



GenerationR

young people improving Research



GenerationR Liverpool
YPAG & Alder Hey
Parent and Carer's
Research Forum Annual
Report
2019-2020



1.0 Introduction & Background:

Welcome to the National Institute for Health Research (NIHR) Alder Hey Clinical Research Facility (CRF) and the University of Liverpool Children and Families Involvement Annual Report. The report describes our commitment to involving and engaging children, young people (CYP), and families in the design and conduct of paediatric health research in the UK and Internationally.

This report is from April 2019 to March 2020 and highlights examples of involvement and engagement activities that have taken place during the year. All activities, progress, and impact are linked to the objectives set out in the NIHR Alder Hey CRF Patient and Public Involvement Strategy 2017-2022: <https://bit.ly/3l3fKB2>

2.0 Involving children, young people and families

Our commitment to involving children, young people and families in the design and conduct of paediatric health research is highlighted predominantly through the work of the GenerationR Liverpool Young Person's Advisory Group (YPAG) and Parent and Carer's Research Forum, both funded by the NIHR Alder Hey Clinical Research Facility (CRF). Involvement work with disease-specific groups of children, young people, and families take place on a needs-basis. Additional funding to support our work with children and families is sourced from non-industry and life science studies.

2.1 GenerationR Liverpool YPAG

The GenerationR Liverpool Young Person's Advisory Group (YPAG) was set up in 2006 and currently has 20 members aged between 9-21 years old. Some members have experience of taking part in health research, some have experience of living with a condition or disability, and some wish to pursue a career in medicine/research/science. The Liverpool YPAG meets approximately every six weeks at the Institute in the Park at Alder Hey Children's NHS Foundation Trust.

2.2 Alder Hey CRF Parent and Carer's Research Forum

The NIHR Alder Hey CRF Parent and Carer's Research Forum was set up in 2018 and is made up of 23 parents and carers. All members have experience of having a child with a long-term chronic condition. The Forum's role is to support the design and delivery of paediatric clinical trials. Members were recruited across the Northwest region after a series of outreach activities and visits to many different charities and support groups. The forum meets approximately every six weeks on a Saturday, usually alongside the GenerationR Liverpool YPAG.

2.3 Involvement activities 2019-2020

GenerationR YPAG and parent/carers members have been involved in a number of projects over the past year and their input has played a valuable part in many national and international clinical trial designs (see section 2.4). In addition, we have been able to offer opportunities at a national and international level via attendance at conferences and steering group membership on relevant paediatric clinical studies. Interactions in between meetings take place via an active closed Facebook Group (for parents) and a WhatsApp group for YPAG members to share information, events and to check on general wellbeing. Over the last year, the YPAG and forum have built up excellent working relationships with international pharmaceutical companies and NHS and NIHR organisations. We continue to recruit new members to both groups from an ongoing outreach strategy.

2.4 One-Stop Support Service for Researchers:

In total nine YPAG meetings and forum meetings were held in the reporting period between April 2019 - March 2020. A total of 22 projects have been presented in meetings. The diversity of projects and the range of specialties and organisations represented is evidenced in Appendix 1.

Planning & Processes of accessing the Liverpool YPAG and Parent and Carer's Research Forum:

If a researcher or research team wishes to access the group a discussion takes place with either the Senior Patient and Public Involvement/Engagement (PPIE) Manager or Youth and Family Participation Officer. A study detail form (Appendix 2) is then completed to address questions such as study details (e.g. type of study, stage of the study, etc.); type of PPI activity (e.g. review of a protocol, review of a patient information sheet, outcome measures, etc.); expected outcomes from the activity and evaluation methods.

Once a decision has been made as to the type of activity required, the researcher will be then asked to sign a Researcher Agreement Form, (Appendix 3) which sets out very clearly what to expect from the group and what the group expects in return. We strongly encourage researchers to attend YPAG meetings face to face so that effective dialogue can be achieved but this isn't always possible so the PPIE Manager or Youth Participation Officer is happy to undertake the activity specified.

Several weeks after the consultation has taken place the Youth Participation Officer will contact the researcher to gain some feedback (Appendix 4) as to what happened as a result of the young people's and parent/carers input, for example, did anything change to the protocol or patient information sheet as a result of the comments received, and did this go through ethics without any problems? This is really important as it demonstrates the impact of young people's and families' roles in the design and delivery of paediatric research. See the feedback and impact section below.

