



# GenerationR

young people improving Research



GenerationR Liverpool Young  
Person's Advisory Group (YPAG)  
& Alder Hey Clinical Research  
Facility Parent & Carer's  
Research Forum  
**Annual Report 2021-2022**



# Introduction

Welcome to the National Institute for Health and Care 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 2021** to **August 2022** and highlights examples of involvement and engagement activities that have taken place during this period. 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>

## Involving children, young people, and families

Our commitment to involving CYP and families in the design and conduct of paediatric health research is grounded in a **child rights-based approach** (CRBA), which calls for human rights to guide relationships between rights-holders (CYP & families) and duty-bearers (health researchers, funders, policymakers). A CRBA is a principled and practical framework for working with CYP (and their families), grounded in the **UN Convention on the Rights of the Child (UNCRC)**, which was ratified by the UK in 1991.

Implementing CYP and families' right to be heard, all involvement activities delivered by the Patient and Public Involvement team at Alder Hey CRF, follow the nine basic requirements for meaningful and ethical children's participation as laid out in **General Comment on Article 12** of the UNCRC. [1]

### Nine basic requirements for effective and ethical participation

**Requirement 1: Participation is transparent and informative**

**Requirement 2: Participation is voluntary**

**Requirement 3: Participation is respectful**

**Requirement 4: Participation is relevant**

**Requirement 5: Participation is child-friendly**

**Requirement 6: Participation is inclusive**

**Requirement 7: Participation is supported by training for adults**

**Participation 8: Participation is safe and sensitive to risk**

**Participation 9: Participation is accountable**

[1] UN Committee on the Rights of the Child (CRC), General comment No. 12 (2009): The right of the child to be heard, 20 July 2009, CRC/C/GC/12.

## GenerationR Liverpool YPAG

The GenerationR Liverpool Young Person's Advisory Group (YPAG) was set up in 2006 and currently has 28 members aged between 11-22 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. Since the COVID-19 pandemic our ways of working changed from meeting every six weeks face-to-face to meeting online over Zoom as and when required (normally every four weeks). Now that COVID-19 restrictions have been lifted we have developed a hybrid model (following discussions with YPAG members) that combines regular online meetings (via Zoom) with four face-to-face training days to equip members with the relevant skills to ensure they are meaningfully involved in our activities. Our first training session was held on the 14th of April 2022 at Liverpool Football Club. The focus of the day was to train young people in research methods (designing surveys and interviews with young people) and thank them for all their contributions during the COVID-19 pandemic. These training days will also support the development of our new 2022-2027 PPIE strategy including how we evaluate and measure the impact of our work.



## Alder Hey CRF Parent & Carers Research Forum

The NIHR Alder Hey CRF Parent and Carer's Research Forum was set up in 2018 and is made up of 10 parents and carers who live across the UK. 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. While we have not met face-to-face since the pandemic, the group has been extremely active in a number of research projects, including becoming co-investigators for some parents.



## Involvement activities 2021–2022

GenerationR YPAG and parent/carer 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 sections below). 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.

## One-Stop Support Service for Researchers

In total 14 YPAG meetings and forum meetings were held in the reporting period between April 2021 – August 2022. A total of 24 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 & Carer's Research Forum

When a new application is submitted to join the YPAG or Parent and Carers Research Forum, the Youth and Family Participation Officer arranges a meeting to introduce themselves and explain how the groups work, followed by an opportunity for young people or families to ask questions before they commit to becoming a member.



## Continued.....

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.**



We continuously ask for feedback from researchers for all activities performed. Several researchers also provided thank you letters to the group to be kept for their portfolio of activities. Below are some example of thanks and recognition the group receives as a result of their input:

*"Sammy was really helpful in facilitating the group so that we could get responses from all the children of different ages. This was particularly useful given the online set up. We would be grateful for an opportunity to work with GenR again further down the line with our projects and perhaps also to work with parent groups to discuss acceptability of RCT for young infants".*

**Researcher**

## Continued.....

*"Thank you very much for giving me the opportunity to meet everyone in the group giving me invaluable feedback to improve on my project." **Researcher***

*"This was a really helpful consultation and we were impressed by the young peoples' interest and engagement with the subject without prior information. It was an extremely time effective consultation for us and I would have no hesitation to refer others or ask to consult again on a future topic. The group appeared diverse and was chaired in a way to allow all voices air time". **Researcher***

