



# GenerationR

young people improving Research



GenerationR Liverpool  
YPAG & Alder Hey  
Parent and Carer's  
Research Forum Annual  
Report  
April 2020 to March 2021



## **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 2020 to March 2021 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 takes place on a needs-led 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. Due to the COVID-19 pandemic as of March 2020, all YPAG meetings were held by Zoom.

## **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. Due to the COVID-19 pandemic as of March 2020, all YPAG meetings were held by Zoom.

## **2.3 Involvement activities 2020-2021**

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:**

Due to the COVID-19 pandemic very quickly a new model of operation was undertaken to continue the involvement of young people and parents safely and following government guidelines. Our meetings moved from face to face to online via Zoom. After consulting with our groups, it was decided that this allowed the greatest level of accessibility and involvement. IT support and advice were offered to anyone who may have needed it.

Whilst many studies were at first suspended we were asked to plan a number of specific focus groups looking at a variety of health issues concerning young people and Covid-19. These included studies looking at inflammation markers in paediatric hospital admissions and Covid -19 testing on young people and families.

Our young people were enthusiastic to allow the voice of young people to be heard during the pandemic and stepped up to the challenges brought by this involvement. Many commented that it was a time when they felt scared and unsure of the future. They had huge concerns for the health of their families and their education. By having the opportunity to directly inform COVID-19 studies they felt empowered and able to share their concerns and thoughts. They were giving something back and playing an active role.

Due to the nature of the studies, our YPAG often had very little notice of meetings but still attended in high numbers and gave excellent support to the work being undertaken by our clinicians.

Over time our usual study support returned, and our meetings have continued very successfully over Zoom. We have actually been able to hold more meetings than usual due to the use of Zoom and because the young people and parents have enjoyed the concise meeting time and being able to join from home. In total 16 YPAG meetings and forum meetings were held in the reporting period between April 2020 - March 2021. 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.

Whilst at the beginning of this year we were plunged into a huge time of uncertainty and fear, we are immensely proud of the work of GenR Liverpool YPAG and Parent and Carers' Forum during this time. We have adapted our working practice, informed crucial studies, continued with our ongoing PPI strategy, and have been able to support and encourage our young people during a time that was unprecedented. Our young people were enthusiastic to allow the voice of young people to be heard during the pandemic and stepped up to the challenges brought by this involvement. Many commented that it was a time when they felt scared and unsure of the future. They had huge concerns for the health of their families and their education. By having the opportunity to directly inform a Covid study they felt empowered and able to share their concerns and thoughts. They were giving something back and playing an active role.

### **2.5 Young person led COVID-19 project:**

Our young members have been through an incredibly difficult year where many decisions were taken about them concerning education and examinations without consultation. One of our members recognised that young people were not being consulted in many areas concerning the effects Covid-19 was having on education. She decided to address this and designed an online survey to allow young people to voice their opinions. The survey was shared on a number of national young people's educational forums and was very well received. In just over a week there were over 1500 responses from across the UK. Findings from this work were written up into a report and paper that was shared widely to attempt to influence policy. The full details of this project can be found here:

<https://osf.io/preprints/socarxiv/mdjsn/>

### **3.0 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.



#### 4.0 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 a paper and book chapter with young people, parents, and Pfizer colleagues about our experiences to be published in 2021-2022.

#### 5.0 Feedback from researchers & impact:

Feedback from researchers was received for most of the activities performed. 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 receives as a result of their input:

*"The members of the YPAG were bright and intuitive. They asked really smart questions and their advice was extremely helpful. We have used their comments to edit the study protocol. I hope to come back to the YPAG for help with the Patient Information Leaflets if the study is funded".* Keele University Researcher

*"This was my first time undertaking PPI with a very sensitive topic and I was quite nervous, the group were very welcoming and supportive and gave me lots of ideas and things to consider. I cannot imagine how research can be undertaken with children without having such input. I would definitely use the group again and recommend them to anyone who is looking to undertake research with or for children".* Ph.D. Researcher

*"Being introduced to the YPAG has been the most important stage in my research career to date. The expertise within the group, from children, young adults, parents, and facilitators has been extremely valuable to my research topic and ideas. The group were able to provide clear and practical recommendations for my work, also how best to communicate with the children and parents who will potentially take part in the study. The group are always very*

