



# GenerationR

young people improving Research



GenerationR Liverpool  
YPAG & Alder Hey  
Parent and Carer's  
Research Forum Annual  
Report  
2018-2019



## **Introduction & Background:**

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 Liverpool Young Person's Advisory Group (YPAG) was set up in 2006 and currently has 20 members aged between 8-21 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.

## **NIHR Alder Hey Clinical Research Facility (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 every 6/8 weeks on a Saturday, usually alongside the GenerationR Liverpool YPAG. Members have been involved with a huge variety of studies over the past year and their input has played a valuable part in many national and international clinical trial designs. 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 studies. The

group has an active closed Facebook Group that is used to share information and events. Over the last year the Forum has built up excellent working relationships with international pharmaceutical companies and NHS and NIHR organisations. We continue to recruit new members from an ongoing outreach strategy.

Both groups are funded by NIHR Alder Hey Clinical Research Facility (CRF). The group supports the key objectives of the CRF PPIE strategy providing a Local, National and International forum for advice to researchers working on paediatric research. Read our plans for involving and engaging young people and families in our PPIE Strategy for 2017-2022 <http://bit.ly/30VDVqW>.

### **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 1) is then completed to address questions such as study details (e.g. type of study, stage of study etc.); type of PPI activity (e.g. review of protocol, review of 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 2) 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 is happy to undertake the activity specified.

Several weeks after the consultation has taken place the facilitator will contact the researcher to gain some feedback (Appendix 3) as to what happened as a result of

the young people’s input, for example, did anything change to the protocol or patient information sheet as a result of the group’s comments and did this go through ethics without any problems? This is really important as it demonstrates the impact of young people’s role in the design and delivery of paediatric research. See the feedback and impact section below.

### **One-Stop Support Service for Researchers:**

In total 8 YPAG meetings and Parent Carer Research Forum meetings were held in the reporting period between April 2018 - March 2019. A total of 31 projects incorporating clinical research have been presented in meetings. The diversity of projects and range of specialities, and organisations represented is evidenced in the list below:

<b>Date</b>	<b>Name of activity and related condition</b>	<b>Level of activity</b>
<b>21st April</b>	<b>YPAG meeting / Parent and Carer Research Forum</b>	
	<b>Adverse Drug Reactions Project</b>	PIS Review and questionnaire review
	<b>Psychology PHD Study</b>	PIS Review
	<b>Eczema study - Pfizer</b>	Protocol review and PIS review

<p><b>23rd June</b></p>	<p><b>YPAG meeting/Parent and Carer Research Forum</b></p> <p><b>Psychology Services</b></p> <p><b>DETECT Study</b></p> <p><b>FORCE/MILK Studies</b></p> <p><b>WORD Day 2019- Introduction SA</b></p>	<p>PIS/ Discussion</p> <p>PIS/Study design</p> <p>Logo/study design and PIS approval</p> <p>Ideas for design and planning of the event</p>
<p><b>15th September</b></p>	<p><b>YPAG/ Parent and Carer Research Forum</b></p> <p><b>Play Specialist Study</b></p> <p><b>Patient Consent</b></p> <p><b>Ashfield Healthcare</b></p> <p><b>Tookie products (SME)</b></p>	<p>Initial ideas and discussion</p> <p>PIS and consent approval</p> <p>Study design approval of study materials</p> <p>Product design approval and</p>

	<p><b>Experimental Arthritis Treatment Centre (EATC4Children)</b></p> <p><b>Lupus Study</b></p> <p><b>PCT Conference- Pain Clinic</b></p>	<p>assessment of ideas</p> <p>Website, Logo Design</p> <p>PIS Review</p> <p>Parent feedback on conference ideas</p>
<b>13th October</b>	<p><b>YPAG</b></p> <p><b>EATC4Children</b></p> <p><b>Training and Development Day- YP involvement in Research</b></p>	<p>Website and logo design and feedback</p> <p>Training workshop.</p>

