

**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.

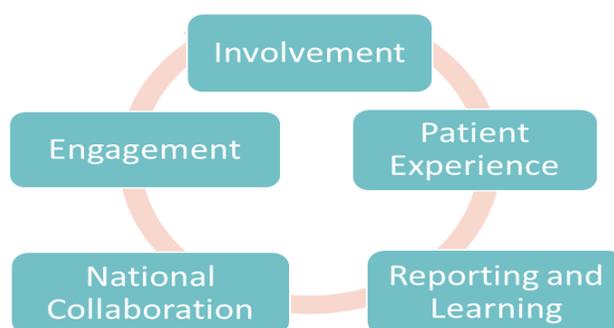
complement the:

- 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.

2

Engagement

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.

3 Patient Experience

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.

4 National Collaboration

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.

5 Reporting and Learning

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.

<p>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.</p>
<p>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.</p>
<p>5.4 Ensure a visible GOSH presence and contribution at local, national and international PPI E events and conferences.</p>

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 PPIE, 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

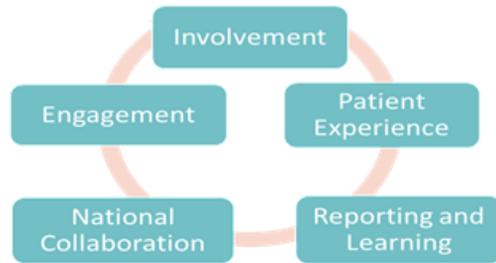
We ensure the community of interest voices are heard, valued, and included in decision making.

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/

**Annex D. NIHR GOSH Biomedical Research Centre (BRC) and Clinical Research Facility (CRF)
Patient and Public Involvement Engagement (PPI E) OPERATIONAL PLAN (2018 – 2020)**
(Updated yearly)

PPIE Strategy Five Key Objectives:



Which align with the: UK Standards for Public Involvement in Research:

1. INCLUSIVE OPPORTUNITIES - Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.
2. WORKING TOGETHER- Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.
3. SUPPORT AND LEARNING- Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.
4. COMMUNICATIONS- Use plain language for well-timed and relevant communications, as part of involvement plans and activities.
5. IMPACT- Seek improvement by identifying and sharing the difference that public involvement makes to research.
6. GOVERNANCE -Involve the public in research management, regulation, leadership and decision making.

Key Objective 1. Involvement				
Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
1.1 Continue to engage our Research Advisory Groups : Young Persons' Advisory Group (YPAG) and Parent and Carer Advisory Group (PCAG) to keep them informed and identify opportunities for involvement in GOSH: Research Hospital Initiatives, Biomedical Research Centre (BRC), Clinical Research Facility (CRF)				
1.1.1 Research Hospital Plan	PPI E Lead to attend monthly Research Hospital (RH) meetings and work in liaison with RH Manager & Research Communications Manager on projects: linking opportunities and cascading information to Advisory groups.	Ongoing/1./2./3.	<p><i>PPI E updates added to quarterly Research Hospital (RH) Implementation Plan. Develop communications materials and provide input into specific projects.</i></p> <p>2018:</p> <ul style="list-style-type: none"> - Review RH communications materials with YPAG including research participant 'Thank You' postcards; - Co-production with YPAG on animation script for GOSH Sample Bank project & YPAG member provides animation voiceover. <p>2020:</p> <ul style="list-style-type: none"> - GOSH NIHR newsletter continues to be distributed every two months. - GOSH YPAG and PCAG members gave feedback and input into communication materials for National Seroprevalence Programme 	<p>2019:</p> <ul style="list-style-type: none"> - GOSH Sample Bank (RH flagship initiative) launched, YPAG member contributes to articles for staff magazine/ website/social media platforms including International Day of Women and Girls in Science; - YPAG member launches Sample Bank project animation at GOSH ICH Strategy Launch & Trust AGM. <p>2020:</p> <ul style="list-style-type: none"> - Advisory group input to Tissue Access Committee on projects' approval for sample access; - Ensure Sample Bank project is promoted at key research PPI E events and Trust wide events. <p>2020-21</p> <ul style="list-style-type: none"> Sample Bank Star Sandra's blog was featured as part of International Youth Day <p>Sample Bank Stars</p>
1.1.2 Biomedical Research	PPI E Lead to attend monthly BRC Science	Ongoing/1./2./3.	<i>PPI E updates report as a standing item at each</i>	2019:

Centre (BRC)	Board meeting (SBM) and facilitate PPI E involvement in BRC engagement events: linking opportunities and cascading information to Advisory groups		<p><i>BRC SBM meeting & taking note of other BRC related PPI E activities across the themes. YPAG: updates and opportunities on meeting agendas. PCAG: updates included in meeting minutes.</i></p> <p>2018:</p> <ul style="list-style-type: none"> - New and current advisory group members invited to sign up to BRC newsletter, and attend BRC showcase events; - Presentations from YPAG members at BRC Academic Training weekend. <p>2021:</p> <p>BRC Academic Training event held online- PPIE Lead joined to give PPIE advice and support in breakout rooms.</p>	<ul style="list-style-type: none"> - Presentations from YPAG members at GOSH ICH strategy launch event; - PCAG member on BRC Novel Therapies Funding call panel. <p>2020:</p> <ul style="list-style-type: none"> - YPAG involvement at BRC Academic Training weekend; - Develop guidelines for involving Lay members on funding panels; - Advisory Groups involvement in new BRC award planning. <p>2020-21</p> <ul style="list-style-type: none"> -More detailed info in PPI E Narrative Report- 2 Advisory Group members and 1 member of the public sat on PPI E panel for BRC New Projects Call in Dec 2020/ Jan 2021. - New involvement guidelines and training session delivered. - Advisory groups will be formally consulted around BRC Competition- summer 2021. - 3 parent carers attended webinar on _“intro to statistics” slides distributed to all PCAG members after the event.
1.1.3 Clinical Research Facility (CRF)	PPI E Lead to attend : a) quarterly CRF Senior Management Team	Ongoing/1./2./3./5.	a) PPI E updates report as a standing item at each CRF SMT – 2018: to include diversity	2020: a) To include Impact

	(SMT) meetings; b) monthly Patient Experience Meetings and enable PPI E involvement in CRF engagement events, linking opportunities and cascading information to Advisory groups.		reporting - stats re: ethnicity/gender/age of YPAG members; b) Referrals for YPAG and PCAG discussed and joint working on CRF related engagement events planned. 2018: b) BRC Family Fun day stall activity co- hosted by YPAG members (mock clinical trials & training by research nurses). International Clinical Trials day stall activity planned with YPAG.	reporting; b) International Clinical Trials Day planning. 2021: b) ICTD online – working with comms manager to deliver this. 2019: b) BRC Family Fun Day stall activity co-hosted by YPAG members & CRF staff involved in Careers Drop-In which YPAG attended.
Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
1.2 Develop our Research Advisory Groups : Young Persons' Advisory Group (YPAG) and Parent and Carer Advisory Group (PCAG)				
1.2.1 Promote Advisory Groups among patients and researchers	Raise profile of the groups to: a) Patients and their families; b) CRF staff/ research community; c) External organisations.	Ongoing/1./2./3./4.	<i>Ensure PPI E communication materials are updated and adhere to Trust and NIHR branding guidelines and that all channels are utilised to reach out to key stakeholders.</i> 2018/2019: a) - PPI E Poster boards in CRF include information on groups and updates after each meeting / YPAG photoshoot for refresh of YPAG leaflet/ regular opportunity emails through FT Get Involved e- newsletter/ face to face at key Trust events: AGM/ BRC Family Fun Day/ main reception digital screen runs YPAG video/website pages advertise groups; - Refresh of digital screen in hospital main reception with One film from 'The Future of Children's Research' pioneering a GOSH CRF trial 2018 onwards: b)- Regular PPI E news stories updates on GOSH Intranet & 'Headlines' weekly staff e- newsletter;	2020: a) - YPAG codesign new YPAG logo to update comms materials in line with new NIHR & GOSH branding; - new posters for CRF treatment rooms and wards; - review PPI E website pages and materials; - plan the outline of annual PPI E activity report (web & printed version for events. 2021:update on above - Updated posters produced for advisory groups and delivered to CRF for patients and families. - PPI E pages update has