Life science collaboration:

Since 2018 the PPIE Manager has been working with the NIHR CRNCC to encourage the active involvement of patients in the early stages of protocol development with life science industry studies. Liverpool GenerationR YPAG and Parent and Carer Research Forum were involved in the very first pilot exercise of the Patient Engagement in Clinical Development Service alongside Pfizer Ltd. A case study of the pilot can be found here

<https://bit.ly/3hh08Yh>

The pilot informed processes such as reimbursing patients for their time and effort and tackled issues such as contracting and confidentiality agreements that can normally delay interactions between patients and industry. This national process then informed the AHCRF and University of Liverpool processes of working directly with life science industries and young patients and families. In this reporting period, we have utilised these processes on five industry projects, cutting the time between the first contact with industry and getting a contract signed in two weeks. Reimbursement for patients and patient involvement expertise will ensure the sustainability and growth of patient involvement in AHCRF and University of Liverpool activities.

Feedback from researchers & impact:

Feedback from researchers was received for most of the activities performed (some are still being collated). Several researchers also provided thank you letters to the group to be kept for their portfolio of activities. Below is an example of thanks and recognition the group receive as a result of their input:

“In any design and development process especially in healthcare involving patients and families is fundamental, so much so that without their engagement a product or device will not be adopted by the NHS no matter how good it is because it lacks the most important element, patient and advisory group feedback.

I was introduced to The GenerationR Liverpool Young Person’s Advisory Group (YPAG) at an early stage in my Innovation Pathway. The facilitators were incredibly helpful and understanding so I fully understood what was expected in my presentation on my first attendance. I was afforded plenty of time to present and enough time for questions and answers which I found hugely beneficial.

*What really impresses me most whenever I return to present to GenR is how informed the group is and their readiness to engage and importantly challenge. I have continuously used group feedback to inform my design process and they have become one of my most important touch points on the Innovation Pathway towards NHS product adoption. Jenny, Sammy and the whole group I thank you so much for all your assistance and continuous interest in the Tookie journey as I am in yours.”. **Stephen Tooke, Commercial Director, Tookie Limited.***

“The GenerationR team based at Alder Hey Hospital, Liverpool have been a fantastic help to me as a clinical researcher. The team have facilitated me discussing my research with patient/parent focus groups, this was a personally and professionally rewarding opportunity. The team also spoke at a workshop I organised to promote public engagement activities to academic pathologists from around the country. Their contribution was pivotal to the day and extremely well received. Finally, the GenerationR team continues to be a 'go-to' source of inspiration and opportunity for me in terms of public engagement and I feel lucky to have such a well organised and pro-active team to turn to for help and support”. **Researcher**

“I worked with GenerationR during my Ph.D. application preparation, they were instrumental in the development and design of my project that I hope will help many children with a debilitating condition, and are even responsible for the amazing logo to go with it! Sammy and Jenny run a fantastic group and I can't thank them enough for their help with my work!”. **Student**

Reflections from YPAG and Parent Members

“It is great to be able to make the NHS more child and young person friendly and to help to change the way information is given to children and young people, therefore, making it more understandable”. **YPAG Member**

“It is nice to feel you have a say in some of the decisions about how children and young people receive information about hospital and their health”. **YPAG Member**

“ The group helps to expand knowledge of different charities and organisations as well as helping to show that the way information is shown and presented can have a big impact on the how we receive it”. **Parent**

"I enjoy being part of the forum because we do loads of fun stuff and are making better progress together in clinical research, this is important so we can help cure people who have diseases or viruses.....such as covid-19!" **YPAG Member**

"Being a part of Generation R parent forum has been a complete privilege. I have enjoyed contributing to the clinical research process and have benefitted from really useful personal and professional development opportunities as a result. I joined the forum to be a voice for parent-carers and I feel I have been gifted with much more than that. Jenny & Sammy are wonderful facilitators, networkers and professionals. It has been a pleasure to get to know them and the other parents & children involved and I am excited to see what else we can do as a forum going forward". **YPAG Member**

Impact

We continuously obtain feedback from patients and families regarding their experiences of involvement in AHCRF or individual study activities, routinely recording, monitoring, reporting, and acting on feedback. Evaluating the impact of PPIE activities is a key priority and in March 2020 the senior PPIE Manager embarked on a fellowship and Ph.D. to explore evaluating, reporting and sharing the impact of young people's involvement in the design and conduct of paediatric clinical research. This is partly to address the recommendations highlighted in the UK Standards for Public Involvement, and following the work we undertook, commissioned by the James Lind Initiative. Click here: <https://bit.ly/3aJCt07> for the full report and a peer reviewed paper is in press.