<p><b>24th November</b></p>	<p><b>YPAG/ Parent and Carer Research Forum</b></p> <p><b>Paediatric MS Study- Languard,</b></p> <p><b>Promote study</b></p> <p><b>CCA Clinical Research Study</b></p> <p><b>Paediatric Kidney Study</b></p> <p><b>SCIENCE Study</b></p>	<p>Study design, website and PIS</p> <p>Interview analysis</p> <p>PIS Review</p> <p>Study Design approval and PIS</p> <p>Ethics discussion</p>
<p><b>19th Jan</b></p>	<p><b>YPAG/ Parent and Carer Research Forum</b></p> <p><b>Detect Study</b></p> <p><b>Genomics England</b></p> <p><b>PRMU Acceptability Study</b></p>	<p>Study design and discussion on recruitment</p> <p>Ethical issues involving YP - Group discussion and debate</p>

		Discussion on study design and idea
<b>2nd March</b>	<b>YPAG/ Parent and Carer Research Forum</b>  <b>C4C- Patient Involvement Case Study Review, training.</b>  <b>APP/ Technology Design</b>  <b>Antibiotic Awareness Project</b>  <b>Paediatric Task Force Development</b>	PPI Case Study review and assessment  Assessment of design and PIS  Information sharing and facilitation  Initial planning and introduction to project
<b>30th March</b>	<b>YPAG/ Parent and Carer Research Forum</b>  <b>Genomics England</b>	Ethical review and patient letter assessment PPI blogs

	<b>NIHR Patient engagement in clinical development</b>	Blog writing
	<b>C4C PPI assessment</b>	PPI case study assessment continued

### **Feedback from researchers & impact:**

Feedback from researchers were received for most of the above activities (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:

*“I contacted GenerationR to help advise Genomics England on the best approach to seeking consent from young people in the 100,000 Genomes Project (the Project) once they reach the age of majority (i.e. 16). We have approximately 16,000 young participants in the Project and we have committed to seeking consent from them once they reach the age of majority. We are engaging with young people to hear from them how they would want this to be done”.*

*“The aim was to provide some background to the Project and to get the Groups view on how we contact them; how we explain the research; and how many times they think it is reasonable to try and get in touch. The group were very engaged and provided a really useful insight into how they think we can manage this. I will use their input to draft some materials which I would like the group to feedback on in the future if possible”.*

### **Genomics England**

## Reflections from members

*“Since becoming a member of the Generation R Young Person’s Advisory Group I have thoroughly enjoyed the group meetings and opportunities provided by being a part of this group. It is extremely rewarding to see the input our group has had on the resources for different trials that we are asked to advise on. To know our advice has been acted upon and is used to improve the hospital and medical experience of other children shows the great impact I believe we have on improving the information given to these young patients. Helping to create a logo and animation for the EATC was also a great opportunity to see our ideas in a creative way to help explain the centre to other children”.*

### **Member aged 15**

*“GenerationR tells the truth to researchers and research companies. We represent the perceptions of young people who usually do not have a voice in clinical trials and the way information is presented. We try to develop information to make them as understandable and accessible to other children and young people. Allowing the patient to feel confident, informed and fully in control of their health”.*

### **Member aged 14**

## 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 priority and plans are underway to address the recommendations highlighted in the PPI Standards (INVOLVE) and following work we undertook, commissioned by the James Lind Initiative <http://generationr.org.uk/wp-content/uploads/2018/05/GenR-annual-report-17-18.pdf>

## **GenerationR Alliance**

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 led by Jenny Preston, Dr William van't Hoff, Director of the GOSH Clinical Research Facility and 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 two face to face meetings have been held hosted by Alder Hey CRF, and Great Ormond Street Hospital CRF. A national event hosted by the GOSH Digital Research, Informatics and Virtual Environments (DRIVE) is planned for April 2019 to bring together members of GenerationR YPAGs to feed into DRIVE's Patient and Public Involvement Strategy. Further information can be found on <https://generationr.org.uk/generationr-alliance/>

## **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 developed with various stakeholders

including young people, teachers and parents. In November 2018 RAIiSE achieved official charitable status. RAIiSE is led and founded by GenerationR member Sophie Ainsworth. In this reporting period, Sophie has continued to promote RAIiSE at various events including European Conferences such as the Paediatric Rheumatology European Society (PReS) in Amsterdam where she was an invited speaker. Sophie and two other RAIiSE trustees were invited to the RCPCH launch of the State of Child Health Report that was held at Westminster. Sophie was also the young person keynote speaker. In December Sophie was invited to present as a young person living with Lupus at the Royal Society of Medicine in London. Another young member and trustee of RAIiSE represented the charity at a strategy meeting held by NICE to develop guidelines involving young people. For further information about RAIiSE follow @raiiiseuk

## **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 (also Young Patient Research Ambassadors) 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. Here are some of the activities 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 a NIHR HTA-funded study called BATCH (Biomarker-guided duration of antibiotic treatment in children hospitalised with confirmed or suspected bacterial infection), which aims to reduce antibiotic exposure in hospitalised children with infection [www.batch-trial.co.uk](http://www.batch-trial.co.uk).