			<ul style="list-style-type: none"> - Information stall at GOSH Open House week and Open Day ; - Information stall at GOSH People Strategy Launch week(2019); - PPI E Lead promotes at set CRF Induction slots & Research Hospital Manager promotes at set Trust Induction slots (2019); - CRF staff champions who support/attend YPAG sessions promote it to their patients and PCAG to their families; - Designated PPI E research poster boards in staff canteen. <p>Ongoing:</p> <p>c) Ensure all printed and web based communications materials are up to date for display for external audiences: UK CRF Conference, BRC Showcases.</p>	<p>started- more work will be done in 2021.</p> <ul style="list-style-type: none"> - New publication: PPIE Highlights Report 2020-21 published on PPI E pages of website as part of NIHR GOSH BRC PPI E Annual Report <p>b) & c) Develop a set of Case Studies from PPI E Small Grants Scheme & other activities to demonstrate impact throughout and at key stages of the research cycle.</p> <p>2021:update on above b) & c) Set of six PPI Impact Case Studies published on PPI E pages of website as part of NIHR GOSH BRC PPI E Annual Report</p>
1.2.2 Expand and diversify groups membership	<p>a) YPAG: enable group membership to grow thus supporting a more diverse membership, (including patients with clinical trial participation).</p> <p>b) Recruit new members to Parent and Carer Advisory Group.</p>	Ongoing/1.	<p>2018/2019:</p> <ul style="list-style-type: none"> a) - Establish 'virtual YPAG' who are on a waiting list to join and can be involved in YPAG activity online; - Maintain database of membership including ethnicity & gender and provide stats report to BRC SBM & CRF SMT. <p>b) advertise the group through FT Get Involved e newsletter opportunity emails (3 members recruited).</p>	<p>2020: <i>YPAG membership currently stands at 30 (3 members have participated in clinical trials)</i></p> <ul style="list-style-type: none"> a) Move to a larger more accessible venue for meetings enables capacity for more members including those with mobility needs and those currently on waiting list & 'virtual YPAG' and CRF

<p>1.2.2.1 support opportunities for YPAG to develop their skill sets</p>	<p>PPI E lead to maximise on opportunities arising for YPAG and facilitate their involvement both internally and with external collaborators.</p>	<p>Ongoing/1./2./3.</p>	<p>2018/2019: YPAG members involved in:</p> <ul style="list-style-type: none"> - Public speaking at BRC Academic Training weekend (2018) / ICH launch strategy (2019); - Co-hosting a mock trial engagement stall with CRF staff at BRC Family Fun Day (2018); - Supporting a YPAG visiting researcher to co-host a research stall at BRC Family Fun day (2019); - Teenage Twitter takeover at BRC Family Fun Day (2019); - Sample Bank animation voiceover (2019); - Co-design and hosting engagement sessions with GOSH Arts for interactive stations at new Zayed Centre for Rare Disease in Children ‘Together festival’ (2019); - GOSH Patient Led Assessments of the Care Environment (PLACE) Inspections (2019); - Attend co-design workshop for new MSc in Mental Health Sciences at UCL. 	<p>patients to join.</p> <p>2021: <i>YPAG membership currently stands at 33. PCAG recruited two new members</i></p> <p>b) - Plan a recruitment drive: advertising to those parents who joined focus groups in PPI E Small Grants Scheme;</p> <p>- Update ToR and Role Description accordingly.</p> <p>2020 & 2021: YPAG members:</p> <ul style="list-style-type: none"> - attend co-design workshop for new modules for UCL MSc in Mental Health Sciences <p>2020-21:YPAG</p> <ul style="list-style-type: none"> - Join GOSH Summer Placement Scheme- yes but Young Visitors observation sessions;(on hold due to covid) <p>Website articles:</p> <ol style="list-style-type: none"> 1. -“as lockdown eases” article on website & posted on social media August 2020 2. International Day of women and girls in science article on website
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				<p>Pod casts:</p> <ol style="list-style-type: none"> 1. ‘Clean Air’ podcast with GOSH CEO. 2. -“what is GOSH YPAG” as part of 3. PPI E Podcasts 4. ‘Diversifying Research’ eYPAGnet podcast. <p>Voice overs:</p> <ol style="list-style-type: none"> 1. GOSH Garden voice overs 2. Gene therapy explained animation voice overs
1.2.3 Consider and implement new ways of engaging with group members including methods for virtual consultation	<ul style="list-style-type: none"> - Investigate other methods for engaging with groups, trial methods: - YPAG to review PIS online in between meetings. 	Ongoing/1./2.	<p>a) 2018 /19 - established a ‘virtual YPAG’ who review PIS online and receive presentations for YPAG meetings & can join YPAG waiting list</p> <p>b) Parent and Carer Advisory Group – dial in facilities are available and used by some members.</p>	<p>2020:</p> <p>a) New meeting venue has enabled YPAG expansion for ‘virtual YPAG’ members to join.</p> <p>a) & b) Explore use of online platforms: WebEx/Google hangout/Google meet/Zoom</p> <p>2020-21:</p> <p>All YPAG meetings move online from May 2020 due to COVID-19 and a blended way of working is planned post pandemic.</p>
1.2.4 Explore methods to provide training and support	Link with external organisations and in-house trainers to provide learning and mentoring	Ongoing /3 /4.	<p>2019:</p> <p>- PCAG members attended ‘Introduction to</p>	<p>2020 :</p> <p>PCAG members attended</p>