GenerationR Alliance

GenerationR Alliance is a National Young Persons' Advisory Group (YPAG) made up of local YPAGs across the UK. Groups are funded by the National Institute for Health Research (NIHR) and/or other National Health Service (NHS) organisations, through various channels. The GenerationR Alliance was established in 2017 to create a community of existing (and new) YPAGs to collaborate; provide national oversight of children and young people's involvement; facilitate work based on the GenerationR recommendations (set out in the 2013

report); act as a forum to collate and disseminate information GenerationR Alliance activities, and work together to build an evidence base in the UK and internationally on the impact of the involvement of children and young people in health research. The Alliance is coordinated by Jenny Preston, with support from Dr. Pamela Dicks, (ScotCRN Manager) who oversees the activities of the Alliance to monitor and ensure it meets and adheres to its objectives; approve membership of interested organisations, groups or individuals; coordinate national activities; organise regular meetings with Alliance members; provide training & support in maintaining pages on the GenerationR website and blog writing, and share good practice through various means (GenerationR website, blogs, etc.).

During this reporting year, three face to face meetings have been held hosted by Alder Hey CRF, and Great Ormond Street Hospital CRF. A national event was also hosted by the GOSH Digital Research, Informatics, and Virtual Environments (DRIVE) team in April 2019 to bring together members of GenerationR YPAGs to feed into DRIVE's Patient and Public Involvement Strategy. 25 children and young people came together and took part in four interactive health tech workshops where they met and advised digital researchers and industry colleagues to help them think about how their products could be improved to better meet their needs. Further information can be found here: <http://bit.ly/2RRXUU2> which includes a full report of the day and next steps.



Young Person Led Project – Raising Awareness of Invisible Illnesses in Schools and Education (RAiSE)

Alder Hey CRF continues to support the RAiSE Project, which is a young person led project to support young people living with invisible illnesses. The project is in the process of finalising an educational pack for schools to support young people living with an invisible illness. The pack has been completed and was developed with various stakeholders including young people, teachers, and parents. In November 2018 RAiSE achieved official charitable status. RAiSE is led and founded by GenerationR member Sophie Ainsworth. In this reporting period, Sophie has continued to promote RAiSE at various events including European Conferences such as Euler Congress in Madrid where she was an invited speaker. Sophie and two members of GenerationR Liverpool YPAG alongside Sammy Ainsworth and Jenny Preston led a young person and family workshop in Liverpool in August 2019. All stakeholders attended and planned further developments for RAiSE. Sophie and the RAiSE team have worked hard to develop links with many charities and support groups both locally and nationally including Lupus UK, rheumatology support groups in Manchester, and The Joshua Tree Young person cancer support charity. For further information about RAiSE follow @raiiseuk.

Engagement, Involvement and Promotional Activities

Engaging, informing, educating, and stimulating thinking about clinical research is achieved through our Research, Education, Awareness, Program (REAP).

The PPIE and CRF team, Liverpool YPAG members and members of the Parent and Carer's Research Forum are hugely committed to engaging with a variety of audiences including young people, clinical staff, patients, and members of the public to raise awareness and promote research in children.

This year many engagement activities have been undertaken including: presenting alongside patients at over 15 UK and global conferences to promote CYP and family involvement and inclusion in the design and delivery of paediatric experimental medicine and early phase research; distribution of patient experience surveys; supported International Clinical Trials

Day and the NIHR 'Be Part of Research' campaign with a variety of activities, including the launch of the antibiotic drama written and performed by young people, and a video recording of a parent talking about their research experience; promoted research linked to AHCRF themes at various health and research awareness events (World Lupus Day; WORD Day, and World Kidney Disease Day). The PPIE lead also continues to publish extensively in the field of children and young peoples' involvement in the design of clinical trials, and this year has authored or co-authored 10 publications (9 Journal articles, 1 book chapter) see <https://orcid.org/0000-0003-4800-234X>