*"The young people and Sammy supported me to think through the appropriateness and literacy level of words to be included in the experimental task. The young people were thoughtful and reflective, considering how young people may respond to the stimuli based upon their own experiences". **Researcher***

*"Sammy was really helpful in facilitation of the group so that we could get responses from all the children of different ages. This was particularly useful given the online set up. We would be grateful for an opportunity to work with Gen R again further down the line with our projects and perhaps also to work with parent groups to discuss acceptability of RCT for young infants". **Researcher***

## Life science collaboration

Since 2018 the PPIE Manager has been working with the NIHR Clinical Research Network Coordinating Centre (CRCCC) 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>

We continue to build on this work and are currently co-authoring several papers and a book chapter with young people, parents, and Pfizer colleagues about our experiences (published in 2023).

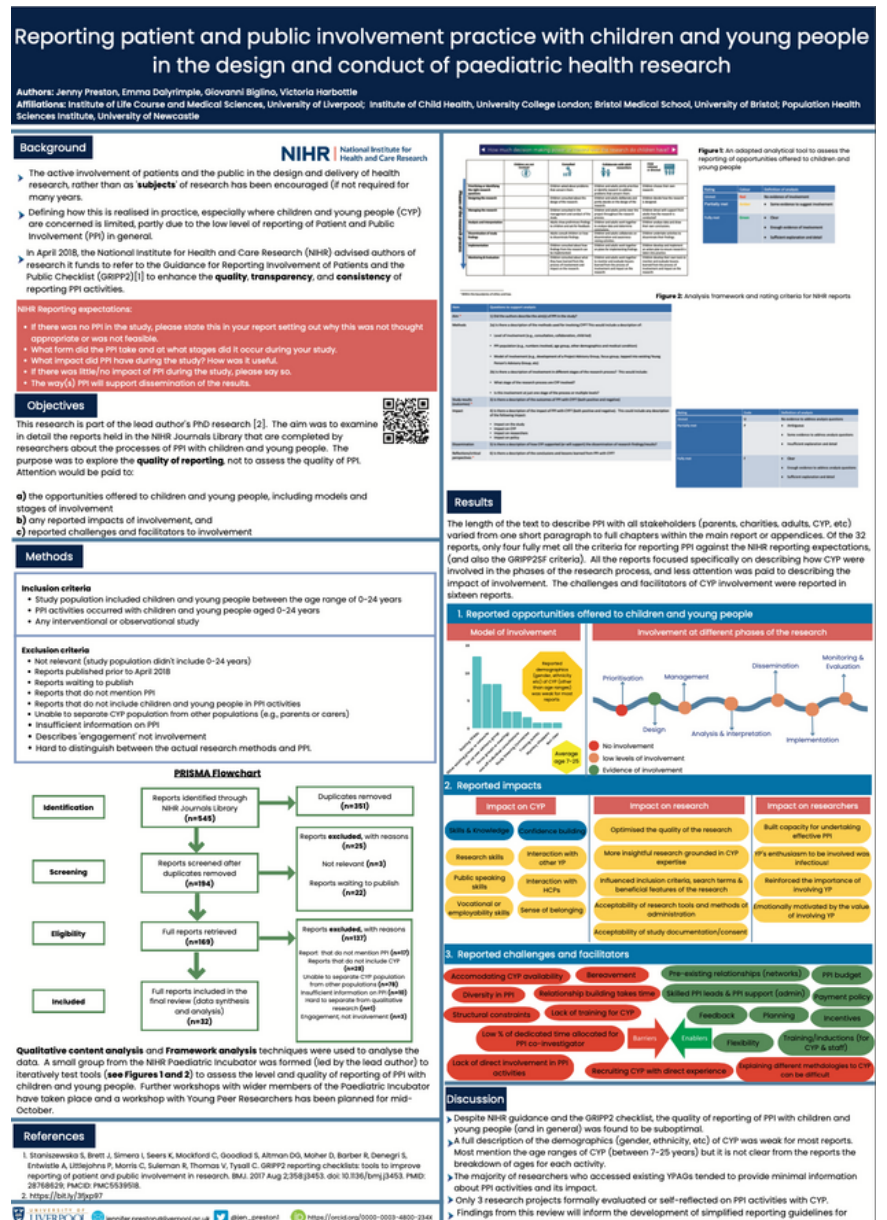


# Impact

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**. We are aware however that more needs to be done in this area.

