



GenerationR

young people improving Research

GenerationR Liverpool YPAG Annual Report 2017-2018

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Introduction & Background:

GenerationR is a National Young Persons' Advisory Group made up of local young people's groups across the UK. Groups are funded by the National Institute for Health Research and/or other National Health Service organisations, through various channels.

The GenerationR Liverpool Young Person's Advisory Group (YPAG) was set up in 2006 and currently has around 15 young people aged between 13-19 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.

The group is funded by NIHR Alder Hey Children's NHS Foundation Trust 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 latest PPIE Strategy for 2017-2022 at <http://generationr.org.uk/liverpool/>

Planning & Processes of accessing the YPAG:

If a researcher or research team wishes to access the group a discussion takes place with the 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.

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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 were held in the reporting period between April 2017 - March 2018. A total of 20 projects incorporating clinical research have been presented at YPAG meetings. The diversity of projects and range of specialities, and organisations represented is evidenced in the list below:

Date	Name of activity and related condition	Level of activity
April 2017	YPAG meeting:	

	Boehringer Ingelheim – venous thromboembolism Langland Communications (no specific condition)	Patient Information Sheet Review Video Production
May 2017	YPAG meeting: Raceno - Asthma Study	Patient Information Sheet Review
May 2017	Focus Group meeting: Dermal Dose Micro-Injection Device	Device acceptability workshop
June 2017	YPAG Meeting:	Review

	Novartis – Production and review of a thank you letter for young patients taking part in research	
September 2017	<p>YPAG Meeting:</p> <p>Lily – Cancer Study</p> <p>Vitaflow – Dietary Study</p>	<p>Patient Information Sheet Review</p> <p>Patient Information Sheet Review</p>
October 2017	<p>YPAG meeting:</p> <p>Paediatric Early Warning Signs</p> <p>Uncertainties in medicine dosage in children – formulations project</p> <p>Pharmacy Project - formulations</p>	<p>Feasibility discussion & testing of proposed device</p> <p>PHD Project</p> <p>PHD Project</p>

	<p>Childhood Atropine for Myopia Progression (CHAMP Study) - Opthamology</p>	<p>Patient Information Sheet Review</p>
<p>November 2017</p>	<p>YPAG Meeting:</p> <p>Biomarker-guided duration of Antibiotic Treatment in Children Hospitalised with confirmed or suspected bacterial infection -BATCH Study</p> <p>Information for young people on reporting Adverse Drug Reactions -Yellow Card Scheme</p>	<p>Patient Information Sheet Review</p> <p>Information for young people</p> <p>Dragon's Den exercise to produce a young person's information sheet</p>

<p>November 2017</p>	<p>Focus group:</p> <p>NIHR Springboard Digital ‘thank you’ App focus group</p>	<p>Patient Digital Communications</p>
<p>January 2018</p>	<p>YPAG meeting:</p> <p>Self-management interventions for children aged four to 11 living with long-term, chronic conditions and their families: a realist synthesis protocol (iSMART Project)</p> <p>Healthcare App – Clinical Photographs</p> <p>Digital Alder Hey</p>	<p>PHD Project</p> <p>Medical Device Review</p> <p>Review of current projects</p>
<p>February 2018</p>	<p>YPAG Meeting:</p> <p>Pfizer study – eczema</p>	<p>Early Protocol Design</p>

	What is it like being a member of a YPAG? - Qualitative research	Masters Qualitative Project
	Designing acceptability tools for children's medicines – Formulations Project	PHD Review

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:

“We wish to pass on our gratitude to the team and young person’s input and enthusiasm....The questions posed from members of the group were intelligent and thought provoking and the suggestions made around the level of detail and visual representation of some of the study assessments have proved to be most helpful in the creation of the informed consent document. The informed consent document is currently being finalised, but we can confirm that wording as to why the blood tests are required and visual representation of some of the study assessments have been changed because of their feedback..”

Evaluating the role and impact of the group

Having contributed to such a wide variety of research projects over the course of the year it was important for the group to reflect and explore the impact their contributions make to the design of research but more importantly to child health in

general. In February 2018 we undertook a Body Mapping exercise which involved several activities that included splitting the group into small teams to address the following:

- Discussing the different types of activities the group had been involved with in 2017-18
- Labelling different parts of the body that the activity had addressed
- Discussing the impact of the groups contributions to potential child participants taking part in these studies and the impact it might have on their lives and health.

Group reflections

The biggest reflection from the group was that they hadn't realised they had contributed to so many studies and projects during the year. The Body Mapping exercise allowed the group to reflect on their role and discuss the perceived impact they had on studies, and ultimately to the lives of children living with various health conditions. The group felt proud they had contributed to such a wide range of projects but felt more could be done by some researchers to feedback what had happened as a result of their input. They felt some researchers were really committed to providing feedback by returning to the group with study progress updates and preliminary findings but others provided little information as to what happened as a result of the groups input.

Impact

Feedback from the group reinforced the findings from a report written by the PPIE Manager and Louca-Mai Brady (independent researchers and consultant) following a project commissioned by the James Lind Initiative early 2017. The project looked at young people's involvement in the design and delivery of research studies adopted by National Institute for Health Research (NIHR) Clinical Research Network: Children (CRN Children). The project wanted to find out what information was available on how and when young people are involved in health research, and what difference this involvement makes to research and to the young people involved. We looked at the information the NIHR Clinical Research Network (CRN): Children and the GenerationR Young People's Advisory Groups collect on when and how young people are involved in research, and then talked to professionals who work in public involvement. We found that:

- Most of the information collected is about the stages of research in which people have been involved, but there is hardly any information on who was involved and how;
- There is currently no way of finding out which young people were involved in CRN Children studies, whether studies had involved young people rather than their parents, or what difference any involvement may have made.