Here are several exemplar engagement activities that were undertaken this year:

Raising Awareness of Antibiotics

The PPIE Manager (Preston) received additional funding from the University of Liverpool, Knowledge Exchange & Impact and Public Engagement Voucher Scheme to project lead an innovative youth-led drama project to raise awareness of antibiotic resistance with children, families and healthcare professionals. The project links to both the infection and inflammation themes highlighted in the Alder Hey CRF Strategy and commenced in January 2019, and forms part of the dissemination activities of an NIHR HTA-funded study called BATCH (Biomarker-guided duration of antibiotic treatment in children hospitalised with a confirmed or suspected bacterial infection), which aims to reduce antibiotic exposure in hospitalised children with infection www.batch-trial.co.uk.

Summary of findings:

- Two live performances of the play were conducted to school-aged children and young people
- 400 children and young people took part in the project overall (average age 11 years old)
- All resources (video, survey's, educational handouts) made available to schools and anyone working with young people. Click here: <http://bit.ly/2BjyKFC> for the links to resources
- Feedback from children and young people was extremely positive.

Using drama as a means to engage young people about health issues:

This young-person led project illustrates that using drama as a means of increasing knowledge and sharing information about health issues with children and young people has many advantages, including making the topic more relevant to children's lives; it generated a conversation and made children consider their own self-management of healthcare for maybe the first time, and despite the serious nature of the issue the performance included take-home messages that were delivered in a fun and informative manner.

For a full report of the project click here: <http://bit.ly/39hKp7x>

Liverpool Child-Friendly City Initiative:

In 2019 the PPIE Manager was approached by the Liverpool City Council to develop and support the establishment of a young person's scrutiny group (based on the GenerationR model) to inform the Council's Child-Friendly City Initiative. The Child-Friendly City Initiative (CFCI) is a UNICEF-led initiative that supports municipal governments in realizing the rights of children at the local level using the UN Convention on the Rights of the Child as its foundation.

It is also a network that brings together government and other stakeholders such as civil society organizations, the private sector, academia, media, and, importantly, children themselves who wish to make their cities and communities more child friendly.

The young person's scrutiny group was established in 2019 and have met on several occasions to inform children and young people's priorities (including health issues) and to obtain full child-friendly city status. This process has involved mapping existing child-friendly provisions across the city and consulted 1000+ children and young people.

Working alongside the Council has opened up additional opportunities for the Parent and Carer's forum including attendance at a Participation, Engagement, and Co-Production Workshop.

Health, Privacy and Trust in a Digital World:

In August 2019, GenerationR Liverpool Young Person's Advisory Group (YPAG) and CYP MedTech hosted a workshop delivered by UNICEF to inform the drafting of a new General Comment by the UN Committee on the Right of the Child on 'Children's Rights and the Digital Environment'. 15 young people (aged 11 to 19) from GenerationR Liverpool YPAG,

Alder Hey Children and Young Person's Forum, University of Liverpool YPAG and Liverpool Schools Parliament took part. This was part of a Global consultation in 26 countries with approximately 600 children and young people taking part. The results of these consultations will shape and inform an important international children's rights tool; the General Comment on Children and the Digital Environment. General Comments enhance the understanding of children's rights as outlined within the United Nations Convention on the Rights of the Child (UNCRC); the world's most widely ratified human rights treaty and the set of rights that apply to all children, no matter who they are or where they grow up. This particular General Comment will support States, Businesses and NGOs to interpret the UNCRC for the digital age. The approved General Comment will be adopted in 2021. A blog <https://bit.ly/2EqdblH> of the workshop was produced as was a full report: <https://bit.ly/32d9zLq>

Co-Produced Education Project:

The PPIE Manager was successful in obtaining European funding from the EiT Health initiative to co-create the development of a training programme to ensure that all members of existing YPAGs working across Europe are trained within a standard curriculum about clinical research and patient involvement and advocacy. This will be in the form of a Multimedia Toolkit, aimed at young people but with a section dedicated to educators. This toolkit will provide online educational and guidance resources (video capsules, serious games, quizzes, educative comics, etc.) in the field of clinical/health research. It will be shared via the European Young Person's Advisory Group Network ([eYPAGnet](#)) and implemented in schools across Europe who are interested to educate young people to be involved in activities of citizen science in the health and research setting. Further information can be found here: <http://bit.ly/2PuojXi>