	opportunities.		Routinely Collected Data for use in Research' training run by GOSH and ICH researchers. 2021: -PCAG members attended 'Introduction to Statistics' webinar run by Oxford BRC	London Leadership Academy three-day leadership programme training; - YPAG members to join GOSH Summer Placement Scheme & Young Visitor observation sessions; - Work with ICH team to investigate joint working on a more centralised scheme for work placements across GOSH/ICH. (on hold due to covid) 2020-21: - 'Introduction to Routinely Collected Data for use in Research' training for YPAG; - Summer Code Club planning; (on hold due to covid) - Develop YPAG Handbook
1.2.5 Offer involvement with PRAI (Patient Research Ambassador Initiative)	PPI E Lead to raise the profile of the initiative and link with Clinical Research Network (CRN) North Thames Lead to develop and signpost.	Ongoing/1./3.	2018/2019: - advised CRN Lead on development of a Role Description for PRAI; - see 3.2.1(b); - signposted PCAG and YPAG to PRAI for training & development; - GOSH PRAI representatives from advisory groups spoke at ICH strategy launch 2019.	2020: Rebranded as ' <i>Research Champion</i> ' the national programme will be rolled out across North Thames in early 2020.
Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
1.3 Support researchers to actively involve patients and the public in their research				
1.3.1 Promote existing resources and local support available to support PPI E activity.	- Utilise internal GOSH /ICH communication channels to increase awareness of PPI E Lead role for support. Liaise with R&I Grants Advisory and Governance teams for	Ongoing/3.	2018 onwards: - PPI E website pages updates with information for researchers; - Regular use of GOSH 'Headlines' e-newsletter	2020: - Develop PPI E website pages to include links to online Toolkit for

	<p>signposting researchers;</p> <ul style="list-style-type: none"> - Ensure up to date printed materials available for GOSH staff events. 		<p>and ICH e-newsletter for staff to outline support available and Advisory group information.</p> <ul style="list-style-type: none"> - PPIE Small Grants Scheme opens in 2018 <p>2019:</p> <ul style="list-style-type: none"> - Research awareness slots at Trust staff Inductions; - Store of printed materials in stock for use on information stalls at GOSH Open House/Strategy weeks and Trust AGM. <p>2020</p> <ul style="list-style-type: none"> -Consistent visibility in internal comms channels (e.g. Roundabout, including Chief Exec's column). -Slot for a research story every week in the new hospital newsletter (Headlines). -Inclusion of a research highlight slide at SLT meetings fortnightly <p>2021: move to digital</p> <p>PPI E Podcasts for researchers as part of GOSH Learning Academy will be available from July 2021</p>	<p>researchers through GenerationR Alliance and bespoke online GOSH/ICH Guidance on delivering PPI E and Impact evaluation;</p> <ul style="list-style-type: none"> - Develop a set of Case Studies from BRC PPI E Small Grants Call & activities. - Maintain good links with UCL Centre for Co-production <p>2021 update:</p> <ul style="list-style-type: none"> - online Researcher Toolkit hosted on the European Young Persons' Advisory Group network (eYPAGnet) website - PPI Impact Case Studies 2020-21 published on PPI E pages of BRC website
1.3.2 Provide bespoke advice to researchers	<ul style="list-style-type: none"> - Utilise internal GOSH /ICH communication channels and face to face opportunities to promote bespoke support offered by PPI E Lead; - Support researchers with planning and activities for engagement events. 	Ongoing/3./4.	<ul style="list-style-type: none"> - Face to face and online support sessions allotted to researchers including support for them to work with advisory groups, funding applications and PPI E related documents;(On Zoom from 2020) - Support offered to those researchers applying for NIHR GOSH BRC PPIE Small Grants Scheme. <p>2020-2021</p> <ul style="list-style-type: none"> - updated Guidance notes for researchers for PPIE Small Grants Scheme and Catalyst Fellowship Award 	<p>2020-2021</p> <ul style="list-style-type: none"> - Develop new GOSH/ICH Policy & Procedure for PPI E costing- in line with new guidance from NIHR Centre for Engagement & Dissemination; - Produce Researcher Handbook <p>2020/2021</p> <ul style="list-style-type: none"> - Support and help facilitate 'Young Visionaries' event. - Support and facilitate at Norrie Family Day
1.3.3 Design and deliver PPI E training/signpost to training	Utilise internal GOSH /ICH communication channels and groups to promote training and	Ongoing/3.	<p>2018/19:</p> <ul style="list-style-type: none"> - PPI E Lead joins work stream development of 	<p>2020:</p> <ul style="list-style-type: none"> - Bespoke PPI E training

