

Young People's Public Health Reference Group

Pilot Project - Final Report

January 2008

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NCB promotes the voices, interests and well-being of all children and young people across every aspect of their lives.

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About PHRC: The Public Health Research Consortium (PHRC) is funded by the [Department of Health Policy Research Programme](#). The PHRC brings together researchers from 11 UK institutions and aims to strengthen the evidence base for public health, with a strong emphasis on tackling socioeconomic inequalities in health. For more information, visit: www.york.ac.uk/phrc/index.htm

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Contents

| | |
|--|----|
| 1. Executive summary | 3 |
| 2. Introduction..... | 5 |
| 3. Aims and objectives of the young people's group | 6 |
| 4. Recruitment to the group | 6 |
| 5. Outline of meetings | 7 |
| 6. Methods used during the meetings | 9 |
| 7. Key messages from the young people | 9 |
| 8. Dissemination and publicity | 13 |
| 9. Evaluation – Section written by Jennifer Gibb..... | 13 |
| 10. The future | 24 |

1. Executive summary

Background

The Young People's Public Health Reference Group (YPPHRG) was established by the Public Health Research Consortium (PHRC) in November 2005, as a pilot project to contribute to its research work on public health issues relating to young people. The National Children's Bureau (NCB) is a main collaborator in the PHRC and facilitates the YPPHRG with support from the PHRC and INVOLVE (an organisation which promotes public involvement in NHS, public health and social care research). This report looks back over the progress of the group during the period November 2005 – December 2007, and makes recommendations for the future.

The overall aim of this project was to establish a model for a reference group through which young people could contribute to the UK's public health agenda. Specific objectives were:

- to provide an opportunity for young people to articulate their views and priorities for public health, including public health research and policy,
- to contribute to the work of the PHRC,
- to feed into the work of other agencies seeking to promote the interests of young people and the development of public health.

Group membership

At the start of the project 15 young people were recruited from across London and the South-East, and a core of around eight to ten have maintained engagement over the last two years.

Meetings

To date seven all-day meetings have been held, with one further meeting scheduled for February 2008. The content for each meeting was agreed in consultation with PHRC members, INVOLVE, and group members. A variety of methods have been used to maintain the young people's interest across the day, including ice-breaker games and focus group discussions, and stimuli such as statement cards and mind mapping were used to explore group member's views and develop ideas.

Meetings included discussion of topics that reflected the priorities of the PHRC (eg obesity and smoking), as well as exploration of group members' own priorities for public health research. These priorities will inform the PHRC's own priority-setting for a new 5 year programme of work starting in 2010. Several PHRC members worked with the group on specific activities related to their research - including designing a young people's summary of a research report on child health in England; contributing to a focus group on self-harm and giving their views on a project website. The group also received training on research methods and the research process, and worked with INVOLVE and the NCB group coordinator to consider how they, and other young people, could best be involved in public health research.

Dissemination and publicity

In addition to information about the group being placed on NCB and PHRC websites, information has also been disseminated through INVOLVE (including a paper at their 2006 conference), 11 Million and other networks. A summary produced by the group of an Association of Public Health Observatories (APHO) report was disseminated nationally, and publicised via NCB and APHO websites and press releases. A proposal for a poster version of the summary will be presented at the UK Public Health Association conference in April 2008.

Evaluation

In order to assess the effectiveness of the group's contribution to the work of PHRC, INVOLVE and the wider public health agenda, and to identify any lessons that can be learnt, an evaluation of the project was conducted by NCB's Research, Evaluation and Evidence Department in collaboration with the project coordinator. NCB, PHRC and INVOLVE informants involved with the project were interviewed, and two focus groups were run with young group members. All participants testified to the learning enabled through the pilot project. The evaluation found that while the group's activities have been limited by time and resource constraints, what was always an exploratory project has already demonstrated development in line with young people's aspirations. As well as more intangible gains, concrete outputs have been produced and tasks completed to the satisfaction of all concerned, and already some of the group's work has reached and generated interest among a wider audience. It is also encouraging to see that young members' aspirations for the future of the group were shared by its supporters in the PHRC and INVOLVE, and that there are opportunities for the group to make a growing contribution to the public health agenda.

The future

In July 2007 a proposal was submitted to the Wellcome Trust by NCB and the UCL Institute of Child Health, with support from the PHRC. In December we were told that a conditional award had been made, subject to amendments currently under negotiation. The proposed project will build on the work of the YPPHRG by setting up a number of young people's reference groups, development of a related website and other activity (including conferences, training and other young person-led activities/outputs) so that public health research can be communicated by, to and between children and young people.