International Collaborations

European Young Person's Advisory Group Network (eYPAGnet)

eYPAGnet provides a platform for children and young people to have a voice across Europe and provide their opinions, and experience to a variety of issues in clinical trials, such as

relevant endpoints, protocol design, formulations, age-appropriate information, and patient tools.

eYPAGnet was founded in 2017 by Jenny Preston and colleagues from Barcelona, France, and Scotland and is accredited by the European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA). It provides a centralised point of contact and a platform on which investigators and industry can access the opinions of young people in a manner that is regulated with standard contracts, confidentiality agreements, agreed payments for services, and is ethically sound.

For further information <http://eypagnet.eu>

Rheumatology focused activities

The Youth Participation Officer (Ainsworth) is a board member of The European Network of Arthritis in Children (ENCA). With a specific interest in research and rheumatology she has been part of the team leading on World Young Rheumatic Disease Day or WORD Day alongside colleagues involved in the Experimental Arthritis Treatment Centre for Children (EATC4Children) at Alder Hey Children's Hospital. Word Day is now an internationally recognised day to raise awareness that children and young people can be diagnosed with rheumatic diseases and how early intervention can have a significant impact on health outcomes. The campaign has steadily grown over the past two years with involvement from countries across the globe including Australia, India, South Africa, Canada, and Europe.

Lupus Europe

The Youth Participation Officer took part in a joint session with Dr. Eve Smith at Lupus Europe which was held in Liverpool in November 2019. The session highlighted the work of GenerationR, the JSLE study and the work of the EATC4Children. Lupus Europe is the collaboration of many European Lupus charities and organisations and the presentation was very well received.

Training and workshops

PPIE Training: Building on significant national expertise, we deliver outstanding PPIE training especially in the field of involving children and young people, *locally* (e.g. CRF induction programs to all new staff), *nationally* (e.g. Health Research Authority ‘the ethical issues of research involving children’) *internationally* (e.g. European Network of Research Ethics and Research Integrity Bootcamp, and Conect4Children)

Website and social media

We have a dedicated CRF webpage incorporated into the Alder Hey website <http://www.alderhey.nhs.uk/research/nih-r-alder-hey-clinical-research-facility/> highlighting the research we undertake to increase interest and participation in our studies.

All PPIE activities are linked and promoted via the GenerationR website <http://generationR.org.uk> officially launched in April 2015. A considerable amount of work has been undertaken to re-design the website to incorporate the work of other YPAGs across the country who are part of the GenerationR Alliance. The website will continue to be developed by young people to promote awareness-raising of testing treatments to a young audience, which includes working with schools, patients, and members of the public.

We disseminate news and blogs to 2681+ Twitter followers (an increase of 1231 followers from last year) on a daily basis using @GenrYPAGs @LiverpoolGenR1

Conclusion

The GenerationR Liverpool YPAG and Parent and Carer’s Research Forum continue to bring insight, intelligence, enthusiasm, and compassion to discussions with researchers and other key stakeholders. The group has achieved a considerable amount over the year and continues to be an invaluable resource for researchers across the Globe. Looking ahead for 2020-21 brings exciting new projects as well as maintaining a high standard of support for researchers. The group will be involved in the development of educational tools and curriculum to teach more young people about key issues in clinical research; work alongside life science partners throughout the lifecycle of a study; collaborate with other YPAGs across

the UK through the forum of a GenerationR Alliance, and the European Young Person's Advisory Group Network (eYPAGnet).

The report was written by Jenny Preston, Senior Patient, and Public Involvement Manager and Sammy Ainsworth, Youth and Family Participation Officer, NIHR Alder Hey CRF, and the University of Liverpool.

