

no one left out
friends
kindness
family
hand in hand
a part of
understanding
in cooperation
everyone
together
unity
support
individuality
giving people a voice
disability
team
welcoming
co-creation
joining in

Patient and Public
Involvement and
Engagement (PPIE)
in Research

Highlights Report 2021-2022

Welcome to the report

Read on to find out all about our PPIE work in the past year and how we continued to develop and deliver our activities in response to the changing COVID-19 landscape.

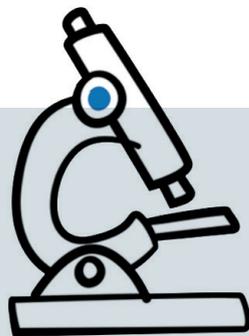
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Front Cover graphic 'Being Seen and Heard in research – word cloud' created by GOSH Young Persons' Advisory Group (YPAG) for research.

Spotlight on Researchers

Support, training, consultation and engagement



“ PPIE has been invaluable throughout my research journey. Having parents engage at all points of the research ensures it is relevant and realistic. It motivates me to ensure there is genuine impact. ”

GOSH Researcher

Approximately

70



researchers received individual support sessions with the GOSH BRC PPIE Lead

‘Writing and presenting for patients and the public’ workshops



- 13 researchers attended four workshops with follow up support and reading materials
- Four researchers received coaching for lightning talk presentations at the NIHR GOSH BRC Showcase **event** and 3 minute thesis competition

PPIE Induction training delivered to



- 2021 GOSH BRC Summer Studentships scheme
- Chief Nurse Junior Fellows research study day
- ORCHID Internships, with follow up support given to five researchers



Blood Cells and Cancer



Sight and Sound

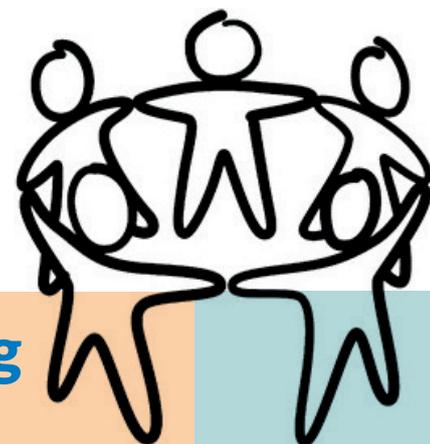


Operations and Images



Brain

Spotlight on Researchers



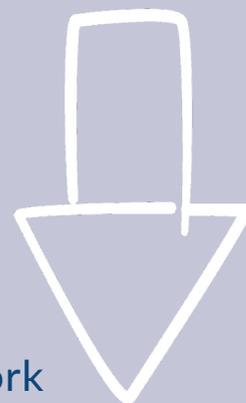
Online PPIE in research training podcasts for researchers

 <p>GOSHpods - PPIE Part 1 What is PPIE and why is it so important?</p>	 <p>GOSHpods - PPIE Part 2 Tips and ways to carry out PPIE</p>	 <p>GOSHpods - PPIE part 3 An interview with a GOSH YPAG member</p>
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58

researchers completed a 'PPIE in Research' survey to help us map out our PPIE future plans

Patient and Public Engagement Presentations delivered to



- Clinical Research Network
- King's College Hospital NHS Foundation Trust, Knowledge Exchange Seminar
- UCLP PPIE Committee (2020-2021 PPIE Impact Case Studies) and Q&A

Spotlight on Researchers



5 projects awarded funding to carry out 12 PPIE activities to 47 patients and their families online

11 researchers attended 'Running online focus groups' training

One off focus group held with **16 families** to identify areas of future research for patients with an inherited cardiomyopathy

One off focus group held with **four families** and opportunity to engage with them about current research around Neuromuscular electrical stimulation (NMES) and benefits other patients have had from using the NMES units

Six Zoom interviews held with parents to help improve future research into surgical treatment and head shape appearance

Four workshops held with **four families** to discuss the trial design and trial protocol for Baricitinib for the treatment of Juvenile Dermatomyositis/JDM-JAKI (Juvenile dermatomyositis – janus kinase inhibitor trial)

Five workshops (co-facilitated by a parent) held with **17 families** to co-design a Digital Information Booklet as an aid to increase families' knowledge and informed consent about the novel research treatments for Thymus Transplantation

Spotlight on GOSH Young Persons' Advisory Group for research (YPAG)



Support, collaboration, awards, consultation and engagement



I think it's important for GOSH scientists to ensure their research is explained in an accessible and engaging way for children and young people, and to make sure taking part in research is as stress free for patients as possible.



