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Generation Research: setting up an eye-and-vision-specific Young People's Advisory Group for Research

1. Involving children and young people in research improves the feasibility of research studies, the readability of information material, and dissemination of findings
2. In the UK, Generation R (Generation Research) is the umbrella organisation for Young People's Advisory Groups (YPAGs) for research, at all major children's hospitals/departments. There is currently no YPAG for children with eye/vision conditions
3. Drawing on the experience of YPAGs in the UK, Europe and the USA, we have set up an eye-YPAG at Moorfields
4. We will share our curriculum and signpost other WAEHs towards educational resources for children and young people
5. We will present the content and outcomes of our first YPAG meeting (March 2019)

Summary

Background/Aims

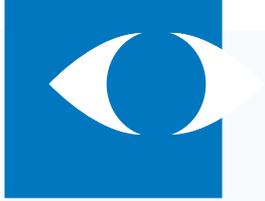
Research runs better when designed with input from people with relevant conditions. Researchers struggle to find children and young people to discuss their projects with. Young People's Advisory Groups for Research (YPAG) train children and young people in all aspects of clinical research. At present, no group exists specific to eye-and-vision conditions.

Methods

In November 2018 we ran two workshops with children, young people and parents. Both led to changes in protocols that researchers had

previously designed and gained insights into family preferences regarding the feasibility of the new group.

To formalise a regular YPAG, we collected the experience of the established UK YPAGs, linked by the Generation R alliance.



WAEH
W O R L D
A S S O C I A T I O N
O F E Y E H O S P I T A L S

Results

We collated published education material for children and young people about ethical, regulatory and practical aspects of clinical research. We drew up a curriculum to enable them to provide an advisory and co-design service for researchers. After securing funding, the first eye-and-vision-specific YPAG group in the UK and worldwide will meet in March 2019.

Conclusions

Setting up an eye-and-vision-specific YPAG may improve quality and accessibility of research with children and young people. Educational material and expertise are available. With adequate funding, a valuable new service can be developed.

Descriptive CV

Annegret Dahlmann-Noor is a consultant ophthalmologist and honorary clinical associate professor at University College London. Her research activities are based at the National Institute of Health Research Biomedical Research Centre for Ophthalmology at Moorfields Eye Hospital and the UCL Institute of Ophthalmology. She has successfully set up research projects not only in London, but as collaborative projects with secondary care sites and child development centres in Bedfordshire, UK, and as collaborations with centres in the developing world. Annegret aims to involve children and young people in research and to help them develop into people who can make decisions and shape research and medicine in the future.