

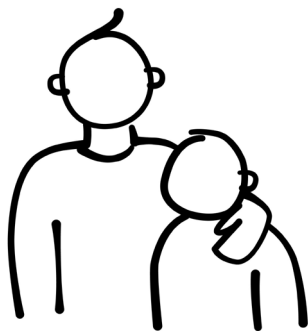


Patient and Public  
Involvement and  
Engagement (PPI E)  
in Research

Highlights  
Report  
2020-2021



# Why do we include PPI in the research process?



“Including the voices of young people in research is important because we are the next up and coming generation, and in a few years we will be the ones filling these roles so I think it’s important we have a say in how our future is going to be like”

*GOSH YPAG member*

## Our PPIE Strategy says we will:

**Support researchers** to actively involve patients and the public in their research

- Provide bespoke advice to researchers on involving patients/public in individual research projects and programmes of research, including advice/input on grant applications;
- Design and deliver PPI training for local researchers, and/or signpost to training opportunities;
- Support the active involvement of children and young people and patients to help and improve studies so patients want to participate.



## Researcher Support

Over **60** researchers received one to one sessions with follow up



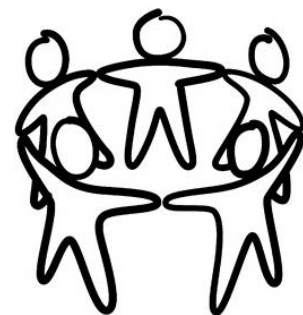
**Four** of these researchers awarded a National Institute for Health Research (NIHR) Clinical Doctoral Research Fellowship

## Researcher Support

**21** researchers attended two ‘Delivering online PPI E Focus Groups’ Training Group sessions via Zoom (in collaboration with Orchid)



# PPIE Small Grants Scheme 2020



- **11** applications received
- **7** projects awarded
- **Four** projects delivered to date to **48** patients and their families

1. **Two CHARM Focus Groups** (Charting Hurdles in Anorectal Malformations) to identify what research matters  
**13 children & families attended**

2. **Telephone Interviews with 6 parents** to look at research questions into improving developmental assessments for children with neurodisabilities

3. **Two Focus Groups with 11 boys** to look at research priorities for boys and young men with Duchenne Muscular Dystrophy (DMD)

4. **Two Focus Groups with 10 parents & 8 teenagers** on perspectives of parents and young people on the research priorities for children with cochlear implants

## Activity carry over into 2020/21

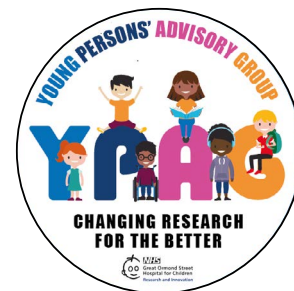
Two projects delivered to date to 20 patients and their families

5. **Focus Group** held with **7 families** to identify research priorities for children and families affected by arrhythmogenic cardiomyopathy

6. **Young Visionaries Day** held with **three families** to establish their perspectives to see if there is a need for the creation of a new rare eye disease YPAG



# Young Persons' Advisory Group (YPAG)



It's important for young people to have their say on research because we have different views and needs

It's only logical for us to shape the world we live in



GOSH YPAG members

- Aged between 10-21 years old and believe in making health research relevant to young people
- Meet six times a year to advise GOSH and other researchers on their work
- Some members have taken part in a clinical trial
- Are part of Generation R – a national network of young people improving health through research.

## YPAG Activity:

**Five** Zoom day long meetings held with **19** researchers

### Extending invitations to GenerationR & others

- **YPAG Meetings:** three Moorfields Eye YPAG, two Southampton YPAG & three GOSH Young People's Forum (YPF) members
- **Work experience student/Clinical Nurse fellow/Moorfields Research nurse**
- **Three new members** joined the group this year
- **GOSH Minecraft Day:** four other YPAG's, GOSH YPF & GOSH patients (13 in total)
- **ChromaDose Project:** 16 YPF members completed an online questionnaire

## Online review:

- Patient Information Sheets for **16** researchers
- Lay English Summaries for **four** researchers
- Questionnaires for **five** researchers



# YPAG Additional Activity

# Parent and Carer Advisory Group

1. GOSH Minecraft Day  
– 13 young people attended
2. GOSH Clean Air Podcast
3. Sensing Spaces of  
Healthcare Workshop
4. RIO Study Logo design  
competition
5. GOSH Garden voiceovers  
– work in progress
6. Gene Therapy explained  
animation – script and  
voiceovers
7. UCL Division of psychiatry  
collaboration – 9 attended
8. International Day of Women  
and Girls in Science
9. Co-design of our new  
YPAG logo!

**Engagement:** BRC  
Deputy Director of  
Operations delivered  
two 'Research at GOSH'  
talks and Q&A to YPAG  
at their meetings

Meet four times a year and support researchers online to provide 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



We have to keep improving and collaborating to make important change that is patient centred. Research will help us improve the health and well-being of patients and families whilst improving knowledge, skills and improving treatments that are cost efficient and effective. This has been proven with the current vaccine for COVID-19. You need to invest to progress and make successful change!

*Parent and Carer Advisory Group member*



## Three Zoom meetings held with 7 researchers

### Online review:

- Patient Information Sheets for two researchers
- Lay English Summaries for four researchers
- Questionnaires for two researchers

### Extending invitations to others

- Two GOSH parents & GOSH Senior Research Fellow Lead in Learning Disabilities joined a disease specific session

**Engagement:** Three members attended a webinar on 'Introduction to Statistics'

## Advisory Groups joint involvement

- Parent and Carer Advisory Group meetings in May and July opened up to YPAG members with an interest in research around the transition process
- A representative from YPAG and PCAG sat on the GOSH BRC New Projects Funding Call Lay PPI panel

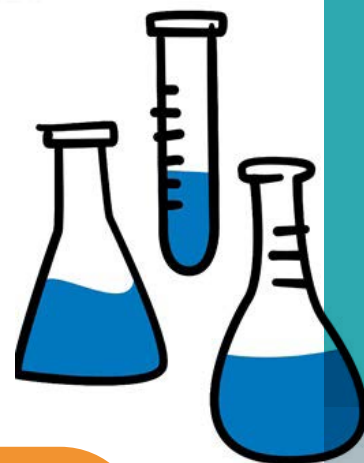
## Online engagement: Rare Disease Day A different way to mark a special day

- ~50,000 views of the posts on social media
- 4,500 views of the patient video on YouTube and Twitter
- Double expected engagement in a crowded 'market'
- Hospital lobby screen
- Screensavers
- Patient entertainment bedside screens

## Online engagement: Genomics and Systems Medicine

Videos on whole genome sequencing (GOSH YPAG had input on content and script) have now been translated into Chinese. This means they are now available in English, Chinese, Turkish and Bengali.

- For China there were 136.8 thousand views in total on Chinese 'Twitter' in a week of being up
- UK ones on YouTube have 30,000 views



Online  
engagement  
Science4U

RAREDISEASEDAY.ORG





# A Journey Together



“The waters in the river flow in a journey to the sea. Joining a trial is the start of a journey for the patient and the doctors. It is the start of “a journey together”

*GOSH YPAG member Vincent (and artwork)*

## 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