opportunities and develop skills and knowledge.	engagement opportunities and PPI E Lead role details for support.		<p>online UK CRF PPI E Induction;</p> <ul style="list-style-type: none"> - Deliver PPI E Induction Training for new CRF staff; - PPI E Lead has input into training session content and signposts researchers to UCLH BRC to access PPI E training; - ‘Introduction to Public Engagement’ workshop ICH session delivered for early career researchers including ‘becoming a STEM ambassador’ (as part of the ICH Public Engagement Group) -two early career researchers signed up to join Careers Drop-In at Family Fun Day 2019. <p>2020:</p> <ul style="list-style-type: none"> - Partnership work with GOSH Orchid to pilot two online researcher training sessions: “ How to run online PPIE Focus Groups” with additional guidance to take away; (21 researchers/wide attendance across professions at GOSH) 	<p>session developed and delivered for AHP and Research Nurse specialists with follow up face to face sessions;</p> <p>See 1.3.1: 2020/2021 One Research Associate now supports YPAG meetings as an YPAG ambassador. 2 Medical students also facilitate</p> <p>2021-2022 Develop an online training module for researchers – on GOSH GOLD to deliver as part of new training package for future researchers with Researcher Handbook as part of offer. Possibility of partnership working with UCLP to co-develop and deliver online training sessions to a wider audience</p>
1.3.4 Support the active involvement of children, young people and patients to help improve research studies.	PPI E Lead provides 121 support to researchers who access YPAG to ensure they are prepared.	Ongoing/1./2./3./4.	<ul style="list-style-type: none"> - Initial face to face meeting followed by review of materials and presentation; - Researchers are requested to complete an Impact Evaluation form post meeting and follow up research development to relay back to the group; 	<p>2020:</p> <ul style="list-style-type: none"> - See 1.3.1: 2020; - Develop YPAG Induction Handbook.
Area	Deliverable	Timeline/UK Standard	Activity	Updates and future plans
1.4 Working in partnership with other PPI groups (internal/external) to increase diversity of involvement				
a) GOSH Young Peoples’ Forum (YPF) & FT Membership;	a) PPI E Lead attends monthly GOSH YPF Leads meetings to ensure joint working, sharing of good practice & cross referral;	Ongoing/1./3.	<p>2018 onwards:</p> <ul style="list-style-type: none"> a) - Provide regular involvement engagement opportunities postings for YPF e-newsletter for e.g. 2018/19: Children’s Commissioner Takeover week, 2019: Christmas Lectures & Public Science Lecture series; 	<p>2020:</p> <ul style="list-style-type: none"> a) - 6 YPAG members attend YPF; - YPF members attend a ‘Young Voices in research focus group.

<p>b) Generation R Alliance;</p> <p>c) External groups.</p>	<p>b) PPI E Lead takes active role in the ongoing development of Generation R Alliance;</p> <p>c) Ensure partnership working is fostered with external organisations.</p>		<p>- Sign up of new YPAG members to FT membership to avail of membership group opportunities.</p> <p>b)- GOSH regularly hosts Generation R Alliance meetings , PPI E Lead contributes to work stream and ensures any referrals from other YPAG leads to YPAG are followed up.</p> <p>c) - Respond to all external queries and support and develop new YPAG's;</p> <p>- Maintain partnership with UCL Division of Psychiatry to involve YPAG in co-design materials for research with C&YP in UCL MSc in Mental Health Sciences;</p> <p>2020/2021: Please see our PPIE in Research Highlights Report 2020-2021 on BRC PPI E website to see how we have expanded our reach to involve GenR Alliance/YPF and patients at our Advisory Group meetings.</p>	<p>Please see PPI E in Research Highlights Report 2020- 21</p> <p>b) 2020: GOSH PPI E Lead led on GOSH Minecraft Day event – August 2020 13 CYP across GenR Alliance attended.</p> <p>Developed online GenerationR Toolkit</p> <p>c) 2019/2020: - support and ongoing advice given for set up of new EyeYPAG at Moorfields; - KCL PPI E Lead attends GOSH YPAG as observer; - iCAN poster abstract submission. - Foster future partnership with Careers Dept.at UCL for future student engagement events</p>
Area	Deliverable	Timeline/UK Standard	Activity	Updates and future plans
1.5 Ensure adequate funding is available for PPI E activities				
<p>Maintain annual PPI E budget setting and funding allocation for development of new PPI E projects.</p>	<p>PPI E Lead meets regularly with BRC Finance team and BRC Deputy Director of Operations to monitor spend and set budget.</p>	<p>Ongoing</p>	<p>Budget spreadsheet updated regularly & yearly audit of budget expenditure; GOSH BRC PPI E Small Grants Call 2018 & 2019 funding allocation meetings held; - 2018: 8 projects & 2019:16 projects funded.</p>	<p>2020: GOSH BRC PPI E Small Grants Call 2020: - Updated application form/ procedure and guidance notes.</p>

Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
1.6 Through GenerationR Alliance and BRC led projects - explore and develop further links with industry				
Develop a more collaborative approach between Generation R Alliance YPAG's and pharma and other industry companies.	a) Work with GenerationR Lead to support pharma company requests; b) Plan and run a GenerationR Health Tech event.	2019 & ongoing/2.	2018/2019: a) - Pharma company signposted to PCAG to advise on two Phase III global paediatric MS studies; - NIHR 'Patient Centricity' project launched & updates/training at GenerationR Alliance meeting. b) Generation R DRIVE health tech event held. A GOSH led initiative. 7 YPAG groups represented - 25 children and young people attended, 4 Industry partners.	2020: a) - Take up any offer of engaging with pharma through GenerationR Alliance signposting. b) - Report published print version distributed to all participants; - Investigate opportunities for future collaboration.
Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
1.7 Explore and support other opportunities for patients/public to be actively involved in research at GOSH				
Facilitate involvement of advisory group members and other patients/families in committees, focus groups, steering groups across GOSH/ICH.	PCAG membership on: - Clinical Research Adoptions Committee (CRAC); - Research Data Access Committee (RDAC); - Project Advisory Group for NIHR Fellowship; NIHR GOSH BRC PPI E Small Grants Scheme	From 2018 From 2019 From 2019-2021 From 2018	CRAC meets monthly to review and approve clinical research proposals. RDAC meets bi-monthly to help review clinical governance issues relating to the secondary use data platform for data extracts to be released for specific projects. Meet every 6 months: review Lay English Summary & Ethics application, be involved in data analysis & dissemination and as co-authors in publications. Since 2018 our annual PPIE Small Grants Scheme has enabled approx.70 patients and their families to help shape 24 research projects	2020: - Update ToR for PCAG accordingly; - Update Role Description. NIHR GOSH BRC PPI E Small Grants Scheme 2020.

Key Objective 2. Engagement				
Area	Deliverable	Timeline/ UK Standard	Activity	Activity updates and future plans
2.1 Hold Engagement events for external audiences				
Hold an annual research open day event for the public and additional engagement events.	Support researchers to plan for hands on research engagement activities, laboratory tours, and other activities.	Annually/1./2./4.	<p>2018 Family Fun Day (FFD) for research 2019 Family Fun Day (FDD) for research</p> <p>2019 FFD new activity 'Careers Drop In'; 2019 GOSH ICH Christmas lectures for schools (17-18 year olds); 2018 BRC Showcase event; 2019 BRC "Translational Research in Paediatric Rare Diseases" Symposium (info stands/networking from many partner charities).</p>	<p>2020</p> <ul style="list-style-type: none"> - Planning for Christmas Lectures event; - Planning a programme of monthly Public Science Lectures. <p>Due to COVID-19 Pandemic it was not possible to hold a BRC Family Fun Day in 2020 Or 2021</p>
Area	Deliverable	Timeline/ UK Standard	Activity	Activity updates and future plans
2.2 Hold Engagement events for internal audiences				
Plan a rolling programme of events which align with national and international research events and themes and support other events as opportunities arise.	<p>a) Plan engagement events for patients and the public in the hospital and at external venues; b) hold/promote individual researcher engagement events/ activities.</p> <p>Utilise our social media platforms to promote events and reach out to other communities.</p>	Annually/1./2./4.	<p>2018/2019:</p> <ul style="list-style-type: none"> a) -Rare Disease Day (RDD); -International Clinical Trials Day (ICTD); - GOSH AGM Research Awareness Stall: (sign up to Research Ambassador/Be Part of Research campaigns & GOSH Sample Bank) b) 'Jeans for Genes Day' (Genetic Disorders UK), 2018. <p>-Work with GOSHCC Comms team to update GOSH Twitter with events.</p> <p>2020 International Clinical Trials Day Due to Covid-19 Restrictions we were unable to hold a physical engagement event however the day was marked over GOSH social media channels and intranet /GOSH Headlines newsletter and articles for Roundabout- "Diary of an ICU Research Nurse...during a pandemic"</p>	<p>2020:</p> <ul style="list-style-type: none"> - Rare Disease Day (RDD) 2020 held in conjunction with the London North Genomic Laboratory Hub. b) 'Big Yellow Friday', Children's Liver Disease Foundation day. <p>Rare Disease Day (RDD) 2020 tweet picked up by other rare disease pages in Ireland. 2021Rare Disease Day (RDD) A different way to mark the day Including patient videos this year</p>