GOSH YPAG member



- Aged between 10-21 years old, patient and public members
- Advise GOSH researchers and other researchers on making their health research relevant to children and young people
- Some members have taken part in a clinical trial
- Are part of **GenerationR** – a national network of young people improving health through research

Keeping connected online

6 full day meetings held via Zoom to support **36** researchers

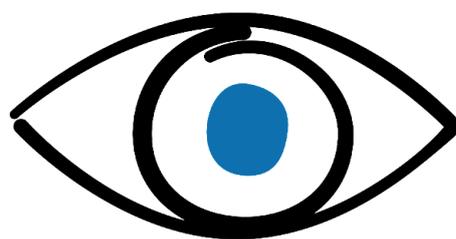
9 Patient Information Sheets and Lay English Summaries reviewed

12 new members join the group!

Spotlight on GOSH Young Persons' Advisory Group for research (YPAG)

Being seen and heard – making our meetings more inclusive and interactive

- Pre meeting side rooms available for YPAG members to meet and mingle, with peer support available for new members
- Extended invitations to Moorfields eyeYPAG and GOSH YPF to attend some of our meetings
- Two GOSH YPAG members now co-facilitate breakout room groups
- GOSH YPAG facilitator piloted a Mindfulness meditation session to help members combat zoom fatigue
- Introduced Padlet and Mentimeter (real time feedback interactive software) and Miro (online whiteboard tool)
- Used Otter.ai live transcription service
- Held fun research and science quizzes as an aid to learning



GOSH YPAG collaborations

we believe in working in partnership

UCL Division of Psychiatry

10 members attended the annual MSc in Mental Health Sciences course session to co-design research materials with students

University of Bristol & GOSH Arts

17 members attended two creative research methods workshops with '**Sensing Spaces of Healthcare**' to help improve hospital design. GOSH YPAG are credited in an article published in the Journal of Applied Arts & Health and co-wrote a **Blog** about the collaboration

C-POS team

Abstract co-authored for submission to the international palliative care conference on joint work with the **C-POS** team researchers and GOSH YPAG

GenerationR

Four members attended behind the scenes **Nattering with the NHS** a new live streaming project and podcast with plans to co-host future episodes.



I joined the livestream and found it incredibly insightful, adding to my understanding about this particular career path!



Young person



An exciting collaboration between @YPAGne & GOSH YPAG Nattering returns for two episodes

Wednesday 16th March – with Charlotte Bendall, F2 Doctor

and

Wednesday 4th May – with Victoria Harbottle, Physiotherapist

GOSH

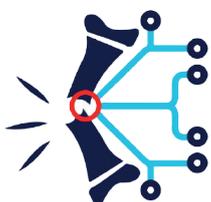
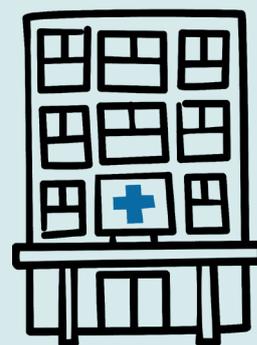
One member co-presented to the GOSH Speech and Language Research team

Four members reviewed Case Studies for the NIHR GOSH BRC funding application

One member represented YPAG at the NIHR funding interview

Four members attended the GOSH BRC Showcase event

Four members have joined the FRACTURE Study Steering committee



FRACTURE

Fast Reporting using Artificial Intelligence for Children's Traumatic Radiology Examinations

GOSH Learning Academy

One member co-presented and took live questions at the annual GOSH Conference: 'AI & Me' and won 'Best Oral presentation award'.

