



People in Health
West of England

Better involvement • Better research • Better health

Report on the work with Children and Young People



Mike Bell
with Hildegard Dumper
April 2015-April 2016

Promoting a strong public voice...



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1. Background

Children and young people are often under-represented in consultation exercises and finding ways to access them can be difficult. Researchers into children's health in Bristol were in danger of losing two separate projects involving children and young people (CYP) in health research. To ensure the continuation of this valuable resource, Bristol Health Partners stepped in to provide direct support in the form of a Patient and Public Involvement facilitator. The first task was to find out what groups existed and then to identify ways of working together to ensure they were all viable. This report covers the period from 1 April 2015 to 5 April 2016.

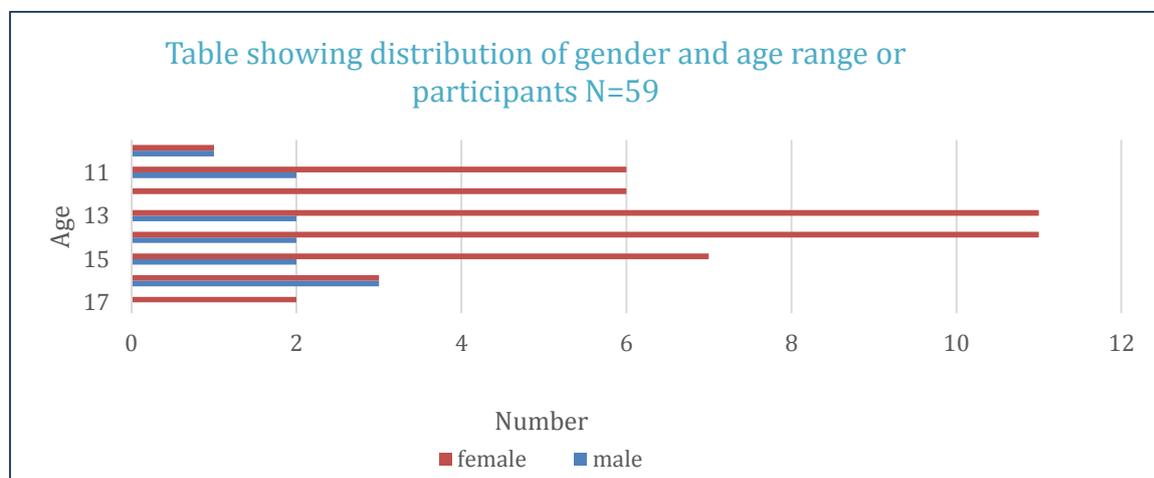
2. The three main cohorts of young people we worked with

There were three main strands of work involving young people in shaping health research and service improvement. These were being undertaken by Generation R Young Person's Advisory Group (YPAG), a research programme being run in Redland Green School Year 12 and Fairfield School Year 9, and Young HealthWatch.

2.1. Generation R Young Person's Advisory Group.

The Young Person's Advisory Group (YPAG) was, and remains, based at the Bristol Royal Hospital for Children and is part of the national [Generation R](#) project. The group is made up of young people aged between 11 and 18 (though the project allows for members aged 8-19) who meet during holidays and half term breaks to help health researchers with their projects by offering critical evaluation of research ideas, information and methodology. The group had been set up by Senior Research Nurse, Tracey Bingham under the guidance of the National Generation R national leadership team. Up until April 2015, Tracey had provided facilitation and admin to run these meetings with ad hoc support from other members of the Women and Children's Research Team. With increasing call on her time as a research nurse, Tracey found it more and more difficult to administer the group meetings. In response, BHP agreed that part of the PPI facilitator post could be used to support the group and the facilitator (Mike Bell) took over the main management of the group with Tracey providing advice when needed and active support during meetings.

The group met four times between 1 April 2015 and 5 April 2016. Over that period four new members were recruited.





2.2. Redland Green School Year 12 and Fairfield School Year 9

From 2010 two secondary school based Young People’s Advisory Groups had been run from the Centre for Child and Adolescent Health (CCA) to provide researchers with access to first-hand knowledge of being a young person in the current world. Unlike most YPAGs they run on a weekly basis during school term time from October to Easter enabling quick access for researchers, with a new cohort recruited each academic year. The two schools with whom strong relationships had been established are Redland Green Post 16 Centre (RGS) and Fairfield High School (FHS). The participants are volunteers, usually from Year 12 at RGS and Year 9 or 10 at FHS, who provide advice and critical analysis on all aspects of research with children and young people. In return, they receive a taught programme on research and research methods provided by members of the CCAH team.