Evaluating the impact of PPIE activities is a key priority and in March 2020 the senior PPIE Manager embarked on a fellowship and PhD to explore evaluating, reporting, and sharing the impact of young people's involvement in the design and conduct of paediatric clinical research.

This year the PPIE Manager completed a review of all NIHR reports in the NIHR Journals Library to assess how PPI with children and young people is reported. Findings are currently being written into a paper but a summary of the findings was presented at a recent **International Clinical Trials Methodology Conference** and received a 'runner-up' prize for best student poster (see QR code below).





## Feedback from CYP and Parent Members



*"I have been a member of YPAG/ GenerationR for seven years now, it is lovely to see researchers come back and update us on the progress of their project/research. It is amazing the number of professionals we get to meet and all the new innovations we get to see. It is also nice to be able to know what kind of research is going on in the medical field"* **YPAG member**

*"Being involved with the parents forum has been an incredibly rewarding experience. Recently I had the opportunity to contribute to a research paper as a co-author which was an amazing experience for me. Having my voice and contributions heard as a person with lived experience, alongside professional academics was excellent for my self-esteem and confidence as well as enabling me to see how I can help other parents and carers to contribute to research. Thanks to Jenny and Sammy for creating these networks for us as parents and carers and ensuring public and patient involvement is at the forefront of all researchers minds".* **Parent**

*"Being part of the research forum has been highly rewarding. I have enjoyed making a contribution and I am hopeful that my voice and opinions are part of making the patient - user experience clearer, easier and less ambiguous".* **Parent**

*"I love being a part of the parent forum at Alder Hey, I have been lucky to take part in so many interesting and exciting opportunities. It feels so important to make our voice heard, as a parent of a child with a chronic condition, you so often feel that you are invisible and that no one is listening. I would recommend anyone to get involved, as long as you don't mind speaking up and saying what seems obvious to you as parent you will fit right in!"* **Parent**



# GenerationR Alliance

GenerationR Alliance is a National Young Persons' Advisory Group (YPAG) Network, 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.

The GenerationR Alliance was established in 2017 to create a community of existing and for anyone interested in working with children and young people in health research. The aims of the Alliance are:

- 1 Facilitate work based on the GenerationR recommendations (set out in the 2013 report)
- 2 To collaborate and work on national/international child health projects
- 3 To 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.
- 4 To increase the opportunities offered to children and young people

The Alliance currently has 19 YPAGs and is growing steadily. The Alliance is coordinated by Jenny Preston, with support from Sammy Ainsworth who oversees the activities of the Alliance to monitor and ensure it meets and adheres to its objectives.

BeGOOD Citizens	Bristol	Eye-YPAG
Hertfordshire	Imperial YPAN	Kent, Surrey & Sussex
Leeds Young Research Owls	<u>Leicester</u>	Liverpool
London	Manchester VoiceUp	North East
Nottingham	ScotCRN	Southampton (8-18)
Southampton (16-24)	West Midlands	YourRheum
Young Dynamos	<a href="https://generationr.org.uk/meet-the-team/">https://generationr.org.uk/meet-the-team/</a>	

During this reporting period, three meetings have been held via Zoom. The focus of the meetings was to share learning and opportunities to work together. Two opportunities were shared with the Alliance for members of YPAGs to come together and inform the design of an App, and work with Pfizer in the production of educational materials for children in schools to teach them about clinical trials.

# Engagement, Involvement, and Promotional Activities

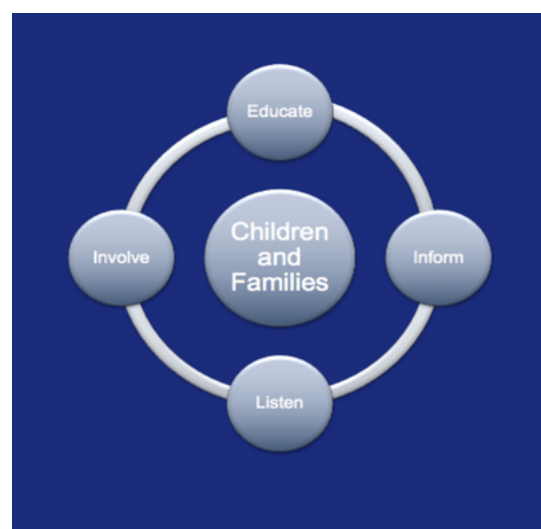
**Engaging, informing, educating,** and **stimulating** thinking about clinical research is achieved through our Research, Education, Awareness, Program (REAP).