*friendly, professional, and enthusiastic to hear the ideas presented. They have also been very proactive and adapted their way of working which has allowed me to access this support during the COVID-19 pandemic through an online platform. I can't thank the group enough for their ongoing advice and support."* Researcher

## **5.1 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**



## 5.2 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 link to a peer-reviewed paper:

<https://www.scienceopen.com/document/read?vid=8c47110b-3808-4206-b2fa-fd945c5cfee2>

## 6.0 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 Sammy Ainsworth 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 meetings have been held via Zoom. The focus of the meetings was to update an online Toolkit to support the researchers or anyone interested in setting up a Young Person's Advisory Group. The Toolkit was designed by Alliance members, and colleagues from eYPAGnet. The Toolkit is designed to take you through each part of the process of setting up a YPAG, and is split into four sections: Understanding why it is important; getting started; delivering a meeting, and evaluating the work, and the impact a YPAG can have on both the participants themselves and on child health research. The Toolkit is hosted by eYPAGnet <https://eypagnet.eu/toolkit/> and is now on the updated NIHR Centre for Engagement and Dissemination Learning for Involvement section of the website <https://www.learningforinvolvement.org.uk/>. A series of UK and International webinars have been undertaken to share this resource across the Globe, presented by the senior PPI lead and members of the Liverpool YPAG.

## **7.0 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 COVID-19 pandemic many PPE activities have been undertaken including: presenting alongside patients in both UK and global conferences to promote CYP involvement and inclusion in the design and delivery of paediatric (EM/EP) research;

distribution of patient experience surveys; promoted research linked to AHCRF themes at various health and research awareness online events, including, International WORD Day (see below). The PPIE Manager and PPI Officer continue to publish extensively in the field of children and young people's involvement in the design of clinical studies, and this year has authored or co-authored 5 publications (4 Journal articles, 1 book chapter).

## **7.1 Word Day 2021**

The annual World Young Rheumatic Disease Day or Word Day was held again on the 18th of March 2021.

The day aims to raise awareness of paediatric rheumatic diseases across the globe, ultimately aiding early diagnosis. It highlights emerging treatments and research, allowing the global rheumatic disease community to come together to support children and young people.

Word Day is led by Dr Eve Smith (Alder Hey EATC) supported by the Youth & Family Support Officer (Ainsworth) and involves an international team of parents, charity, and clinical partners. Events are held across the world in places including Northern and Western Europe, North and South America, The Far East, South Africa, and Australia.

For the second year, our Word Day campaign was affected by the global pandemic. Our strategy changed to an online presence involving a targeted social media campaign with over 1.9 million views online and series of successful webinars. 2021 proved to be our most successful year to date with over 500 people registering for our round table webinars involving young patients, parents, charities, and clinicians from across the world. Word Day events were held in a number of new countries this year including Argentina, Saudi Arabia, and Vietnam allowing a diverse and exciting reach to our campaign.

## 7.2 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 700 children and young people taking part. The results of these consultations have shaped and informed an important international children's rights tool; General Comment No25 on Children's Rights in the Digital World. 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 was approved in February 2021. A blog <https://bit.ly/2Eqdblh> of the workshop was produced as was a full report: <https://bit.ly/32d9zlq>

## 7.3 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 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](https://www.eypagnet.eu/)); NIHR Learning for Involvement website <https://www.learningforinvolvement.org.uk/>, and implemented in schools across Europe.

## **8.0 International Collaborations**

### **8.1 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>

### **8.2 Rheumatology focused activities**

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 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. This year and despite the COVID-19 pandemic WORD Day involved a targeted social media campaign with over 1.9 million views online and series of successful webinars. 2021 WORD Day proved to be our most successful year to date with over 500 people registering for our round table webinars involving young patients, parents, charities, and clinicians from across the world. Word Day events were held in a number of new countries this year including Argentina, Saudi Arabia, and Vietnam allowing a diverse and exciting reach to our campaign.

## **9.0 Training and workshops**

PPIE Training: 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.

## **10. Website and social media**

We have a dedicated CRF webpage incorporated into the Alder Hey website <http://www.alderhey.nhs.uk/research/nhr-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 2748 Twitter followers on a daily basis using @GenrYPAGs @LiverpoolGenR1

## **11. 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 2021-22 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 medical devices, building on our work in clinical trials; 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.

