

# Involvement of children and young people

Report 2016/17



## Introduction

Over the last year, People in Health West of England with two partner organisations, NIHR CLAHRC West and Bristol Health Partners, have continued to support the involvement of children and young people. This meant that health researchers based in Bristol and the surrounding area and undertaking research on or about young people have been able to benefit from the combined wisdom and critical analysis of two Young People's Advisory Groups (YPAGs) during 2016/17.

The first group is based at Redland Green Post 16 Centre (RGS) and was originally set up by the Centre for Child and Adolescent Health (CAAH) in 2010. It runs at lunchtime on a weekly basis between October and Easter enabling quick access for researchers, with a new group of year 12 students recruited each academic year. Participation is voluntary. In return for taking part, students receive teaching on research and research methods and are then supported to develop, design and carry out their own research study. On completion, they are awarded certificates of achievement and offered a reference to support future applications to university, college or employment. Snacks and drinks are provided to soften the blow of missing lunch.

The second, based at the Bristol Royal Hospital for Children, is part of the national [Generation R](#) project. The group is made up of young people aged between 10 and 18 (though the project allows

for members aged 8-19) who meet for up to six hours during school holidays and half term breaks to help health researchers with their studies by offering critical evaluation of research ideas, information and methodology. The group was set up by Senior Research Nurse, Tracey Bingham under the guidance of the National Generation R leadership team. All members are volunteers and are taught about health research but on a less formal basis than the RGS group.

## **Redland Green School YPAG– 2016/17**

In 2016, Mike Bell from People in Health West of England began managing the programme following the retirement of Clair Novak (CCAH) with Dr Jo White (UWE) providing the academic lead. With the support of Professor Jenny Donovan, researchers were recruited from NIHR CLAHRC West to teach the first part of the programme and provide informal support during the second stage.

The programme began on 28 September 2016. By the fourth week, a core group of fifteen students had formed who then stayed with the programme to its end. In what seems to be the norm for YPAGs, girls outnumbered boys (by 13 to 2).

The students have to mirror real world research by putting together a research proposal and getting ethical approval. In a change to previous years, ethics guidance was provided not by an individual but a panel consisting of Dr Trudy Goodenough from the CCAH, Dr Tracey Stone, an ethics specialist from CLAHRC West and one of the students who took part in the previous year's programme, Isaac Wales to give a school and student perspective.

During the programme, the group was consulted on five occasions: Dr Penny Whiting and Geraldine Cooney who wanted help developing plain language summaries for Cochrane diagnostic reviews. Hannah Shilling wanted the YPAG's views on a questionnaire about young people's use of pornography and the internet. Dr Georgie MacArthur was looking for insights into the views of young people around potentially effective intervention models for the prevention of harmful alcohol use. Cathy Williams asked the group's opinions on "Eye Train" an app/game designed to help young children with eye movement disorders as well as opinions on the design of the RCT to study the effectiveness of the App and Helen Malson wanted their input into a Gender positive intervention in secondary schools aimed at challenging restrictive gender norms. Students were also recruited into other research programmes outside the group.

## **Student Presentations**

YPAG members presented their own research studies using PowerPoint or Google Slides to a mixed audience of fellow YPAG members, teachers, researchers from NIHR CLAHRC West, colleagues from CCAH and other invited guests. There were five presentations this year. These included a study to discover whether labelling the same recipe cookie dough as "gluten free", "dairy free" or just "cookie dough" would influence people's preference and another looking for links between use of social media, wearing of make-up and self-esteem in girls. Two students, recognising the importance of exams in their lives and the lives of their peers, designed a study to discover the effects of differing levels of stress on performance in examinations. The presentations were of a very high standard and all students were presented with a certificate of achievement by Professor Alan Emond, Professor of Community Child Health and Director of the Centre for Child and Adolescent Health.

**Tim Duroux, Subject Leader of Social Sciences at Redland green said:**

“It is this model - being an 'access group' offering guidance to public health researchers along with the opportunity to conduct their own research - that makes this program so successful; the students are provided with a unique experience to not only meet and witness the process of actual public health research, but the opportunity to have an impact on this research as well.....aside from the educational benefits, the students grow and develop in confidence and self-assurance through the process of advising and educating adults, and especially through having to stand up and present in a university setting.”

## **Generation R YPAG – 2016/17**

The Generation R YPAG was managed by Mike Bell with support from senior research nurse Tracey Bingham from University Hospitals Bristol NHS Trust. It met four times between May 2016 and March 2017. Each meeting lasted five hours which meant that although access was limited to four or five sessions a year, researchers could book a longer and more in-depth session and reach a wider age range of young people. The group members were given lunch and snacks and at least one session each meeting was geared towards teaching about research.

The group currently has over 30 members and each meeting was attended by between 14 and 15 young people aged between 10 and 18. Like the RGS group, girls outnumbered boys although this is improving and in one of the meetings the split was 6/8.

The group was consulted by 12 different researchers during the year with two returning to give updates and ask for further help. One group of researchers returned for the fifth and last time with a prototype medication adherence device for young people, a device that the group had previously helped to design.

Over the year, the group has been asked to comment on a diverse range of studies including an app designed to treat young people with eye movement disorders, the design and functionality of a web based treatment for Chronic Fatigue Syndrome and the age at which young people should be able to consent to immunisations.

Comments from researchers included:

“Great group to work with; engaged, smart and on the ball! Exactly what we needed.” – Jess Ridgers, Designability

“We will use the information (from the YPAG) to inform our development of a control game for a randomised control trial in the future. We will also use the ideas generated from the group to inform how we discuss children/young adult patient relevant outcomes of our app, such as when writing papers, presenting our work and writing future grants.” – Rosie Clarke, Eye Train app.

Two members of the group went on to train as peer researchers for a research project led by Dr Jo White at The University of the West of England (UWE).

We would like to thank all the children and young people, teachers at Redland School and health professional colleagues for their help this year.

Mike Bell

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