During the autumn and spring terms, researchers visit the school between 15 and 18 times. This varies due to competition with exams, holidays and the vagaries of the Christian calendar around which the school timetable is based.

Following a change in senior management, Fairfield chose not to take part in 2015/16 leaving only the Redland Green group of year twelve students. At the same time, a change in funding meant that one of the researchers from the CCAH was no longer available, leaving only Claire Novak to carry on. BHP stepped in to provide support to Claire through the PPI facilitator. What follows is a brief report from the 2015/16 intake.

During the period from October 2015 to Easter 2016, the group met fifteen times. Initial interest was shown from thirteen young people. This fell to eight over the first four weeks. These remaining eight students all participated right through to Easter although not all attended each weekly session.

Visits by Researchers

Three researchers consulted the group directly by attending the regular sessions.

<p>Dr Jo White – (twice) University of the West of England</p>	<p>Development of a peer-led research project to understand young people’s sexual activity</p>	<p>Very early consultation about approaches, documentation and information for young people to be recruited to study as peer-researchers</p>
<p>Dr Jo Keston (UoB) UoB, UCL, & Queens University, Belfast</p>	<p>STEALTH Lifelong Activity through play</p>	<p>YPAG asked to comment on suitability of mission based activities</p>
<p>Roxanne Parslow (3rd consultation) PhD student UoB</p>	<p>Developing Patient Recorded Outcome Measures (PROM) for Chronic Fatigue Syndrome</p>	<p>YPAG asked to trial PROM to assess if understand what is required, the suitability and acceptability of PROM</p>



Student Research Projects

Over the fifteen week period, the students are encouraged to identify an area of interest for research, design a study, undertake the research and present the findings.

To do this most effectively they are encouraged to work in groups and design research that can be undertaken in the school environment. The three topics the students chose were:

- A study to investigate how concepts diffuse through adolescent peer group environments. A two stage study using moral dilemma questions designed to discover how influential individuals impacted the opinions of a group and individuals within the group.
- A study to investigate how stress levels impact on Year 12 mock examination results. They predicted a relationship between stress levels and examination performance. They designed a before and after study.
- A study to test a predicted link between self-esteem and obedience. The students used a standard scale to measure self-esteem followed by an observational exercise of their peers from Year 12 to test compliance to rules of behaviour in school.

The findings were presented to a group of teachers, researchers and academics at the University of Bristol and each students received a certificate.

One of the students from this group went on to join the Generation R YPAG. From Autumn 2016, the remaining researcher from CCAH will not be able to continue so creative ways of covering her role will need to be sought.

2.3. Young Healthwatch

The last group is the Young Healthwatch. Until December 2015 this group was facilitated joint by Ellen Devine from Healthwatch and Nicole Zographou who was employed by the CCG. Nicole's contract ended in early 2016 with the end of the CCG's consultation process and the group is now facilitated by Ellen Devine.

They have played a pivotal role in advising the Bristol Clinical Commissioning Group (CCG) on recommissioning of [Children's Community Health](#) services, are aged 11-25 and meet regularly in central Bristol and have met with commissioners on a regular basis advising on website design and consultation methods.

The BHP HITs facilitator has attended these meetings on an ad hoc basis and has invited the coordinator Ellen Devine to attend the Generation R YPAG. Information about the two YPAGs is shared between the facilitators/coordinators to enable best use of both forums. The two groups cooperated in devising and presenting a workshop on how best to consult young people in the style of Dragons Den at a regional conference in 2015.



2.4 Other ways the youth project fed into research

Dr Andy Gibson Assoc. Prof UWE	Developing a study about advertising influence on young people's drinking.	Recruitment of YPAG members to support development of this study.
Judi Kidger School of Social and Community Medicine UoB	Self gender - identification on questionnaires	Ethics committee were concerned they had only two options on questionnaire regarding identification of gender
Nicola Stock Cleft Pallate Collective, UoB	Design of self- report questionnaire	Developed by NHS psychologists & researchers. Keen to make questionnaire child-friendly. Considering using some arts-based methods. No previous experience. Need guidance and advice.