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Appendix 1

Date	Who	Activity	What happened?
April 2019	Joint YPAG and Parent and Carer Research Forum meeting	SCIENCE Study – group discussion on recruitment procedures and how best this can be explained to children and families.	Patient information sheet review and child friendly questionnaire developed.
May 2019	Joint YPAG and Parent and Carer Research Forum meeting	Metabolic Action UK (Charity) – group discussion on ways to engage with children, young people and parents in Charities work.	Metabolic Action have taken the groups feedback and will incorporate this into their Patient and Public Involvement Strategy.
		University of Liverpool (Cancer pathology study) – overview of study design and discussion on the ethical use of tissue collection.	Discussions focused on the use of tissue taken from children anonymously and if this was feasible as some children may have passed away. Parents were asked to give their input into planned study design.
		Sanofi study - Patient Information Sheet review	Detailed feedback shared with company.
		Conect4Children (c4c) – visual contents for informed assent documentation for paediatric clinical trials.	Individual member completion of a questionnaire to identify child appropriate images for paediatric informed assent documents. Documentation shared with c4c.
		Update: 100,000 Genomics Project	Research team returned to the groups to give an update on what the research team had achieved since they had consulted with the groups. Last feed back was positive and the young people's suggestions were being implemented.
		Update: Antibiotic Awareness Project	Principle investigator gave an update on progress with the project and shared the script of the play for comments. No comments were received.
June 2019	Joint YPAG and Parent and Carer Research Forum meeting	University of Liverpool/Health Education North West	Ways to increase knowledge and information connected to medical adherence were given from a young person

Appendix 1

		Technology Project – group discussion on the use of technology to improve medical adherence with children’s medicines.	perspective. Our young people provided good ideas and feedback on the planned protocol.
		Liverpool Health Partners (LHP) ‘Starting Well and Living Well’ Project – Informing children and young people’s health priorities in Liverpool	LHP presented the detailed plans for obtaining young people’s health priorities in Liverpool. Ways to communicate and reach out to young people where discussed as well as how feedback to local groups, schools and communities.
		Update: FORCE and SCIENCE Study updates and progress with recruitment. Input into the design of a logo for a new study.	Chief Investigator gave an update on progress with both studies and recruitment rates and retention, which are very positive. The young people voted on their preferred logo for a new study.
August 2019	YPAG Away Day & UNICEF Workshop	Interactive away day that included workshops and tour of the University laboratories. We also held a workshop delivered by UNICEF exploring health, privacy and trust in a digital world.	<p>During a tour of the laboratories the young people were able to see first hand what happens in a cancer research lab and discuss the work with scientists and researchers. This was particularly meaningful as one of our young members has a blood cancer. He was able to look at cancer cells through a microscope and ask many thought provoking questions. The University of Liverpool workshop included breaking down cell membranes of strawberries, observed under a microscope and built a cell activity using sweet treats.</p> <p>The Unicef workshop invited young people from various groups in Liverpool including YPAG members. The aim was to explore young people’s views on health, privacy and trust in a digital world. The results of this workshop alongside other workshop across the Globe will shape and inform an important international children’s rights</p>

Appendix 1

			tool; the General Comment on Children and the Digital Environment.
September 2019	Joint YPAG and Parent and Carer Research Forum meeting	Perthes Management Study - Logo design and study management overview	The Chief Investigator presented his study for YPAG comments and approval. The group then designed the logo collaboratively.
		Cerebral Palsy Study - Study design approval and Patient Information Sheet review.	YPAG members listened and gave their input into the design of the study protocol before commenting on key information needed in PIS.
		Eating Disorder Study: John Moores University - Study ideas and design.	A lecturer from JMU visited to talk through ideas for a possible study into eating disorders and issues with confidence and self- esteem. The young people gave insightful input into young peoples concerns as well as ways to reach out and engage with young people across the city.
October 2019	Joint YPAG and Parent and Carer Research Forum meeting	Update – Experimental Arthritis Treatment Centre for Children (EATC4Children)	An update was given on the long term animation project that the group had contributed to from conception. The animation is now available on the EATC website.
		University of Liverpool: Technical interventions for young people with long term health conditions. Study design/ Patient Information Sheet review.	The tea, came and asked for input into the design and ideas behind the study. The YPAG then reviewed the Patient Information Sheet.
November 2019	Joint YPAG and Parent and Carer Research Forum meeting	Antibiotic/ Cough Study Patient Information Sheet Review	The proposed study was presented to the group and asked for their input into study design and Patient Information Sheet.