To date two script writing workshops with young people and clinicians have taken place to date, and rehearsals have begun in earnest. The first live performance is set for the 18<sup>th</sup> May in Liverpool to celebrate International Clinical Trials Day. Read the first two blogs here <http://bit.ly/2XcQKLJ>. <http://bit.ly/2HoaZA6>. The aim is to target schools and youth groups in the Merseyside area to reach as many young people and as possible. A communications plan and recommendations for future engagement work will be developed in light of the findings from the project.

## **International Collaborations**

### **July 2018 - International Children's Advisory Network (iCAN) Summit, Edinburgh**

Every year YPAGs and families from across the Globe attend a Summit funded by iCAN to learn from one another, and to network with leading professionals around the Globe. In turn, the Summit also offers the scientific community an opportunity to engage directly with children and parents, so that they may learn about the value and the significant importance of the influence of children on research, medicine and innovation. In July 2018 the Summit was hosted by the Scottish Clinical Research Network (ScotCRN), supported by the Alder Hey PPIE team and wider CRF team who delivered numerous workshops that focused on:

- Designing child friendly Patient Information Sheets
- Child Patient Reported Outcome Measures (PROMs)
- Child friendly formulations

- Adverse Drug Reactions in children and young people (introduction to the 'Yellow Card' Scheme)

GenerationR Alliance members were invited to attend and represent the work of GenerationR YPAGs.

A video of the event is available here:

<https://www.youtube.com/watch?v=kVABrvjTQrg> and a blog written by Sammy Ainsworth <http://bit.ly/2Pbua2h>

### **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 end points, 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.

The goals of eYPAGnet are:

1. Improve the capacity of collaboration between CYP, patients and stakeholders who participate in the research process and development of innovative drugs.
2. Promote the planning and development of clinical research initiatives for children at the European level.

3. Unify the curriculum of training programs for CYP, young patients and facilitators of YPAG's.
4. Promote and support the creation of new groups.
5. Empower young people to have a voice in Europe that is valued.

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

### **WORD day**

On 18th March the first World Young Rheumatic Disease Day was held. This was a joint project led by the European Arthritis in Children Network, ENCA and PReS. The aim of WORD day is to spread awareness that children and young people get rheumatic diseases and that early intervention changes health outcomes. Sammy Ainsworth an ENCA board member is a member of the WORD Day planning committee. Events were held across the world and a successful social media campaign was implemented. Liverpool Gen R YPAG and Parent Carer Research Forum were involved in logo design and discussion WORD Day planning. SA coordinated the Alder Hey involvement. Events included an awareness stand for rheumatic diseases in CYP, a social media photo booth style campaign, a charity cake sale and support drop in discussion area. SA was involved with the planning of the official WORD Day\_2019 video that involved children and young people from across the world as well as an Alder Hey Rheumatology Awareness video. These included members of GenerationR Liverpool YPAG who have been patients of the rheumatology team. For further information and resources

<https://vimeo.com/318626431>

<https://youtu.be/k1bRpka-aMU>



## Global Alliance for Musculoskeletal Health (G-MUSC) - Paediatric Task Force

Sammy Ainsworth has been working with Professor Helen Foster of the G-MUSC Paediatric Task Force. GenerationR Liverpool YPAG and Parent and Carer Research Forum are part of a project to involve patients and parents in CYP health care globally. A large social media campaign will include parent stories, impact and blogs highlighting the need for parents to play a vital role in their child's health. Discussions are underway for GenerationR to link up with parents in the Far East to support the work of the G- MUSC Paediatric Task Force and implement this work.

## 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 programmes to all new staff), *nationally* (e.g. Health Research Authority ‘the ethical issues of research involving children’, see below) *internationally* (e.g. European Network of Research Ethics and Research Integrity Bootcamp, and iCAN Summit).