3. How the consultation influenced the work of the researchers

The response to requests for feedback from the researchers who took part was low. It is hoped that next year this will be done in a more systematic way. Of those that did reply, the following observations were made.

The researchers on the study of sexual health wrote that they recognized the importance of:

- Training of peer researchers to include how to put people at ease and make the study an interesting and stimulating activity and also how to manage the risk of emotional distress and exceptional circumstances in the sharing of personal information which might necessitate the breaching of anonymity, with examples (NB: this latter training is already planned)
- A concerted strategy for reaching "seldom heard" groups
- Creating an informal physical space and including an ice-breaker at the beginning of all future meetings with young people to put people at ease.

The study into children's ear pain (Cedar Project) that the session had helped them identify the following actions:

- As part of trial documentation, provide CEDAR clinicians with a simple "strapline" to prompt them to explain, to children who are old enough to understand what is happening to them, their role in the study in a positive way.



- Explore potential for school nurses to contribute to our research.

- Clarify within the recruitment documentation and Symptom Questionnaire instructions that children who are reluctant to complete the pain score because they are distressed by ear pain, should not be allowed not to do the Face Pain Scale-Revised

Designability has returned since to refine the designs of the Medication Adherence Device.

4. Summary of the plans for next year

This report records the activities of the first completed year of a joint, strategic approach towards the involvement and consultation of young people in research and evidence-based service improvement. It has provided professionals a vehicle to access young people and is part of our commitment to equalities. A key learning point has been to improve how we measure the extent to which the groups have contributed to improving research ideas and proposals. Our plans for next year includes:

- Drawing up a team of people to cover the researcher role provided by CCAH and assist in implementing the programme in Redland Green School
- Identifying another school to replace the withdrawal of Fairfield school in the programme, preferably in an inner city catchment area
- Broadening the demographics of the YPAG Group

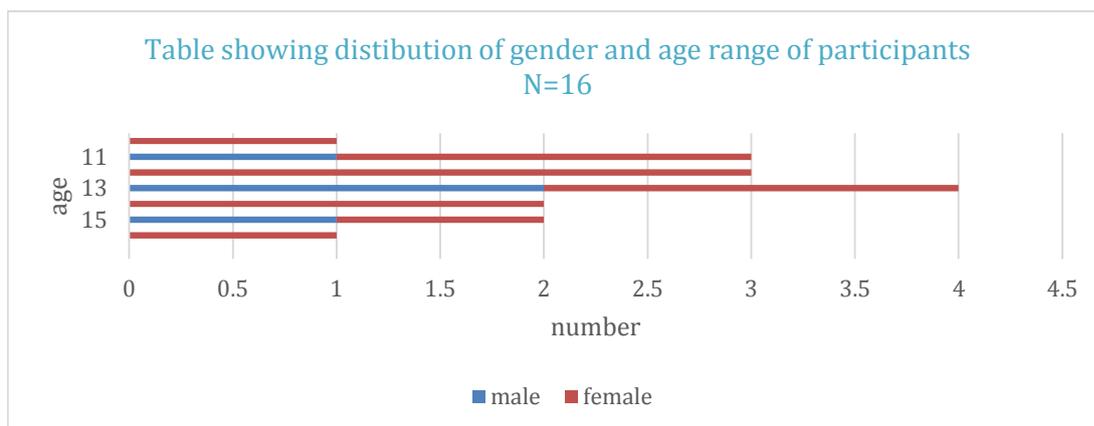


APPENDIX 1. Four YPAG meetings

1 YPAG meeting on 28 May 2015 UHB Education and Research Centre

The group was facilitated by Mike Bell and Tracey Bingham

It was attended by 16 participants whose ages ranged from 10 to 16



Researcher/s	Research Topic
Tracey Bingham	A&E research – what method of anaesthesia would you choose <i>Participants were asked to consider the pros and cons of different ways of dealing with a fracture, including a Bier Block (or intravenous regional anaesthesia), common in Australia but little known in the UK.</i>
Dr Jo White and Professor David Evans , Dept of Health and Social Sciences, UWE	Using peer researchers in a study of sexual health and activity amongst young people <i>The group was divided and older members took part in this topic. Participants were asked for their thoughts on the use of young people trained as peer researchers in a study of sexual health and activity. There were also asked if they would be interested in being trained as researchers.</i>
Lisa Wong	App designed for reporting adverse drug reactions <i>Participants were asked to provide feedback on an app designed to give information and guidance following adverse reactions to prescription medication.</i>
Participants were finally given some CPR training on dummies by current nursing staff.	



