

Young People's Public Health Reference Group (PEAR) –Update to PHRC, October 2009

Background

The Young People's Public Health Reference Group (YPPHRG) pilot project was set up by NCB (National Children's Bureau) in 2005 with support from the PHRC and INVOLVE. The aim of the pilot was to look at ways in which young people could inform public health research¹. In March 2008 NCB, with support from Catherine Law (UCL Institute of Child Health) were successful in an application to the Wellcome Trust to extend and expand the work of the group, which is now known as PEAR. The aims of this new project are:

- To build on the London pilot group
- To establish a similar group in the North of England
- To raise awareness of the group amongst public health researchers and policy makers, and support links between them
- To develop a range of opportunities and methods by which young people can inform public health research
- To improve young people's understanding of public health and develop their research skills
- To produce and distribute information about public health issues and research of interest to young people
- To show how young people's involvement in public health research can be applied to policy and practice

Planned project activity:

NCB will:

- Plan and manage the project, including establishing a project advisory group
- Establish and support the groups – including meetings and residentials
- Raise awareness of the group amongst public health researchers and policy makers
- Provide a range of opportunities for the groups to inform public health research and related policy and practice
- Provide research skills and other training as required
- Provide ASDAN accreditation for group members
- Increase children and young people's interest in health research and policy issues

- Evaluate the project

The young people involved in the group (with support from project staff) will:

- Work with a range of public health researchers and policy makers to inform their work
- Design a public health research website
- Organise a conference – which will opportunities for children and young people to set their own agenda and communicate with public health researchers and their peers on their own terms
- Commission their own small research project
- Produce child-friendly research summaries
- Be actively involved in project activities and evaluation

Update on progress to date (October 2009)

After a competitive recruitment process during summer 2008, each group now has 11 members aged 12-17. Both groups have now had four meetings during school holidays (October 2008, February, April 2009 and October 2009). A joint residential was held in July 2009 so that the two groups could get to know each other as well as working with researchers, receiving further research training, taking part in an evaluation focus group and planning their own project (see below). The next meetings will be in February and April 2010.

A project advisory group has been established, including young people's representatives from the two groups, NCB staff involved in the project and evaluation, Catherine Law from ICH/PHRC, and an independent representative (Sarah Buckland, Director of the INVOLVE Coordinating Centre). This group has met three times. Information on the group has been circulated via the Public Health Research Consortium, INVOLVE and other networks and potential partners (eg NICE).

Group activity

The groups have received training in public health and the development of research skills, including research process and planning, literature reviewing, methods and ethics. They have agreed their priority areas for public health research, assisted the project team in planning a programme of activity and been involved in setting the objectives for the project evaluation. They are also currently playing an active role in the development of the project website (see below) and have started planning a small research project, with support from PHRC members, which they will commission shortly. The groups are also developing scrapbooks which will be used to provide evidence for

ASDAN accreditation for group members. We have also set up an online forum so that group members can communicate with each other in between meetings.

Working with researchers

We have established links with a range of Public Health Research Consortium and other researchers and policy makers, including NICE and INVOLVE.

At the April meeting a researcher from the EPPI Centre came and worked with the group on two systematic reviews around obesity. Sandy Oliver, Professor of Public Policy at the EPPI Centre said that:

“this is a great opportunity not only to hear young people’s views and use them to inform our current work, but also to think about the challenge of inviting young people’s contributions to influence qualitative research and quantitative observational studies”.

At the residential the group worked with researchers on proposals to evaluate an obesity health promotion programme (Prof Catherine Law, ICH), and research on media images and young people’s drinking (Prof Chris Griffin, University of Bath). They also explored the evidence base on their chosen research topic, links between obesity and mental health, with Professor Janet Shucksmith (University of Teeside). In the October 2009 meeting they advised the young person’s involvement lead from DECIPHer (the Centre for the Development and Evaluation of Complex Interventions for Public Health Improvement - one of five new UKCRC Public Health Research Centres of Excellence) on how young people could be involved in the Centre, and discussed possible links between the two projects.