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.

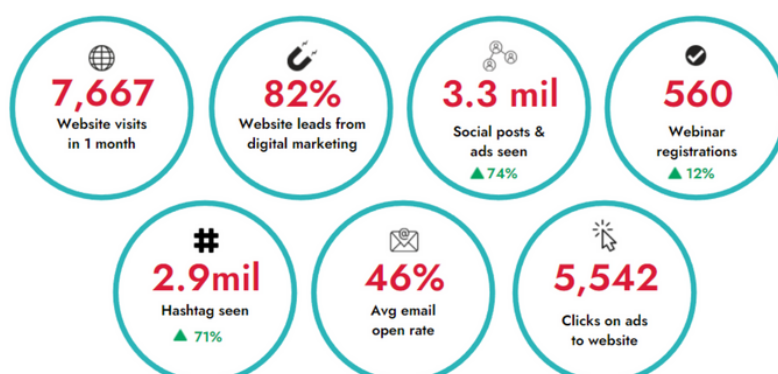
This year despite the slow return back to normal from the COVID-19 pandemic, many Public Engagement activities have taken place. Some examples include: presenting alongside patients in both UK and global conferences to promote CYP involvement and inclusion in the design and delivery of paediatric experimental and early phase research; distribution of patient experience surveys; promoting research linked to AHCRF themes at various health and research awareness online events, including, International **WORD Day** (see below). Also, members of our PPIE team took part in a '**meet the scientist**' event organised by the University of Liverpool Public Engagement team held at The World Museum. Approximately two thousand people attended with many visiting our stand to take part in hands on scientific activities and to hear about rheumatic diseases in children and young people.

## International WORD Day

The Annual World Young Rheumatic Disease Day or Word Day was held again on the 18th of March 2022. Two international webinars were attended by a large audience from around the globe and featured, patients, charity partners, parents, clinicians, and health professionals. A wide-reaching and professionally managed social media campaign was again very successful. Each year the reach and involvement of the paediatric community grow further as the day is marked across the globe.



### KEY OUTCOMES



# Co-Produced Education Project

The PPIE Manager was successful in obtaining additional European funding in 2020 from the EIT Health initiative to continue the co-creation of a training programme to ensure that all members of existing YPAGs and secondary school pupils across Europe are trained within a standard curriculum about paediatric clinical research, patient involvement and advocacy, and involvement in medical technology and device design. The training has been designed by four members of the Liverpool YPAG, and four members of KIDS Barcelona. The training is a Multimedia Toolkit, aimed at young people but with a section dedicated to educators. The toolkit is currently being piloted across Europe and will provide online education and guidance resources (video capsules, games, quizzes, lesson plans, etc.) in the field of clinical/health research and medical technologies. It will be shared via the European Young Person's Advisory Group Network (eYPAGnet); the NIHR Learning for Involvement website <https://www.learningforinvolvement.org.uk/>, and implemented in schools across Europe.



## International Collaborations

In 2017 the European Young Person's Advisory Group Network (eYPAGnet) was founded by Jenny Preston and colleagues from Barcelona, France, and Scotland. It provides a platform for children and young people to have a voice across Europe and provide their opinions, and experiences on a variety of issues in clinical trials, such as relevant endpoints, protocol design, formulations, age-appropriate information, and patient decision-making tools. The network 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, and standardised payments for services.





## Rheumatology focused collaborations

The Youth Participation Officer (Ainsworth) is a 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 (WORD Day) alongside colleagues involved in the Experimental Arthritis Treatment Centre for Children (EATC4Children) at Alder Hey Children's Hospital. Ainsworth has also been invited to talk about our PPIE Strategy at a variety of events including the Paediatric European Rheumatology Association. She has also joined the UK MSK Translational Research Collaboration PPI leads Committee and has recently been invited to be part of the Scientific Planning Committee for PRES 2023.