Evaluation by attendees

Each researcher was evaluated separately using a target on which participants place a sticker. The nearer the bullseye they placed the sticker, the more they enjoyed the session.

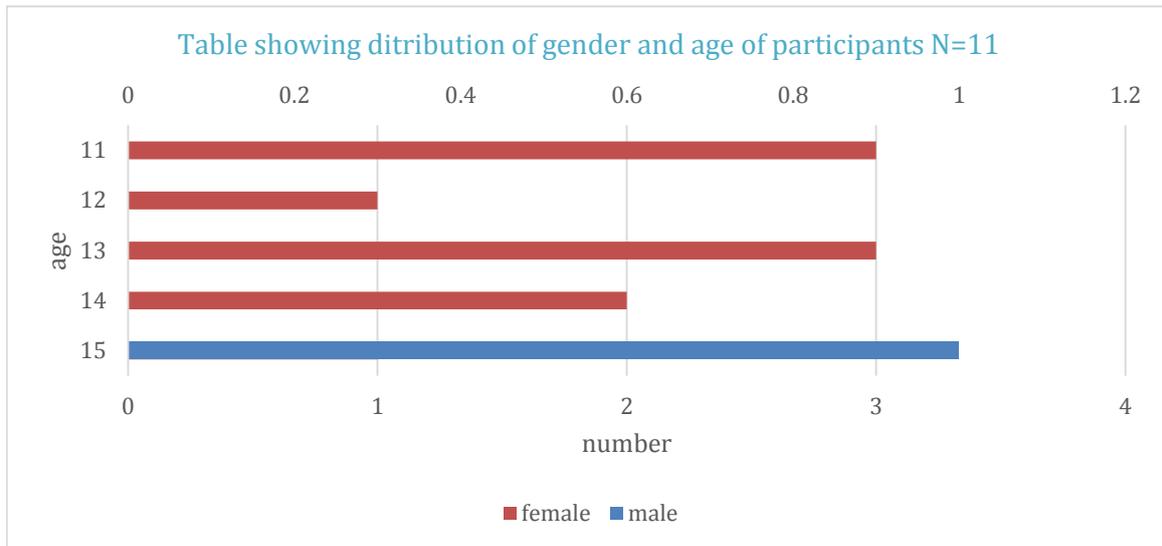


An example of how one of the bullseye targets might provide a snapshot of how the group enjoyed a particular session.

It was felt that while an instant graphic illustration was useful, more information would be needed in future to better evaluate the topics and researchers.

2 YPAG meeting held on 28 July 2015 UHB Education and Research Centre

The group was facilitated by Mike Bell and Tracey Bingham. It was attended by 11 participants whose ages ranged from 11 to 15. Two further boys were due to attend but inadvertently joined a separate research group which was, by chance, in the same building on that day.



Researcher/s	Research Topic/s
Dr Christie Cabral and Mrs Harriet Downing , School of Social and Community Medicine, University of Bristol	<p>Cedar Project – study into children’s ear pain: Cough and ear infections in children and interventions designed to reduce antibiotic prescribing or offer alternatives to antibiotics</p> <p><i>Participants were asked what they understood about anti-biotics and their use. They were also asked if ill, when and at what stage they would refer to a GP or school nurse.</i></p> <p><i>This was a double topic with a short break in between.</i></p>
Paula Brock - Research Nurse, Healing Foundation Children's Burns Research Centre , UHB and Martyn Wood, Manual Handling Advisor, UHB	<p>Low friction “silkie” sheets used for post burns treatment patients and manual handling training</p> <p><i>The participants were asked to evaluate the acceptability of “silkie” sheets against standard sheets. They were then given instruction on using various manual handling equipment</i></p>
Tracey and Mike asked what the participants would like to see on the Generation R Website. Two participants agreed to write a blog (see below)	