For further details contact:

[Jennifer.preston@liverpool.ac.uk](mailto:Jennifer.preston@liverpool.ac.uk)

[Jenny.ainsworth@liverpool.ac.uk](mailto:Jenny.ainsworth@liverpool.ac.uk)



# Appendix 1

Date	Who	Activity	What happened?
11th May 2020	16 Young People	<b>YPAG activity. Target Lupus Study -</b>  PPI Planning and evaluation	Two members of the Target Lupus study team attended the meeting. Firstly, they fed back to the group about previous recommendations from patients followed by a lengthy discussion on the adjustment and planning for online and virtual activities due to COVID-19 The YPAG gave practical advice and alternative ways to plan the ongoing focus group activity.
14th June 2020	19 Young People	<b>COVID-19 YPAG Meeting</b>  Input into a proposed COVID-19 study	This meeting was a special COVID -19 YPAG meeting, requested by a researcher.  The meeting looked at the potential design of a study looking at the effects of COVID-19 on young people and adults with inflammatory conditions.  The YPAG worked with the chief investigator to give the views of young people on the study design. The YPAG were extremely flexible and agreed to meet with very short notice due to the nature of the study.
June 15th 2020	14 Young People	<b>Paediatric Respiratory Study Keele University</b>  Study design, patient facing materials review, design of study logo.	The group advised on study planning and assisted with logo design. They also gave feedback on the patient information sheet.

## Appendix 1

		<b>University of Liverpool Public Engagement Team</b>	The group reviewed the use of comics to relay key research themes around infection. They gave feedback on the content of the comics and gave advice on how to reach and engage with other young people.
<b>13th July 2020</b>	14 Young People	<b>Liverpool Health Partners – COVID-19 Study</b> Review of animation Study design	The researchers presented a study looking at the effects of COVID-19 on young people in schools.  The young people were extremely vocal giving feedback on a survey and the effects that COVID-19 is having on young people in education.
<b>23rd July 2020</b>	5 Parents	<b>Pfizer- Parents Focus group</b> Study design	5 parents with experience of having a child with eczema took part in a focus group to inform an eczema protocol. Parents informed the practicalities of the study design and offered suggestions to the team on how to increase recruitment and retention.
<b>23rd July 2020</b>	8 Young People	<b>COVID-19 Meeting</b> Study design	A special meeting of GenR Liverpool was held to discuss a COVID-19 Study involving young people and transmission. The young people were asked to look at the design of the trial and inform the team on ways to disseminate information to families.
<b>27<sup>th</sup> July 2020</b>	10 Young People	<b>TDI NIHR Consortium</b> Study design and review of multimedia tools	A review of multimedia tools within the study and review of the patient information sheets were carried out by the young people. They also commented on the overall study design.
<b>September 2020</b>	15 Young People	<b>Dova Pharma.</b> Review of Patient Information Sheet	Young people reviewed the Patient Information Sheet from a mixed age range.

# Appendix 1

		<b>Adverse Drug Reaction Research</b>	The YPAG reviewed an online survey about Adverse Drug Reactions in children as part of the MHRA Yellow Card Scheme. The young people have worked with the team on several occasions.
<b>3rd October 2020</b>	16 Young People	<b>Tookie Ltd</b>  Study design and feedback from previous PPI work	Tookie Ltd has presented to the YPAG on several occasions. The purpose of this session was to feedback progress from a previous session about an ongoing study that the YPAG had contributed to. It was also an opportunity to present another study to the group about a proposed new garment design.
		<b>Paediatric Research Medicine Unit (PMRU) – Alder Hey Children's NHS Foundation Trust</b>  Feedback from previous PPI work with the group and input into a new study design	The PMRU team has presented to the YPAG on numerous occasions. Feedback was provided on a swallowability study that the group had informed. The researchers then presented a new study, received feedback on the patient information sheets, and provided advice on how to engage with young people and families during the pandemic.
<b>24th October 2020</b>	17 Young People, and 2 Parents	<b>PhD Student Research –</b>  Patient information sheet review, study name, and	Young people reviewed the patient information sheet, gave advice on the study name, and assisted in the plan for disseminating information about the study.