## Delivering PPI training and workshops

The PPIE Lead has delivered online training, and keynote presentations to audiences of researchers and healthcare professionals around the Globe on the importance and impact of involving children and young people in the design and conduct of clinical trials. PPIE training is also built into CRF staff induction and annual training days. During this reporting period over 20 training and workshops have been delivered with a specific focus on involving children and young people in the design and conduct of child health research.

## Website & social media

We have a dedicated CRF webpage incorporated into the Alder Hey website <http://www.alderhey.nhs.uk/research/nihr-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.



We disseminate news and blogs to 2748 Twitter followers on a daily basis using @GenrYPAGs @LiverpoolGenR1

# Publications

During this reporting period, the PPIE Manager has published four research articles linked to the main themes within the Alder Hey CRF Strategy (1)PPIE methods, (2)systematic reporting of PPIE activities, (3) qualitative study methodology, and (4)children's formulations. A further three publications are in press and will be published in 2023.

(1) Developing a More Tailored Approach to Patient and Public Involvement with Children and Families in Pediatric Clinical Research: Lessons Learned



(2) Standardised data on initiatives—STARDIT: Beta version



(3) Parents' experiences and perceptions of the acceptability of a whole-hospital, pro-active electronic pediatric early warning system (the DETECT study): A qualitative interview study



(4) Children's Preferences for Oral Dosage Forms and Their Involvement in Formulation Research via EPTRI (European Paediatric Translational Research Infrastructure)



## 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 groups have achieved a considerable amount over the year and continues to be an invaluable resource for researchers across the Globe. Looking ahead to 2023 brings exciting new projects as well as an updated and co-developed PPIE strategy which will go beyond our achievements over the years.

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: Study detail log

Date	Who	Activity	Theme	What happened?
May 2021	8 young people and 1 parent	YPAG Meeting	Guideline Planning  PHD project support	Return visit from a Professor who is co-developing a child-rights guideline to support children having procedures (which apply to research procedures also). The YPAG contributed to the design of the information sheet about the project to be shared with other children and young people.  A PhD student presented a musical therapy study. The study aims to help patients when having blood tests. The group were asked to discuss the advantages of musical therapy in clinics to help with pain and fear management (needle phobia was given as an example). The group discussed the advantages and various ways musical therapy could help in clinics when children. The study was at the early design stage.
May 2021	8 young people  2 Parents	Ethics information and training meeting	Ethics and young people	A researcher at the University of Liverpool School of Law and Justice presented on the ethical review of the involvement of people during the covid-19 pandemic. YPAG reviewed a proposed question that will gather information on young people's thoughts concerning the pandemic and how it has affected their lives, education, and mental health.
June 2021	12 Young People	YPAG Meeting	Inflammation (Lupus)	Researchers from the Target Lupus Study findings overview and planning review for PPI going forward. Target Lupus is linked to a fellowship application and has involvement from a large international team. The YPAG advised on study information and dissemination including the possible creation of an animation for young people.
			Pharmacology/Respiratory	A researcher gave a presentation on an asthma study protocol plan for feedback and review. The study is an asthma study linked to



				primary care. The YPAG discussed the ways young people may benefit from this work and how education about asthma can be developed to make it easy to be understood in a young person friendly way.
			Infection/Inflammation (Kidney)	The YPAG reviewed and assessed a Patient Information Sheet and study design for a proposed Kidney study looking at how to test blood in kidney disease. The YPAG reviewed the trial design which will look at prick testing versus a full blood sample for children and young people.
July 2021	12 young people	YPAG Meeting	<p>Orthopaedics</p> <p>Alder Hey Children's Hospital Cardiac team</p>	<p>A team of researchers visited and gave a presentation which introduced a study for cerebral palsy. The study will be looking at methods of stretching and strengthening in different age ranges and its varied benefits. The YPAG discussed the protocol design and chose the study name and logo.</p> <p>Feedback was also given on the study PicBone. The researcher who was visiting for the second time, explained how the study is now at Stage Two of the funding process (via NIHR) and GenerationR Liverpool YPAG has been heavily referenced in the application.</p> <p>A cardiac surgeon and surgical design and imaging expert attended the meeting. A discussion on cardiac image design using virtual reality and AI to increase success in cardiac surgery took place. This approach could potentially allow surgeons to do an operation virtually using exact images of the person's heart before physically operating on them. The YPAG discussed the benefits of this and how disease specific groups need to be included into discussions along with the ethics of rating surgeons and the wider impact on the patient population. The team will keep in touch and possible introductions at a later date with families affected will be explored.</p>