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Paula Brock - Research Nurse, Healing Foundation Children's Burns Research Centre , UHB and Martyn Wood, Manual Handling Advisor, UHB	<p>Low friction “silkie” sheets used for post burns treatment patients and manual handling training</p> <p><i>The participants were asked to evaluate the acceptability of “silkie” sheets against standard sheets. They were then given instruction on using various manual handling equipment</i></p>
Tracey and Mike asked what the participants would like to see on the Generation R Website. Two participants agreed to write a blog (see Appendix 2)	



Evaluation by attendees

Again, each researcher was evaluated separately using a target on which participants placed a sticker. The nearer the bullseye they place the sticker, the more they have enjoyed the session. In addition, each participant was asked to fill in a further short evaluation form (see illustration) for each researcher to give us more detailed evaluation. Below is a selection of comments from the feedback forms

"I found it interesting when we did stories about school nurses"

"One of my favourite researchers (topics) so far and I've been coming here for a long time"

"It was OK but too long"

"There was a lot of time to talk about what we thought"

"I found out new stuff"

"The pain scale was good - lots to discuss"

"We had a laugh about the school nurse stories"

Topic _____

Presenter _____

Did you find it interesting? Interesting Boring

Circle one 5 4 3 2 1 

Tell us more

Do you feel listened to? Yes No

Circle one  5 4 3 2 1

Tell us more

Was it fun? Circle one Yes No

Tell us more 

Could it have been better?

Tell us more 

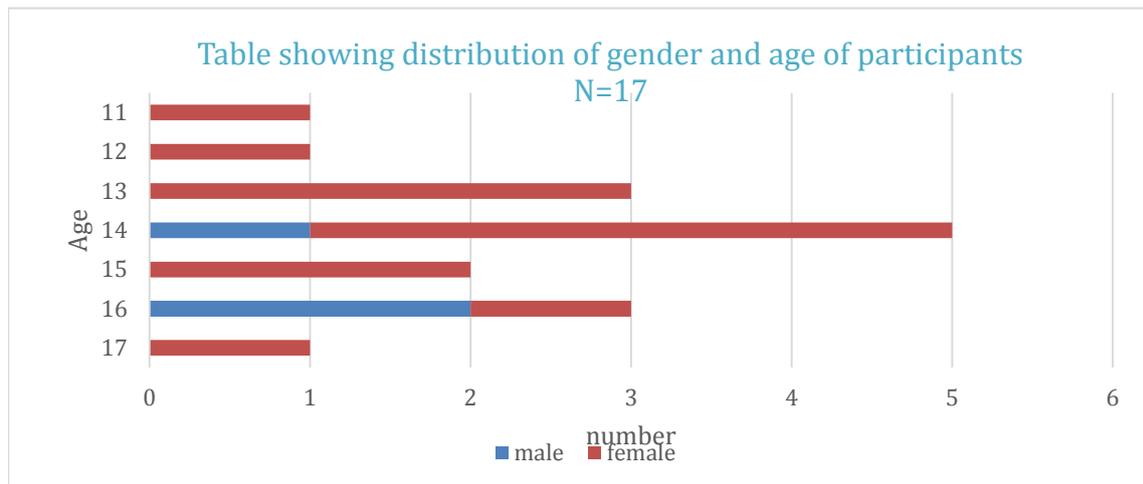
Is there anything else you want to say about this topic?



3 YPAG meeting held on 21 December 2015 UHB Education and Research Centre

The group was facilitated by Mike Bell and Tracey Bingham

It was attended by 16 participants whose ages ranged from 11 to 17



Researcher/s	Research Topic
Pandora Pound - BA(Sur), MSc, PhD(Lond), Research Fellow in Public Health Research Methodology, Research Fellow in Preclinical Evidence Synthesis	<p>Research into teaching sex and relationship education.</p> <p><i>The researcher wanted to gather opinions on who the participants felt was best placed to provide sex and relationship education and in what setting. For example, for some it was clearly a trusted teacher and in school while others preferred someone independent who they were unlikely to bump into during school.</i></p>
Jo Keston - BSc(Lough), PhD(Lough), Research Associate in Social Science (Qualitative) Research	<p>Research into “Stealth Project” getting young people to exercise without describing it as “sport”</p> <p><i>The researchers described a plan to recruit people to take part in “mission games” designed to get young people to be more active and asked for feedback on types of games, settings and who would be interested in taking part.</i></p>