As well as continuing to build on the links between NCB and the PHRC and INVOLVE, the project will encourage dialogue between children and young people and the wider public health research and policy community. The desired long-term outcome is that both the research and policy agendas in respect of public health and young people are better informed, more relevant and therefore more likely to be successfully applied because of the inclusion of young people's perspectives within the process.

2. Introduction

Following the interim report published in January 2007, this report provides an update on the Young People's Public Health Reference Group (YPPHRG) project. As the original funding for the project has now come to an end, the report also looks back over the progress of the group during the period November 2005 – December 2007, and makes recommendations for the future.

The report includes an overview of the recruitment to the group, details of the meetings held, dissemination and publicity for the group's activities and other activity and opportunities. There is also a section outlining findings from the evaluation of the group undertaken by Jennifer Gibb (NCB Evaluation Team).

Background

The project brings together three organisations, each with a strong commitment to involving users, including young people, within all stages of the research process:

- *Public Health Research Consortium*¹ (PHRC) brings together senior researchers from eleven UK institutions in an integrated programme of research. Its aim is to strengthen the evidence base for interventions to improve health, with a strong emphasis on tackling socio-economic inequalities in health. The consortium is funded by England's Department of Health Policy Research Programme for a 5 year period from October 2005. The PHRC is built around a series of research studies, together with associated projects and dissemination activities to facilitate the translation of evidence into policy and practice. The PHRC established the YPPHRG ('the group') to contribute to its research work on public health issues relating to young people.

- *INVOLVE*² is an organisation which promotes public involvement in NHS, public health and social care research (this includes children and young people). INVOLVE has supported the YPPHRG as it is relevant to its agenda, providing funding to pump-prime the group. Louca-Mai Brady, NCB Senior Research Officer and coordinator of the group, is also a member of INVOLVE.

- *The National Children's Bureau*³ (NCB) is a voluntary organisation which promotes the voices, interests and well being of all children and young people across all aspects of their lives. NCB believes that children should be involved in all matters that affect them, including research. NCB is a main collaborator in the PHRC and has facilitated and hosted the YPPHRG.

The YPPHRG project started in November 2005 with funding to run for one year. The interim evaluation at the end of this first year found that:

'there is great potential to develop a useful and potentially influential young people's reference group. A core group of enthusiastic young people has been created and there was evidence to suggest that the

¹ <http://www.york.ac.uk/phrc/index.htm>

² <http://www.invo.org.uk/>

³ <http://www.ncb.org.uk>

PHRC had begun to think strategically as to how this group could be put to work on useful assignments'.

The evaluation found that the group had grown in skills and confidence as the pilot developed, and were keen to expand and develop their work further and see direct, practical results of their input into projects. In October 2006 NCB secured a further year's funding for the group from the PHRC and INVOLVE. With this security of funding some of the issues raised by the interim evaluation started to be addressed. A programme of activities for 2006 – 2007 was developed in collaboration with the young people and other stakeholders. Members of the PHRC and INVOLVE attended meetings and identified specific tasks for the group (see '4. outline of meetings' below). These activities helped to create a more direct input into research activity for the group and also informed the development of a proposal to extend and expand the work of the group beyond this pilot project (see '9. the future' below).

3. Aims and objectives of the young people's group

The overall aim of this project was to establish a model for a reference group through which young people could contribute to the UK's public health agenda. Specific objectives were:

- to provide an opportunity for young people to articulate their views and priorities for public health, including public health research and policy,
- to contribute to the work of the Public Health Research Consortium (PHRC),
- to feed into the work of other agencies seeking to promote the interests of young people and the development of public health.

4. Recruitment to the group

The first objective of the project was to recruit a group of around 10 –12 young people aged between 12 and 18 years. 15 young people were recruited from across London and South-East England via Young NCB (NCB's free membership network for children and young people aged under 18) seven London schools and voluntary organisations with which the NCB research department has contacts. Given the short length of time available to recruit, using known contacts was considered the most effective way of engaging with young people.

The 15 young people recruited comprised five girls and ten boys. Five were aged 12, three aged 13 and the remainder aged 15. The group reflected the diversity of young people in London. Nine members are White British, two members are African, one member is Indian, one member is Bangladeshi, one member has dual heritage and one member is Irish.

Although not all young people attend each meeting, there has been a minimum of six young people attending each meeting and a core of around eight to ten have maintained engagement over the lifetime of the pilot project.

5. Outline of meetings

Meetings are all day events held during half terms or holidays. To date seven meetings have been held (three in 2006, four in 2007), with one further meeting scheduled for February 2008.