## Appendix 1

	dissemination advice.	
	<b>University of Liverpool – Diabetes study</b>  Study design and patient information sheet review	Review of the patient information materials and study protocol.
	<b>PhD Study – Data collection in epilepsy</b>  Study design and review of patient information materials	Reviewed the trial protocol and patient information sheet. The researcher would like to return to the YPAG and pilot the prototype APP used to collect patient experience with 8/10 young people in early 2021.
<b>21st November 2020</b>	15 Young People	
	<b>Liverpool Health Partners - Barriers to physical activity in children with chronic respiratory conditions</b>  Study design and PPI planning	The team from Liverpool Health Partners returned to the YPAG to provide feedback from a previous study the group had contributed to. The YPAG then reviewed the protocol of a new study exploring the barriers to physical activity. The group also advised the team on the plans for PPI activities including focus groups and communication methods.
	<b>Alder Hey Children's Hospital - Endocrinologist</b>	The research team provided the YPAG with feedback from a previous YPAG meeting. They then explained to the YPAG a new study idea into the prevention of diabetes and discussed ways of reaching out to families to try to gain their support for adherence. The young people made many suggestions to

## Appendix 1

		<b>Obesity and diabetes prevention study.</b> Study design	reach out to young people with obesity issues. Terminology and visual images used were discussed in detail.
		<b>PhD Student -Cancer in children and the effects on mental health.</b> Study design and Patient Information Sheet Review	The YPAG discussed the proposed study design and content including recruitment options and survey design to appeal to all ages. Study dissemination plan discussed and advised.
		<b>AHCRF Polyptharmasist.</b> A study looking at how to stop unnecessary medications in children who are taking a large variety as part of their treatment.	The patient information sheets for various ages were reviewed. The YPAG also looked at the content and terminology of a questionnaire aimed at young patients. The research team will return to the group as part of its ongoing work.
<b>16th January 2021</b>	<b>17 Young People and 3 parents</b>	<b>JSLE Treat to Target (T2T) study</b> Study design and patient information sheet review	Treat to Target is looking at a stratified way to treat lupus. The group reviewed the protocol and Patient Information Materials. They were asked to review and comment on the ways of communicating the ideas around the project and how to engage young people and families as interviews have currently been confusing at times. This work is ongoing.

## Appendix 1

		<b>Bereavement Project - Specialist nurse and PhD student.</b> <b>Hull University</b>	The researcher presented the study protocol to the group which was exploring how to support young people suffering bereavement. The researcher wanted input from young people and parents about the study design, and to receive advice on how to connect with young people to be part of the study. The study name and logo were also discussed.
<b>26th January 2021</b> <b>GenR - extra meeting</b>	16 young people	<b>Edgehill University- Clinical holding Project</b>	The young people were presented with a project exploring how children and young people are clinically held in practice, sometimes against their will. The researcher presented to the group what they meant by 'clinically holding' and asked for the young people's thoughts on what was acceptable in the treatment of young patients and how to communicate this effectively in practice.
		Guideline and communication	This is ongoing work that will inform a large international working group.
<b>16th February 2021</b> <b>YPAG focus group</b>	11 Young People	<b>PhD Study – Data collection in epilepsy</b>	Piloting a prototype APP for young people with epilepsy. This is an ongoing project with a researcher and the YPAG.
<b>16<sup>th</sup> February 2021</b>	18 Young People	<b>Bone Infection study - Oxford University</b>  Study design	Researchers presented a study looking at the different ways to treat and diagnose bone infections in children using MRI Ultrasound scans. The study team asked the young people to come up with a name for the study and logo, followed by a general discussion into the study protocol.

## Appendix 1

<b>30th March 2021</b>	15 Young People	<b>University of Liverpool - Alcohol and Drug use in young people</b>	The researchers presented their study ideas to the YPAG, and asked for their thoughts on reaching out to young people in such a delicate topic area. Their thoughts fed into the design of the patient information materials and recruitment processes.
		Study design and patient information sheet review	
		<b>PhD Study – Data collection in epilepsy</b>	Follow up from the APP study where 11 young people from the YPAG were involved. The questions in the APP and design were reviewed and discussed by the YPAG.
		<b>Alder Hey Experimental Arthritis Treatment Centre (EATC) - Kidney Study</b>	Ideas for a lupus-based kidney study were presented to the YPAG for review. Thoughts on how best to recruit to the study and dissemination ideas were also discussed.



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.**