Keir Haines from Designability - BSc (Hons) Industrial Design and Technology, Loughborough University (2005) and Stephen Kitson - CEO Folium Optics	Research into Medication Adherence Devices <i>The participants were asked to design devices they would use to remind them to take medication. They were told not to feel constrained by current technology.</i>
Paula Brock - Research Nurse, Healing Foundation Children's Burns Research Centre , UHB	Short questionnaire about outcomes following burns surgery
Participants were given an opportunity to try to "take blood samples" from a variety of "arms" supported by current research nursing staff	

Evaluation by attendees

Again, each researcher was evaluated separately using a target on which participants placed a sticker. The nearer the bullseye they place the sticker, the more they have enjoyed the session. Each participant was again asked to fill in a further short evaluation form (see illustration) for each researcher to give us more detailed evaluation. Below is a selection of comments from the feedback forms

Topic _____
Presenter _____

Did you find it interesting? Interesting Boring
Circle one 5 4 3 2 1 

Do you feel listened to? Yes No
Circle one  5 4 3 2 1

Was it fun? Circle one Yes No
Tell us more 

Could it have been better?
Tell us more 

Is there anything else you want to say about this topic?

"I liked this session"

"We found out a lot and could express ideas"

"I liked designing"

"Insight into the future"

"Great fun, we interacted a lot",

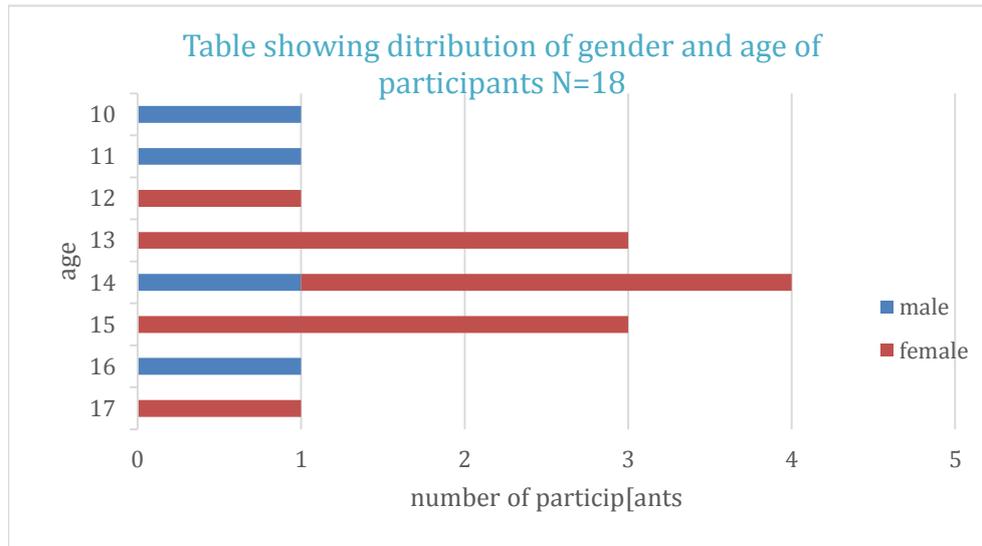
"Interesting and less about random facts about ourselves",



4 YPAG meeting 5 April 2016 UHB Education and Research Centre

The group was facilitated by Mike Bell and Tracey Bingham

It was attended by 16 participants whose ages ranged from 10 to 17



Researcher/s	Research Topic
Tracey Bingham – senior research nurse UHBT.	Swabs – a selection of mouth, throat and nasal swabs
Keir Haines from Designability - BSc (Hons) Industrial Design and Technology, Loughborough University (2005)	Further research into Medication Adherence Devices <i>The participants were asked to consider colour, materials and textures for future adherence devices</i>
Jo Ferrie et al (Bristol Immunisation Group)	Immunisation in Bristol – what is your view



Evaluation by attendees

Again, each researcher was evaluated separately using a target on which participants placed a sticker. The nearer the bullseye they place the sticker, the more they have enjoyed the session. Again, participants were given a separate short feedback form. This time, the final question was changed from “Could it have been better?” to “What would have made it better?”