### Health Research Authority Training – The Ethical Issues of Research Involving Children

One of the biggest problems faced by researchers working with children and young people is understanding the ethical and legal frameworks that researchers need to follow to successfully undertake research in an ethical manner. For many years the PPIE Manager has worked alongside the Health Research Authority to deliver training that focuses on the ethical issues of research involving children, with a specific emphasis on the importance of involving children and young people in the design and delivery of health research. The demand for this training has increased and together with **Dr Hugh Davies** (Paediatrician (retired); Chair, Oxford A REC and former Research Ethics Advisor UK Health Research Authority); **Dr Bob Phillips** (Honorary Consultant in Paediatric and Teenage and Young Adult Oncology, The Leeds Teaching Hospitals NHS Trust; Senior Clinical Academic at Centre for Reviews and Dissemination, University of York), and **Simon Stones** (Patient Advocate, Consultant and Researcher) deliver three training sessions per year for researchers and research ethics committee members. As a result of the training, in 2018 all trainers were commissioned to produce a series of articles on the topic of research with children and young people to be published in the journal Archives of Disease in Childhood. Two have been published in this reporting period (see publications list below) and two will be published in the coming months. The articles offer insight into some of the complexities of undertaking research with children and young people, along with practical strategies of how we can move forward and how we can work together to ensure a better understanding of the need for children, young people and their families to be able to take part, engage with, and

shape research. In addition, we have also produced a series of simple guides summarising the articles with some key messages and strategies, these include:

- **Making research central to good paediatric practice**
- **How to involve young people in research**
- **Top tips for involving young people in research**
- **Principles for designing and reviewing research**
- **Navigating ethical review**
- **Checklist of questions you should be able to answer**

**Research with children and young people**  
**How to involve children and young people in research**

"Research being carried out with or by children and young people, rather than to, about or for them"

Involve children and young people for moral and pragmatic reasons - it's the right thing to do, and can help to improve the quality of research

**Asking the right research question**  
**Prioritising research topics or questions** arising from **informal focus group discussions and questionnaires**, through to more formal and structured processes, such as **James Lind Alliance Priority Setting Partnerships**

**Developing and planning a project**  
 Commenting and advising on **protocols**, including research questions, methodology, specific methods and **search instruments** used in the project, for example **consent or assent forms**, participant **information sheets** and **interview topic guides**

**Research conduct and operations**  
 Involvement in the management and conduct of projects can take several forms, including as members of projects, **trial steering committees** and **advisory groups** through to children and young people acting independently as **co-researchers/peer researchers** with management responsibilities.

**Data collection and analysis**  
 Data collection activities may include disseminating **surveys** to peers, co-facilitating **focus groups** and conducting **peer-to-peer interviews**. Data analysis activities may include identifying and naming **themes** from qualitative data, **commenting** on quantitative analysis and how to portray these findings, and helping to **draw conclusions** to be explored in future research. Children and young people may also be involved as researchers themselves, drawing on **participatory action research methods**.

**Dissemination of study findings**  
 From **press releases**, **blogs** and **social media** posts, to co-authoring journal **publications**, **funding reports** and co-presenting at **conferences**. Enable children and young people to guide you in communicating your research.

Summary publication date: April 2019. Prepared by Shona E. Brown.

**Research with children and young people**  
**Making research central to good paediatric practice**

"Care not informed by good quality evidence can be dangerous, though good quality evidence that is not implemented and practice is essential and can be just as dangerous."

**Key steps to research with children and young people**

Explore risks and differences → Gain informed consent and assent → Transparent reporting of research findings

**Involving children, young people and families in the design of research**

**Principles on how to work together**  
 Five principles from the model of democratic deliberation:

- Evidence-informed**: Arguments should be supported by appropriate and reasonably accurate fact-based data.
- Balanced**: Arguments should be met by contrary arguments.
- Conscientious**: The participants should be willing to talk and listen, with civility and respect.
- Substantive**: Arguments should be considered on their merits, not on how they are made or by who is making them.
- Comprehensive**: All points of view held by significant portions of the population should receive attention.

**Two further principles from the model of accountability for reasonableness:**

- Transparency about the groups for decisions.**
- Procedures for revising decisions in light of challenges.**

Research with children and young people can happen. It takes planning, enthusiasm, resources, thinking, meaningful discussions, people skills, collaboration, a sprinkle of good luck and lots of effort. It is **unethical for it not to be an integral offering of modern, effective healthcare in the 21st century**.

