it’ (Dr Foster’s Intelligent Board report 2010 - Patient Experience). In 2010, Great Ormond Street Hospital defined patient experience as: “This is what happened to me and this is how I feel about it.” In the context of this strategy this is referring to the perception and feelings of children, young people and their families taking part in research.

Annex B. NIHR Six core national PPI standards for research

A framework for improving the quality and consistency of PPI in research.

'They [the standards] should be framed in such a way, and with a clear set of self-assessment criteria, so that organisations across the NIHR see their adoption as integral to their continuous improvement in public involvement.'

Going the Extra Mile, Recommendation 2.

1. Inclusive opportunities

We provide clear, meaningful and accessible opportunities for involvement, for a wide range of people across all research.

2. Working together

We create and sustain respectful relationships, policies, practices and environments for effective working in research.

3. Support & learning

We ensure public involvement is undertaken with confidence and competence by everyone.

4. Communications

We provide clear and regular communications as part of all involvement plans and activities.

5. Impact

We assess report and act on the impact of involving the public in research.

6. Governance

We ensure the community of interest voices are heard, valued, and included in decision making.

Annex C. References

INVOLVE	http://www.invo.org.uk/
James Lind Alliance	http://www.lindalliance.org/
RDS London	http://www.rdslondon.co.uk/
Health Talk Online	http://healthtalkonline.org/
Medicines for Children Research Network	http://www.mcrn.org.uk/
National Children's Bureau Research Centre	https://www.ncb.org.uk/
Generation R	http://generationr.org.uk/
People in Research	http://peopleinresearch.org/
NIHR CCF	http://www.ccf.nihr.ac.uk
Nuffield Council on Bioethics	http://nuffieldbioethics.org/