			PhD project	A PhD researcher attended the meeting to discuss a research project looking at a child-rights based approach to medicine development. The YPAG gave thoughts and ideas around children's rights and how to disseminate information around this work.
18th September 2021	10 young people	YPAG meeting	CYP Medtech - Sheffield Asthma team	A team of research respiratory nurses from Sheffield linked to CYP MedTech attended the meeting. The aim was for the young people to review 7 short videos supporting the asthma project. The project will inform asthma patients concerning the use of medicine and will provide education on the condition.
Sat 23rd October	14 Young people attended	YPAG meeting	Alder Hey Orthopaedic Team  University of Belfast, Infection Team	<p>The research team returned with an information review after previously visiting six months ago. The orthopaedic team wanted to find ways to engage with children who do not use spoken language or if English is their second language when presenting with a broken arm. Following on from the last visit, the team have produced a cartoon themed Patient Information Sheet to allow a child to explain the actions they can/can't do and how hard it is. The YPAG reviewed it again and added comments on how easy it was to understand and if it was visually appealing. The team will return with the final draft for feedback and is happy to send all three copies for a case study of our involvement.</p> <p>The team from Belfast are comparing different ways to treat infection in children and babies. Two different arms of a randomised control trial were discussed and the YPAG were asked for their thoughts on the different ways of treating a possible infection from a young person's perspective. This involved a detailed discussion on risk versus benefit and what is seen as appropriate treatment from a</p>

				young person's perspective. The team will return with an update, and we may be asked to bring a group of parents together at a later date.
November 2021	8 young people	YPAG meeting	Alder Hey Children's Hospital Accident and Emergency Team	The team came to discuss a study that involves the design of a new traumatic brain injury tool to be used in the A&E department. The study is in early application and pre-IRAS. The YPAG discussed blood testing methods, consent and long-term outcomes that young people and families would find appropriate.
January 2022	12 young people	YPAG meeting	National Covid Study	The YPAG were visited by members of a national research team looking at long-term effects of COVID-19 on children and young people. The meeting was led by one of our members, who is a co-investigator on the study supported by the PPI team. All aspects of the logo, study design, PIS, dissemination and impact on young people were discussed during the workshop.
January 2022	9 young people	YPAG meeting	EdgeHill PhD student  Alder Hey Children's Hospital Rheumatology Team	<p>A PHD student came to discuss plans for the co-development of a communication module for nurses. This is part of a qualitative study and aims to look at the best ways to engage with young people when they attend appointments. The young people discussed the study and gave suggested ideas around language and communication that young people would find appropriate.</p> <p>A consultant and PHD student came to share their work looking at information gathered by young people connected to rheumatic disease. They have visited a variety of patient groups and wanted to discuss their study with a research focused group of young people. The activities were very hands-on using online tools and the group were asked to explain where they go for health information. It gave the YPAG the opportunity to discuss young people's attitudes to information, the internet, false versus safe information.</p>



			Alder Hey Children's Hospital Kidney Research Fellow	The researcher came along again to discuss blood monitoring in kidney patients. He discussed his study and the monitoring of bloods taken. The group gave suggestions on the protocol design but noted that kidney patients would need to be consulted to give appropriate feedback.
February 2022	9 young people	YPAG meeting	EATC4C PHD Student  PHD Student University of Oxford	<p>The PHD student came along, to discuss her study regarding mouth ulcers and early warning triggers. She discussed how she would be talking to young people and families and how identifying red flags could help early diagnosis. The YPAG gave suggestions around study information and will support the work going forward. The PPI lead advised on appropriate patient groups to gather lived experience.</p> <p>An Oxford based PhD physiotherapist, brought patient information sheets, consent and assent forms for review. The YPAG assessed the designs and gave ideas for improvement in language, layout, illustration, and content.</p>
April 2022	8 YP	YPAG meeting	EATC4C Rheumatology team	Urine collection study. The group discussed the study protocol which explores home testing as opposed to a clinical appointment. A demonstration by one of our members using the home testing kit took place for the group to assess its useability and design. A discussion took place to assess the benefits of home testing. While the group thought it was a positive idea, they strongly suggested involving a patient group for the thoughts of YP who would be using the tool.