GOSH YPAG member also cited as co-author on article [Engaging children and young people on the potential role of artificial intelligence in medicine in the Pediatric Research Journal](#)

Other Conference and Q&A session

Two members attended [INRICH](#) and took part in live Q&A

Work experience student

[Read her published article here](#)

Awards

Gene Therapy Animation: 'Gene Therapy explained - Changing our body's recipe to treat disease' - wins runner up prize at the Bristol Science Film Festival 2021

"The only film subtitled - which was appreciated, liked that the text was part of the video rather than added in on top"

Lucy Project wins Mental Health Award at the **British Medical Journal (BMJ) Awards**

YPAG member who had work experience with the team attended the interview.

"We are thrilled but obviously couldn't have done any of it without the support of the YPAG group. PPI involvement was mentioned by the panel as a central part of the reason we won"

Four members contributed to our [website](#) celebrating **International Day of Women and Girls in Science**

Consultation

Inform and involve us in decision making

Six GOSH YPAG members, one Liverpool YPAG member & GenR Lead attended the NIHR GOSH BRC & CRF Patient and Public Involvement Stakeholder Meeting

Spotlight on GOSH Parent and Carer Advisory Group for research



Involve us at an early stage so that we feel part of the research and also have a sense of ownership of it. Consider involving people in the identification and prioritisation of the research topic and the development of the research question

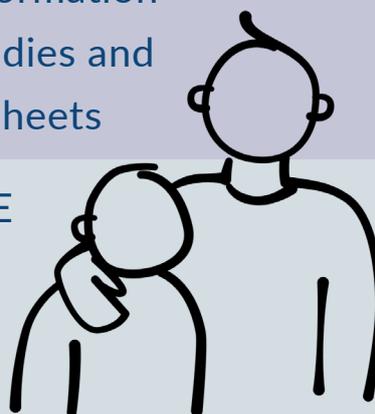


GOSH Parent and Carer Advisory Group for Research

The group supports researchers providing a parent perspective on research carried out into child health

- give feedback on research proposals and funding applications, study design and dissemination;
- help with revision of participant information literature and consent forms for studies and developing accessible information sheets

- **Three members** join the FRACTURE Study Steering Committee
- **Two members** have input to the GOSH **CRAC** committee
- **One member** sits on the GOSH Research Data Advisory Group
- **Four members** attended the NIHR GOSH BRC & CRF Patient and Public Involvement Stakeholder Meeting



Four meetings held with **six researchers**

Five Patient Information Sheets and Lay English Summaries reviewed

Two new members join the group

Spotlight on Engagement

International Clinical Trials Day

- Live GOSH staff virtual Big Brief held in the Clinical Research Facility with walkaround and interviews with research staff and an educational Clinical Trials themed quiz
- What does “Clinical Trial” mean to you? [article published on GOSH Website](#)



GOSH BRC Deputy Director of Operations ran a fun and educational 'biscuit mock clinical trial' where students looked for new drug treatments for COVID-19 and heard all about clinical trials at GOSH



Before today, I didn't really know anything about how new drugs are tested. I now know that it costs a lot of money to produce and test new drugs and it has to go through lots of phases. This is to make sure that when a drug is actually released, it is as safe as possible.



Primary School pupil

Spotlight on Engagement

Rare Disease Day

Patient facing communications to celebrate the day with countdown clock and a relaunch of **GOSH Sample Bank**



Consultation

NIHR GOSH BRC Patient and Public Involvement Stakeholder Meeting is attended by a diverse group of 30 patient and public representatives from the local community and across GOSH and our wider partnerships.

NIHR GOSH BRC PPIEP Steering Committee is formed – watch this space!

Our Journey Continues

Yuvan, a GOSH patient and new member of GOSH YPAG

“I worked with the team in the Young Persons’ Advisory Group for Research to design a game to help children to understand more about leukaemia and the cures in a fun and interactive way. It’s really important how the hospital involves children and young people in their research design.”



GOSH Directorates



Blood Cells and Cancer



Sight and Sound



Operations and Images



Brain



BRC Themes



Gene stem and cellular therapies



Advanced treatment of structural malformations



Novel Therapies



Rare Disease Cohort



Genomics and System Medicine