A copy of the revised feedback form is shown with a selection of comments.

“Didn’t fully understand that there was no vaccination for malaria”

“I learnt new things about certain diseases”

“They absorbed our opinions and fed back well”

*“They looked like they wanted to know.
They also built on my comments”*

“It was fun learning the opinions of others as well as new facts”

“We got to compare experiences”

“Good activities for programme”

Topic _____
Presenter _____

Did you find it interesting?	Interesting	Boring
Circle one	5 4 3 2 1	1 2 3 4 5
Tell us more		

Do you feel listened to?	Yes	No
Circle one	5 4 3 2 1	1 2 3 4 5
Tell us more		

Was it fun?	Circle one	Yes	No
Tell us more		1 2 3 4 5	1 2 3 4 5

What would have made it better?
Tell us more

Is there anything else you want to say about this topic?



Appendix 2. Blog by YPAG

Two of the participants write an occasional blog.

Lottie and Rachael's blog

We are from the Bristol YPAG (Young Persons Advisory Group). The group is led by Mike Bell and Tracy Bingham. We thought about why we should write a blog and we came up with the following:

- 1, to let others know what we do and what research we do,
- 2, to give ideas to other YPAG groups,
- 3, for newcomers to see what we are all about,
- 4, and finally to have an account of all the fun we have.

At the end of each blog post we will rate the day out of ten. This way we can give you a feel of how the day went. We hope you enjoy our blog.

Lottie and Rachael.

On Tuesday 28th July the Bristol YPAG group met for a full day of giving opinions, trying out bed sheets, learning about new things and discussing antibiotics. The plan of the day was full with a breaks for snacks and lunch. We had three different subjects (all related to health of course) and we started the day off with infections and antibiotics.

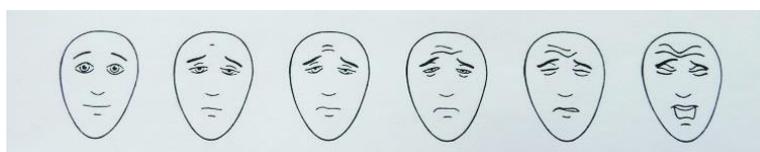
The first researchers we had visit us were Harriet and Christie. They came to talk to us about our experiences with antibiotics and visiting our GP. Whilst getting information from us for their research we also had a laugh about some of the stories we've had from visiting doctors, particularly the school nurse! We then went on to talk about the pain scale, testing it out with previous infections we can remember.

After lunch we went down stairs to a room containing two hospital beds and lots of other hospital equipment. The lady that was part of this study was called Paula and she explained to us that she was working with the "silky study." She explain that the "silky study" was a study of whether silk bed sheets and pillowcases were beneficial to hospital patients with serious burns. We were going evaluate low friction silk bed sheets and give our opinions on how to improve them. We did this by comparing one of the beds which had silk sheets on to the other which had normal sheets on. We found that the silk sheets were slippery but we thought a major aspect of the patient being comfortable would be how hot or cold they were. We learnt a lot about how they dress serious burns and also assessed one of their booklets promoting the study to patients with the burns. It was an interactive exercise which made really interesting and fun. I think we all enjoyed the topic as well as giving advice to Paula.

After completing the Silky Study, we had Martyn teach us about manual handling with patients. We now all know how to control a hospital bed, and use other equipment such as slide sheets and a hoverjack! (Look it up) Martyn taught us so much about how to care correctly for patients, very beneficial for those of us who are looking into the path of medical careers! Thanks Martyn!

To conclude, we both felt the day went extremely well. We both agreed the best part of the day was the manual handling exercises but we also enjoyed all other aspects of the day. The day also taught us many new things, which is after all one of the reasons we come to YPAG. We rated the day 9 out of 10, due to the interaction in the exercises.

Thank you to Mike and Tracey who never fail to keep the day flowing and to all the researchers who came in on the day, we hope to hear from you in the future!



The pain scale



For more information on how you can involve any of these groups in your project contact Mike Bell: Tel 0117 342 1249 or mike.bell@bristol.ac.uk. The Young Healthwatch Group can be reached directly by contacting Ellen Devine ellendevine@thecareforum.org.uk