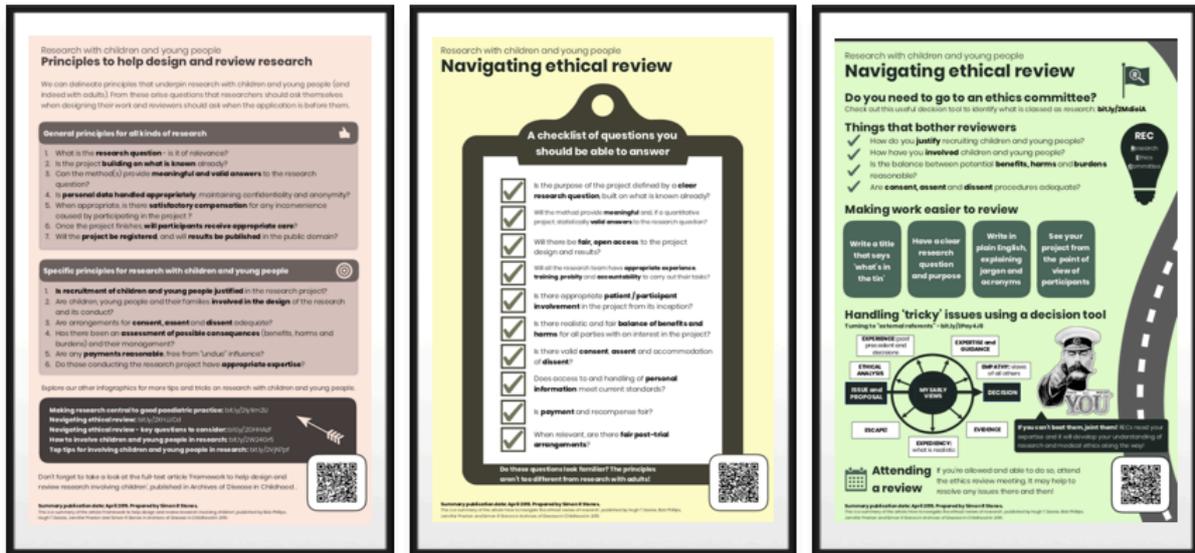
Summary publication date: April 2019. Prepared by Shona E. Brown.

**Research with children and young people**  
**Top tips for involving children and young people in research**

- 1 **Involve us early on** in as many parts of the research as possible, so that we can truly get involved in shaping the project.
- 2 **Show respect for our contribution** - please help to make us feel included and like an equal part of the team.
- 3 **Find ways to ensure we can all contribute** as much as we want to, whatever our age, needs or abilities.
- 4 **Provide training and support opportunities** so that we are better equipped to get fully involved in research.
- 5 **Use words and phrases that we can understand** but without trying to sound young and cool!
- 6 **Make sure our involvement benefits us too**, such as by learning new skills, receiving vouchers, payment, meals out, references or simply by having fun!
- 7 **We have busy lives** and our circumstances, interests and availability might change. Please let us know how to miss a session and fill us in afterwards.
- 8 **Organise meetings at times and places** that are easy for us to get to and where we feel comfortable.
- 9 **Communicate with us in different ways** such as online, text, social media, phone and post. Ask us what we prefer so we do not use social media or email.
- 10 **If there is a gap between meetings, keep in touch and give us updates**, even if it's such a simple hello, here's what has been happening.
- 11 **Give us feedback on what happens after our involvement** - show us what difference we are making, so we know our involvement is worthwhile.
- 12 **Try not to make assumptions** about what we are interested in or what we are capable of - please ask us.
- 13 **If you're able to, please provide decent refreshments** for events and meetings we attend. If you sometimes feel the deciding factor is to whether we attend or not.

Patience and public involvement with children and young people is a self-rewarding benefit that far out-weighs the challenges in research. **Everyone with a legitimate interest in research should be able to contribute to its design, review, conduct and dissemination**, otherwise our venture with children and young people in the driving seat will fail to thrive.

Summary publication date: April 2019. Prepared by Shona E. Brown.



## Publications 2018-2019

**Preston, J.,** Stones, S.R., Davies, H. & Philips, B. (2019). How to involve children and young people in what is, after all, their research. Archives of Disease in Childhood 104(5): 494-500. Doi: [10.1136/archdischild-2018-315118](https://doi.org/10.1136/archdischild-2018-315118).