Appendix 1

		Tookie Ltd: Specialised Clothing update and product review.	The CEO and Chief designer visited the YPAG again to give feedback and an update on his work to date. The YPAG were then asked to review patient and family information on a new product.
January 2020	Joint YPAG and Parent and Carer Research Forum meeting	Alder Hey Psychology Team: Dog fear and the use of virtual reality technologies.	The whole team presented the proposed study to support the work being done to help children after suffering a dog bite. Using virtual reality our YPAG explored the technology tools and gave feedback.
		EATC4C Chronic non-bacterial osteomyelitis Parent Questionnaire	A draft questionnaire was shared with parents prior to it being shared via an International network of parents of children with Chronic non-bacterial osteomyelitis The results will inform an international meeting to inform Chronic non-bacterial osteomyelitis Research in children.
		Paediatric Medicines Research Unit (PMRU) Pelican Study: Study design and Patient Information Sheet review and planning.	Two researchers came and presented the study asking for YPAG input into the design and to help with the production of a Patient Information Sheet.
February 2020	YPAG Meeting	PMRU Update and review	The PMRU team returned to give feedback and updates on both the study and Patient Information sheet changes.
		YPAG activity: Impact measuring and training/ Future planning and evaluation	The PPIE team undertook a session to capture the groups views on what impact they felt they had achieved throughout the year and what they got out of being a member of the group. A discussion about planning future meetings, improvements etc was taken on board.

Appendix 2: Study data capturing form - NIHR Alder Hey Clinical Research Facility

Study data	Field required
Date approached	
PPI lead	Jenny Preston
Name of researcher/investigator	
Contact details	
Name of study	
Protocol Number (If Industry Study)	
Type of study	
Stage of study	
Where did you hear about GenerationR Young Persons' Advisory Group or Parent and Carer Research Forum?	
PPI Activity	
Type of activity (review of protocol, patient information sheet design etc.)	
Background to Study	
Deadline for activities to take place	
Can the researcher attend the next young person's meeting or parent/carer's meeting?	
Outcome of activity (Youth Participation Officer)	
Month activity actually took place	
Is this a one-off consultation or on-going?	
What was the main outcome of the activity?	
Evaluation of the activity (To be completed by Youth Participation Officer)	
Did you evaluate the activity?	
After activity has taken place	
Have you received feedback from the researcher	



Agreement between researchers and GenerationR Young Person's Advisory Group (YPAG)

We are **GenerationR Liverpool Young Person's Advisory Group (YPAG)**, our aim is to improve the way research is done with children and young people. We have lots of experience in aiding researchers.

What we will do for you

- Give our opinions on the study from a young person's perspective
- Help you make the study more child/young person friendly by giving you our opinions
- Review or write patient information leaflets and any other related documents
- We are happy to spend a reasonable amount of time on each task
- We will take part in and conduct focus groups
- Help with your funding and ethics applications

Although we are happy to help with your research, there are a few things we expect in return for helping you with your study.

- We would appreciate a thank you letter for our portfolios in recognition of our efforts
- We would like an update on any changes you have made to the protocol/ information leaflet, successful funding and ethics applications
- We would be happy to receive any feedback/constructive criticism you may have about our input into your study and about our group by completion of a researcher evaluation form

Please sign this agreement to confirm that you are happy with these terms.

On behalf of GenerationR Liverpool YPAG



Researcher.....



GenerationR Liverpool Young Person's Advisory Group
Involvement Feedback form for Researchers

Please tick and provide more details as necessary.

1. How did you hear about the young person's advisory group?

Please specify

2. What was the main purpose of accessing the Young Person's Advisory Group?

Exploring a possible research question – early stages of protocol development	
Ethical approval	
Consultation to research funding application (for example, NIHR Research for Patient Benefit)	
RCT – Protocol review or study design	
Diary design	
Questionnaire design	
Patient Information Leaflets	
Other	

Please specify

3. How much time did you allow for consultation prior to an ethics submission or funding submission (if applicable)?

Less than 1 month	
Less than 2 months	

Appendix 4: Feedback form for researchers.

Less than 3 months	
3-6 months	
6-12 months	
12 months +	

4. How satisfied were you with the process of engaging with the young person's advisory group (Please specify 1 being the lowest level of satisfaction 10 being the highest)

Information provided in advance of the YPAG meeting	
Organisation of meeting with the group	
Outcome from the meeting	

5. Did the responses from the group have an impact on your research?

Yes		No	
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If yes, please specify

6. Did you feel you got everything that you needed from the group?

Yes		No	
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If no, what more could have been done?

7. Would you recommend the YPAG to others?

Yes		No	
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Please add any other comments you have

Thank you for completing this form.