			Alder Hey Children's Hospital A&E team	Alder Hey Children's hospital is leading on a multicentre study looking at children who present with a limp in the A&E department. The study will look at when this is something that needs investigation or is the result of a minor injury. The patient information sheet, consent and assent forms were reviewed along with the study design.
May 2022	4 YP	YPAG meeting	<p>Alder Hey Children's Hospital Orthopaedic Team</p> <p>Rheumatology/dentistry</p>	<p>Pre-application visit to advise before the team applied for ethics approval. This study looks at alternative ways to do eye tests. They are looking at the traditional manual tests versus a new computer option involving a game design. They hope to make the test interactive and appealing for young people when they attend clinic. Study design and recruitment issues were discussed by the group.</p> <p>A dentist linked to rheumatology visited to discuss a project looking at mouth ulcers. The study is looking specifically at young patients who may have Bechets disease and is a QoL study. It aims to improve possible treatments and the impact long term mouth ulcers have on a YP QoL.</p> <p>The study protocol was discussed including interviews plans, PIS, and a possible magazine or other ways to disseminate information.</p>
June 2022	2 YP	YPAG meeting	<p>University of Liverpool Psychology Department.</p> <p>London School of Hygiene and Tropical Medicine</p>	<p>The researcher returned to the group to give an update on her study looking at diabetes and mental health. For several structural reasons, the study will now focus on adults. The team were very grateful for the group's input and will continue to keep in touch with future projects.</p> <p>The LSHTM attended to discuss plans for a long-term project involving the design of a vaccine education animation. Due to small numbers attending the discussion then focused on useful careers advice and tips which was very well received from the two members</p>

				<p>who attended. The researcher has had a very varied career in medicine and so the meeting was an excellent way for our YP to access careers advice. The vaccine animation assessment has been rescheduled.</p>
June 2022	11 YP	YPAG meeting	London School of Hygiene & Tropical Medicine	<p>The LSHTM returned to the group to introduce a long-term international project looking at vaccine education for young people. A video that has been created was presented to the YPAG. The group were very vocal and suggested a variety of changes and improvements including narration style, colours used, overall design, keywords and vocabulary and dissemination of the final video.</p> <p>This work is ongoing, and the team will be in touch to share changes made following the visit.</p>

July 2022	10 young people	YPAG meeting	Young Person Celebration Event	Members of the YPAG attended a joint celebration event organised by the University of Liverpool Law & Social Justice School to showcase the contributions young people make to children's research. This event was the first-time young people came together to share what they have been doing and the impact on both them personally and on the research delivered within the University. The event was attended by the Pro-Vice Chancellor, researchers, and families.
September 2022	9 young people	YPAG meeting	Alder Hey Children's Hospital - Pharmacologist	<p>A pharmacologist came along to discuss an idea that will assess drug exposure in children and young people across Liverpool and Merseyside. The idea is very much still in infancy but the thoughts around acceptability from a young person's perspective were needed. Due to several children and young people presenting with drugs in their system at A&amp;E the researcher would like to plan a scoping study to assess how affected they are by the drugs around them environmentally and socially. The YPAG were very interested in this project and one member has stepped forward to be more involved as a possible co-investigator. We await further updates on this project.</p> <p>The lead researcher visited again to provide an update on the study. PIC Bone looks at ways of measuring inflammation in bone infection.</p>

			University of Oxford - Orthopaedic Team	Previously the group have discussed study protocol and design. The group also chose the name and developed the logo. The researcher presented the patient information sheet for review and the YPAG advised on the script for an animation.
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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?	
<b>PPI Activity</b>	
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?	
<b>Outcome of activity (Youth Participation Officer)</b>	
Month activity actually took place	
Is this a one-off consultation or on-going?	
What was the main outcome of the activity?	
<b>Evaluation of the activity (To be completed by Youth Participation Officer)</b>	
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.**