Several other researchers, from the PHRC and elsewhere, have expressed an interest in working with the group, and we are continuing to explore opportunities within and beyond the scope of the current project.

Outputs and dissemination

The website went live in early September (www.ncb.org.uk/PEAR) and will be a key platform for dissemination of information about, and for, the group. We are pursuing options for a number of peer-reviewed and other publications (some with researchers who have worked with the group) and, with young people co-facilitating, have run two conference workshops on the involvement of children and young people at research: at the INVOLVE conference in November 2009 and the Health and Social Policy Research Centre ‘Critical Perspectives on User Involvement’ conference in April 09.

Next steps

Our key priorities are to further develop the website and get the group’s research project commissioned and underway. We have also started planning the conference which is due to take place in autumn 2010. On a more general level we are continuing to explore

with the groups the balance between the need for them to inform research which is being undertaken by adult public health researchers and having sufficient opportunities for them to undertake their own projects.

We are continuing to publicise the group and liaise with researchers interested in working with them (information is on the PHRC and INVOLVE websites). We have also been invited to give a keynote presentation on young people's involvement in research at a National Research Ethics Service seminar on this topic in November.

Evaluation

NCB's Research, Evidence and Evaluation department is evaluating PEAR over the course of the two year project. The evaluation has three broad aims, which are to:

- identify any lessons that can be learned about the way in which the young people's group has been set up
- assess how good the young people's group is in terms of its contribution to public health research
- explore young people's experiences of the group and assess the impact of participation on young people.

The methodology involves four focus groups with young members (two London and two Leeds groups); a combination of telephone and face-to-face interviews with two project coordinators; two members of the steering group; and four public health researchers at the interim stage and at the end of the project; and an analysis of meeting feedback forms. Group members who expressed an interest in the evaluation are informing the design of the tools.

At the interim stage (September 2009), the findings show:

- Reasons given for joining the group were varied: an interest in studying medicine related subjects at university; something to put on a CV; an opportunity to do something completely different; get incentives; to meet new people; have their voice heard on a subject they know about; to find out what NCB is; put their ideas out there; to learn about research methods, and to learn more about health for their own well-being. The relevance of young people's health to their own lives was also cited as an attraction.
- In terms of the group's purpose, some young people had clear views - to talk about public health, to educate young people about public health through the website, and to develop a research project. Whilst others whom were less clear

highlighted that it would be useful to reinforce the aims and objectives of the group, and to make them more concise so that they could easily tell their peers about the project. They also thought it would be useful to develop targets and progress indicators to help the group achieve its goals.

- The young people reported that the group meetings were well organised and generally worked well. In particular they liked: the room facilities and food; the icebreakers which helped to put members at ease; and the regular breaks which helped them to think about what they learned. They also felt facilitators listened to the feedback they gave and highlighted that it was important that visiting researchers reported back to the group on how PEAR's input has impacted on their work.
- Suggestions for improvement were: to encourage young people to move around more; reduce the length and "wordiness" of facilitator presentations; to increase opportunities for whole group discussion so that their opinions could be heard and they could interact with each other more; and to make more links to further sources of information.
- Communication between the group coordinators and members was said to be good and information received well in advance by letter and email. Young people said that more continuous communication between members outside of meetings, perhaps through a PEAR forum linked to the PEAR website, would be beneficial. They also felt that more frequent emails about the project and less wider NCB emails would encourage them to check their emails more.
- Young people suggested that it would be useful to increase note sharing between the London and Leeds groups so that they could think about the each others ideas. They would also like to give individual group members responsibility for tasks between meetings, for example writing up the meeting notes themselves.
- Through their involvement in PEAR, young people highlighted that they have: gained research skills (e.g. learned how to structure questionnaires and do literature reviews); learned how professional research is done; learned how to critique statistical information presented to them; become more aware of public health issues; met new people; and broadened their horizons. Young people are also keen to do their own research and to get their work 'out there'.