Davies, H.T., Philips, B., **Preston, J.** & Stones, S.R. (2019). Making research central to good paediatric practice. Archives of Disease in Childhood 104(4): 385-388. Doi: [10.1136/archdischild-2018-315117](https://doi.org/10.1136/archdischild-2018-315117)

Vivian W. L. Tsang, Leanne West, Christine Woods, Chester J. Koh, Susan McCune, Theresa Mullin, Sharon R. Smith, Segolene Gaillard, Joana Claverol, Begonya Nafria, **Jennifer Preston,** Pamela Dicks, and Charles Thompson. Role of Patients and Parents in Paediatric Drug Development. Therapeutic Innovation & Regulatory Science 2019. <https://journals.sagepub.com/doi/10.1177/2168479018820875>

Jacqueline Martin-Kerry, Peter Knapp, Karl Atkin, Peter Bower, Ian Watt, Catherine Stones, Stevin Higgins, Rebecca Sheridan, **Jenny Preston,** Danielle Horton Taylor, Bridget Young. Supporting children and young people when making decisions about

joining clinical trials: qualitative study to inform multimedia website development. BMJ Open 2019 <http://dx.doi.org/10.1136/bmjopen-2018-023984>

Gaillard, S. Malik, S. **Preston, J.** Escalera, B. N. Dicks, P. Touil, N. Mardirossian, S. Claverol-Torres, J. Kassai, B. (February 2018) [Involving children and young people in clinical research through the forum of a European Young Persons' Advisory Group: needs and challenges](#). Fundam Clin Pharmacol. doi: 10.1111/fcp.12360

**Preston J.**, Dicks, P., Escalera, B. N., Gaillard, S. (2018) The ethical principles underpinning the participation of young people in the development of paediatric clinical research, in Ethics of Research Involving Minors: A European Perspective. Medical Ethics Vol 29. <http://www.lit-verlag.de/isbn/3-643-90975-6>

Jacqueline Martin-Kerry, BAppSci (Hons) PhD, Peter Bower, Bridget Young, Jonathan Graffy, Rebecca Sheridan, Ian Watt, Paul Baines, Catherine Stones, **Jenny Preston**; Steven Higgins, Carrol Gamble, Peter Knapp: Developing and evaluating multimedia information resources to improve engagement of children, adolescents and their parents with trials (TRECA study): Study Protocol for a series of linked randomised controlled trials. Trials

### **Website and Blog series**

We have a dedicated CRF webpage incorporated into the Alder Hey website <http://www.alderhey.nhs.uk/research/nih-ralder-hey-clinical-research-facility/> highlighting the research we undertake to increase interest and participation in our studies. We have produced a research brochure <http://www.alderhey.nhs.uk/wp-content/uploads/Changing-Lives-at-Alder-Hey-Through-Research.pdf> and produced a video Inside the clinical research facility at Alder Hey CRF <https://www.youtube.com/watch?v=8ndYI3ByZJQ> which has over 1000+ views.

All PPIE activities are linked and promoted via the GenerationR website <http://generationR.org.uk> officially launched in April 2015. The website was funded by

the James Lind Initiative and Testing Treatments interactive (TTi) until March 2019. The hosting and design costs for the website will be transferred to Alder Hey CRF and Great Ormond Street CRF as of April 2019. Work is underway 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.

### **Blog series ‘improving medicines for children’**

We produce a blog series entitled ‘improving medicines for children’ which has been gaining a lot of interest from the general public. You can read the blogs below:

<http://bit.ly/2jaRQI5>

<http://bit.ly/2xTBjLP>

<http://bit.ly/2fRTYjz>

We disseminate news and blogs to 1450+ Twitter followers on a daily basis using @GenrYPAGs @LiverpoolGenR1

### **Conclusion**

The GenerationR Liverpool YPAG and the newly established Parent and Carer’s Research Forum continue to bring insight, intelligence, enthusiasm and compassion to discussions with researchers and other key stakeholders. The group have achieved a considerable amount over the year and continue to be an invaluable resource for researchers across the Globe. Looking ahead for 2018-19 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).

Report written by Jenny Preston, Senior Patient and Public Involvement Manager and Sammy Ainsworth, Youth and Family Participation Officer, NIHR Alder Hey CRF.

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

(Appendix 1) 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	

## (Appendix 2) - 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.....



**(Appendix 3) - 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	

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
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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?
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7. Would you recommend the YPAG to others?

Yes		No	
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Please add any other comments you have
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**Thank you for completing this form.**