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Area	Deliverable	Timeline/ UK Standard	Activity	Activity updates and future plans
2.3 Support researchers' engagement with students from local schools/colleges				
Increase attendance from local schools/colleges at events; Enable researchers to outreach to schools/colleges.	Targeted communications to schools and colleges. Support researchers to outreach to schools and colleges.	Ongoing/1 /4.	2018/2019: -ICTD & RDD themed lessons delivered at GOSH School; - 4 researchers have delivered research themed sessions at schools; - STEM Ambassadors in GOSH /ICH; -Promoted Careers Drop at BRC Family Fun Day & Christmas Lectures event attended by approx.100 students from local schools.	2019/2020: Targeted messaging to local schools and colleges for: FFD Careers Drop In, Christmas Lectures event & Programme of Science Lectures including outreach to local sixth form careers night & signposting to 7 other sixth forms.
Area	Deliverable	Timeline/ UK Standard	Activity	Activity updates and future plans
2.4 Collaborate with GOSH Arts and other creative based organisations to deliver research themed activities				
Link in with : a) GOSH Arts ; b) internal and c) external organisations to facilitate PPI E in their research related projects.	a) Zayed Centre for Rare Disease in Children 'Together' Festival; b) 'Stories From Neverland' creative writing and drama workshops. c) On The Button Theatre	2018/2019/1./2./3. 2018/1./2./3. 2018/1./2./3.	2018/2019: a) GOSH YPAG codesigned interactive research stations for the centre; a) GOSH YPAG members ran engagement stall at the 'Together Festival' (engaging with approx. 70 members of the public). b) Funded through the BRC PPI E Small Grants Scheme 2018: involving patients and families in managing their care, and creating a forum for Healthcare Scientists to engage the wider GOSH community in healthcare science and IPC research. GOSH School and Play Team involved also. c) Funded by the BRC – the company ran two theatre workshops at the 2018 BRC Family Fun Day with support from GOSH/ICH researchers on brain injury (engaging with approx. 50+	2020: Look into offering YPAG members tours of Zayed Centre. (on hold due to covid) b) 2019: (May- December) A 10-month workshop project supported by the Royal Literary Fund to develop the teaching of effective healthcare science writing was run. 2019: c) YPAG member attended rehearsals for script development for external

			members of the public).	showing. 2021: a) Sensing Spaces of Healthcare workshop online b) On The Button Theatre Received top up funding to produce videos of their project to reach out to schools (due to covid)
2.5 Refresh of all PPI E communications materials				
Ensure all materials are up to date – see 1.2.1.	PPI E Lead to collaborate with GOSH Communications Manager and GOSHCC design and web team to update existing PPI E materials and develop new ones- see 1.2.1.	Ongoing /4.	See 1.2.1	2020: - Update all materials in line with new NIHR & GOSH Research & Innovation branding; - Maintain links with UCL Culture.
Key Objective 3. Patient Experience				
Area	Deliverable	Timeline/ UK Standard	Activity	Activity updates and future plans
3.1 Improve our structures for capturing feedback				
3.1.1 CRF Research Participant Experience Meetings.	PPI E Lead to attend and contribute to monthly CRF Research Participant Experience Meetings.	Ongoing/1./2.	Support implementation and monitoring of the development and delivery of both the Trust's and NIHR's Patient Experience and Engagement priorities and plan including Friends & Family Test feedback & methods.	2020: Introduce methods of collating live feedback directly from the children and young people that we aim to share with the next child; this will assist us to gain an insight into their research experience and what matters to them.(on hold due to covid)

3.2.1 Conduct Research Awareness Surveys.	a) PPI E Lead to attend and contribute to the UK CRF PPI E Leads work stream; b) PPIE Lead to link with Clinical Research Network (CRN) Lead North Thames.	Ongoing/1./2.(as opportunities arise)	2018/2019: CRF Research Awareness Survey at GOSH and poster at UK CRF Conference; b) Review, refine and rollout of CRN Patient Research Experience Survey for GOSH CRF patients & their families, approx. 70 surveys completed.	2020: b) Engage with new survey roll out on request. 2020-21 update NIHR Participant in Research Experience Survey (PRES) from November 2020 - March 2021 60 surveys gained over the last year to summarise and present families experiences at GOSH CRF Patient Experience meeting.
3.2 Identify new and innovative approaches of enabling participation and involvement				
Improve our digital reach to key stakeholders.	PPI E Lead to collaborate with GOSHCC digital team to reach out to stakeholders for events and updates.	Ongoing/2./4.	2018: - Launch of GOSH Twitter/Instagram accounts enables research-focused social media postings including YPAG Teenage Twitter takeover at 2019 BRC FFD and Sample Bank My Story; - YPAG codesign Electronic Patient Record (EPR) system my GOSH patient portal for patients opt in to receive research participant activity updates.	2020: work with GOSHCC to develop this area
Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
3.3 Engage with Play Specialist in the Clinical Research Facility (CRF) to enable patient participation				
PPI E lead to mentor CRF Research Health Play Specialist.	PPI E Lead to meet regularly with Research Play Specialist to prepare for YPAG meetings.	Ongoing/1./2.	2018/2019: - Research Health Play Specialist co-facilitates some YPAG meetings and supports patient recruitment to the group.	2020- 21 update : Appointment of new Research Health Play Specialist to take on this role. New appointee has attended all YPAG meetings and an additional workshop with GOSH Arts

