

# YPAG: The Young Persons' Advisory Group

By Dr Erin Walker and members of the London Young Persons' Advisory Group

The London Young Persons' Advisory Group (YPAG) is one of five YPAG groups ([see article by Jenny Preston and Sarah Money Penny](#)). It has been funded by the National Institute for Health Research (NIHR) Biomedical Research Centre (BRC) at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) and University College London, and the Clinical Research Facility (CRF) which is funded by this BRC.

We meet every 6-8 weeks. Membership is open to those aged 8-21 – we have recently increased the upper age limit – and children and young people joining the group must have an interest in improving health research. Some members are patients from GOSH, some are related to GOSH staff, and several have participated in clinical trials. This YPAG meets in the CRF at GOSH. YPAGs are interested in advising on, and providing input to all stages of research, although most frequently they are asked to review participant information sheets for readability, language, acceptability to young people, and overall comprehension.

Now that YPAG has existed for a number of years, several lessons have been learned. Members of YPAG say that:

- They like to hear about different health conditions
- They like to feel useful and that their involvement made a difference
- Remuneration is important. To this end, YPAG were involved in helping the Royal College of Paediatrics and Child Health prepare guidance on payments for involvement in research.

- Meeting at the weekend is best, and scheduled appropriately to accommodate members who live outside of London
- Certificates and acknowledgement of participation and contribution is important.

As the facilitator of the London YPAG, I have noticed that:

- There is a variable level of interest and commitment from the members. Your group should include more members than you plan to have at meetings.
- Young people work and communicate differently than adults, and are not always good with email. Ask each young person what method of communication they like best; some prefer texting. Don't assume they all have easy access to a computer, or regular internet at home.
- It is a good idea to include parents in all communications. They rarely reply, but they do like to be informed, and can remind young people to reply to your emails.
- It is advisable to be democratic about meeting times – offer young people the opportunity to pick the meeting date by setting up a Doodle poll with days that also work well for you.

General lessons learned are:

- Target information sheets for different age categories. Have people from the group who fit in to those age categories review the sheets.
- Fun is important! Mix up ice-breaker activities, some social, some active.
- Revisit often how the group works. The facilitators from all of the YPAGs around the country get together regularly and have planning meetings.
- Do not overload meetings in an effort to accommodate high demand. Children and young people don't like it, it's difficult for the researchers, and it's not quality

involvement.

- Give them time to do the activities properly.
- Avoid overreliance on PowerPoint, and if you use it, keep it simple.
- Information sheets should include pictures and colour.
- Do not condescend, be thoughtful about how you talk with the group.
- Always do a feedback activity with children and young people at the end of each meeting, and incorporate feedback into subsequent meetings.
- Seek feedback from researchers about the impact of the YPAG's input, and pass this feedback on to the YPAG members.

Having children and young people from YPAG involved in shaping research has yielded many benefits, to the research, the researchers, and the children and young people involved. Researchers have reported that consulting with YPAG improved the quality of information sheets, by making them more child friendly and improving the comprehensibility overall. Researchers have been impressed by the observations and quality of feedback given by YPAG, and on how insightful children and young people can be about research. YPAG has also helped researchers improve study design by pointing out what would be acceptable to them, as young people, in several research studies.

Members of YPAG have gained skills in presentation (several have presented at high-profile events including the Otto Wolff lecture at the Institute of Child Health in December 2014, and at the Generation R event in September 2013), communication, and team working. They have worked collaboratively with peers of different ages. With some members, this has led to increased confidence and improved self-esteem. Furthermore, children and young people involved in YPAG have gained knowledge they wouldn't otherwise have gained in school, including what health research is, and about many different

health conditions that affect children and young people.

The London YPAG has been a great success story, for researchers and YPAG members alike. In designing and delivering child health research, it is crucial to access and include the voices of those affected by the research, namely children and young people. They are loud, clear, and very insightful.

The website for YPAG is: [www.crn.nihr.ac.uk/children/pcpie/young-persons-advisory-group/](http://www.crn.nihr.ac.uk/children/pcpie/young-persons-advisory-group/)

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