The report, available to download from <http://generationr.org.uk/liverpool/> makes recommendations about how NIHR could find out more who is involved in research and how, as well as what difference this involvement makes to research and to the

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young people involved. We will endeavor to address these recommendations on activities highlighted in the PPIE Strategy.

Young Person Led Project – Raising Awareness of Invisible Illnesses

Alder Hey CRF continue to support the RAIiSE 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. RAIiSE is in the process of becoming an official charity, led and founded by GenerationR member Sophie Ainsworth. Sophie has continued to promote RAIiSE at various events including the opening key note speech at INVOLVE @21, and European Conferences such as the Paediatric Rheumatology European Society (PReS) in Athens. Sophie and RAIiSE trustees were invited to the Department of Education (DofE) to discuss ways they would like to support the charities work and production of the educational pack. Plans to pilot the pack with DofE support are being made. For further information about RAIiSE follow @raiseuk

Engagement, Involvement and Promotional Activities

Engaging, informing, educating and stimulating thinking about clinical research is achieved through our Research, Education, Awareness, Program (REAP) (Appendix 4) The Liverpool YPAG and Young Patient Research Ambassadors are committed to engaging with a variety of audiences including young people, clinical staff, patients, and members of the public. Here are some of the activities the group, and families have undertaken this year:

International Clinical Trials Day - Events

- **Young Person's Involvement Tweetchat**

Discussions led by young Ambassadors Simon Stones, Sophie Ainsworth and Robyn Challinor about the importance of involving young people in health research design.

- **Production of UK Clinical Research Facility Network (UKCRFN) Research Awareness Survey**

Distributed pilot Raising Awareness Survey's across NHS Organisations via UKCRF network staff, targeting adults, staff, families and young people. The purpose of the surveys was to assess stakeholders views on accessing information about research in NHS Organisations. A summary of the results can be found at <http://generationr.org.uk/liverpool/> and was published for ICTD during May 2017.

- **Young Person's Interview with Radio Merseyside**

Young Research Ambassador Sophie Ainsworth was interviewed for Radio Merseyside for International Clinical Trials Day talking about her experience as a Lupus patient, treatment at the CRF and experience as a Patient at Alder Hey CRF.

- **International Clinical Trials Day Symposium**

Presentation on patient and public involvement in the UK. GenerationR, Patient Research Ambassadors and a gold standard model for involving young people in shaping research was the focus of the presentation.

International Collaborations

July 2017 - Poster for the International Children's Advisory Network (iCAN) Summit in Florida

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- Members of the YPAG developed a poster about GenerationR for the International Children's Advisory Network Summit 2017 the poster can be found on the GenerationR website.

July 2017 - GenerationR attendance at the iCAN Summit 2017

- Three members of the GenerationR Liverpool Group attended the iCAN Summit in Florida. iCAN is a Global consortium of Youth Advisory Groups (YPAGs) working together to provide a voice for children and families in paediatric medicine through synergy, communication and collaboration. Two blogs of the Summit produced by the PPI Manager and a member of the group can be found below:

<https://jennyprestonblog.com/2017/07/21/what-a-month-for-child-health-research-3rd-ican-research-and-advocacy-summit-2017/>

<https://simonstones.com/2017/07/18/3rd-ican-research-and-advocacy-summit/>

Training and Workshops

European Medicines Agency - Data Anonymisation Workshop

PPIE Manager and Young Patient Research Ambassador Robyn Challinor was invited to speak at a workshop at the European Medicines Agency on the 30th November - 1st December about Data Anonymisation in health research.

European Medicines Agency – Patient Training Day

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PPIE Manager and a young person from GenerationR Liverpool YPAG attended a training session delivered by the European Medicines Agency on the 13th November. The training covered how patients can get involved in EMA activities. The next step is to develop similar training aimed at a younger audience.

Website and Blog series

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. 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 is currently 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'

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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 1000+ Twitter followers on a daily basis using @GenrYPAGs.

Awards

Patient Research Ambassador, Simon Stones, was awarded an International WEGO Health Award in the category 'Healthcare Collaborator: Patient'. Check out his blog

<https://simonstones.com/2017/11/12/the-wego-health-awards/>

Conclusion

The GenerationR Liverpool YPAG and Young Patient Research Ambassador's 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 be instrumental in the establishment and development of a European Young Person's Advisory Group Network (eYPAGnet).

(Appendix 1) - Study data capturing form

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?	
PPI Activity	
Type of activity (review of protocol, patient information sheet design etc.)	
Background to Study	
Deadline for activities to take place	
Can the researcher attend the next young person's meeting?	
Outcome of activity (To be completed by PPI Manager)	
Month activity actually took place	
Is this a one off consultation or on-going?	
What was the main outcome of the activity?	
Evaluation of the activity (To be completed by PPI Manager)	
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 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 YPAG

Researcher.....
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Appendix 3 - Researcher Feedback Form

**GeneratiomR 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, RfPB)	
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 young person's 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 young persons' group to other colleagues?

Yes		No	
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Please add any other comments you have

Thank you for completing this form.