Key Objective 4. National Collaboration				
Area	Deliverable	Timeline/UK Standard	Activity	Activity updates and future plans
4.1 Develop new opportunities for GOSH YPAG to contribute to the GenerationR Alliance				
a) Increase awareness of group members of the GenerationR Alliance; b) Engage with them in new ways to be contribute to the GenerationR Alliance.	a) Ensure all existing and potential members are aware of the GenerationR Alliance; b) Plan for a Generation R Alliance event.	Ongoing/2.	a) - All Induction communications to signpost members to GenerationR website. A - All YPAG communication materials to include GenR branding; - Ensure equitable involvement of YPAG writing blogs and contributing to articles for the GenerationR website. b) 2019: GOSH DRIVE GenerationR Alliance Health Tech event.	2021: - GenerationR Alliance Toolkit review by YPAG - YPAG Induction Handbook. Please refer to our PPIE in Research Highlights Report 2020-21.
4.2 Link in with Royal College of Paediatrics and Child Health RCPCH group 'and us'				
Develop relationships with these organisations.	PPI E Lead professional membership on the 'and us' group & YPAG involvement	Ongoing/2.	2018: YPAG members speak at PERUKI conference as part of the RCPCH conference.	2020: Look to engage with the group again if possible; Promote the group to YPAG.
4.3 Continue to develop our work with national bodies				
Nuffield Council on Bioethics; National Children's Bureau (NCB) Research Centre.	Look for opportunities to engage with these organisations.	Ongoing/2.	2018: YPAG took part and judged poster competition for The Association for Young People's Health: 10th anniversary conference.	2020: Reestablish links and joint working opportunities with other national bodies.
Key Objective 5. Reporting and Learning				
Area	Deliverable	Timeline/ UK Standard	Activity	Activity updates and future plans
5.1 Reflect on previous year's activities				
NIHR GOSH BRC & CRF Annual PPI E Report; Appraisal and PDP for PPI E Lead.	Ensure all PPI E activity is recorded and capacity for planning new developments.	Annually/5./6.	Monthly verbal update recorded at BRC SBM; Annual BRC Family Fun Day evaluation report; Quarterly written report for CRF SMT; - Update Operational Plan annually - Update Impact evaluation spreadsheet quarterly.	2020: Annual PPI E Highlights Report on website to cover all activity including Case Studies. - PPI E Lead work streams to align with PPI E Strategy and UK Standards.

5.2 Build/extend networks for learning, development and support with other PPI E Leads for research				
Membership of NIHR BRC PPI Leads Group & UK CRF PPIE Leads network; INVOLVE working group.	PPI E Lead attends and contribute to quarterly meetings and work streams.	Ongoing/2.	2018/2019:- Work stream: review/refresh of UKCRF PPI Induction Framework; - Rollout of the GOSH Research Awareness Survey; results featured in a poster at the UKCRF Conference 2019; - Work stream: INVOLVE Young people in research report	2020-21 NIHR BRC PPI Leads Group Work stream: to support policy development for BRC PPI E payments and expenses.
5.3 Explore methods and implement approaches to evaluate the impact of PPI E				
Develop and update a GOSH PPI E Impact and evaluation toolkit.	Ensure PPI E activity is recorded and Impact is evaluated and measured.	Ongoing/5.	2019: Impact spreadsheet developed and other methods for recording Impact.	2020: - PPI E Lead attendance at evaluating Impact workshop. - Researcher Toolkit will include section on Impact evaluation.
5.4 Ensure a visible GOSH presence at national and international PPI E events and conferences				
Annual UK CRF Conference & INVOLVE Conference.	PPI E Lead attends and contributes to PPI sessions.	Annually/2.	2019/2019:- Attendance at 2018/19 UK CRF Conference; - YPAG ambassador opened INVOLVE Conference	2020: UK CRF Conference cancellation due to COVID-19