The content for each meeting was decided upon after consultation with PHRC members, INVOLVE, Professor Catherine Law (Institute of Child Health, University College London, who acts as a source of expertise on public health issues in respect of the young people's group and is the point of liaison between the group and PHRC), and reflects the wishes of the young people themselves.

First meeting (Feb 2006)

During the first meeting, time was devoted to explaining briefly the work of the PHRC and INVOLVE and how the group might feed into the work programmes of these organisations. Time was also allowed for young people to get to know each other, and the activities were geared towards young people gaining confidence and working together as a group. Two specific topic areas were discussed: smoking and choosing a healthy life. These areas were chosen as they reflect the priorities of the PHRC and were deemed to be issues on which young people would have views and opinions and thus be able to contribute to discussion. The young people were also asked at the meeting to answer a few questions to inform the ongoing evaluation.

Second meeting (August 2006)

The second meeting involved focused discussion on the causes and possible solutions to obesity in young people and the government's policy on weighing and measuring children in schools. The young people also mind-mapped their priorities for public health research.

Third meeting (October 2006)

The third meeting started to address the young people's request for training in research methods. Exercises were devised to illustrate the research process, discuss the advantages and disadvantages of different research methods and designing a research project on one of the public health priorities the group had identified previously. The group also devised an interview schedule to be used when meeting representatives from INVOLVE and the PHRC who were expected to attend the next meeting. Another group activity included submitting an abstract to INVOLVE for inclusion in an information pack to inform people considering becoming involved in health and social care research. The abstract for the "In my experience" section of the pack highlighted the young people's thoughts on being a member of the reference group and what they considered worked well. The meeting also included a session facilitated by the evaluation team seeking to gather the young people's views independently from the project co-ordinator.

Fourth meeting (February 2007)

In the fourth meeting Professor Brian Ferguson, a PHRC member from the Association of Public Health Observatories (APHO) came to discuss APHO's report on indicators of child health in England. The group discussed the report and started to design a summary for young people, based on the issues that they thought were most important. Catherine Law also attended the meeting to run a question and answer session on the PHRC and enable the group to contribute to the debate on weighing and measuring school children.

Fifth meeting (April 2007)

In the fifth meeting the group picked up on the work done in the second meeting on young people's priorities for public health research, to feed into the May 2007 meeting of the PHRC. In the final session of the day Steve Platt and Amy Chandler, PHRC members from the University of Edinburgh, led a discussion on self-harm. The group also continued work on their young people's version of the APHO child health report from last session.

Sixth meeting (August 2007)

In the sixth meeting Sarah Buckland (INVOLVE) facilitated a session with the group exploring their views on how and why children and young people should be involved in public health research. The group also discussed publishing an article in the INVOLVE newsletter in the future, or speaking at their 2008 conference. Maria Maynard, a PHRC member from the Medical Research Council Social and Public Health Sciences Unit in Glasgow, came to the meeting to talk about the DASH project (a large school based study of young people's health). The group were asked to test and give their opinion of the website, and make suggestions for improving its appeal and relevance to young people.

Seventh meeting (October 2007)

The seventh meeting followed on from earlier sessions addressing the young people's request for training in research methods. Louca-Mai Brady and Anthony Ellis from NCB's research department facilitated a session on planning research and developing proposals – looking at the different stages of the research process and how young people could be involved as advisors and/or young researchers. This information informed a bid which, although unfortunately unsuccessful, is likely to be resubmitted in another form in 2008. Catherine Law attended the meeting to give the group an update on the PHRC, and to discuss whether the group would be interested in contributing to a research project on inequalities in access to health in early years. The meeting also included a session facilitated by the evaluation team seeking to gather the young people's views independently from the project co-ordinator.

Eighth meeting (still to take place – February 2008)

At the last meeting of the group in its current form, Jane Cowl (National Institute for Clinical Excellence programme manager for patient and public involvement), will come and talk to the group about their work, and how young people could be involved. The group will also feed into Catherine Law and Anna Pearce's (ICH) research on health inequalities as part of the PHRC programme, and review the public health research priorities they set in 2007 (see '6. key messages' below). Following a successful submission to the UK Public Health

Association 2008 conference, the group will also start work on preparing a poster of the APHO child health report for the conference.

6. Methods used during the meetings

At the outset of every meeting ground rules are re-iterated so that boundaries are set. The young people established these rules, which include listening to each other, respecting each other's opinions, no racism or sexism and only speaking when they felt comfortable.

A variety of methods have been used to maintain the young people's interest across the day, including ice-breaker games and energizers. Other methods used include traditional focus group discussions, work in smaller groups, laptops with internet connections (for website testing), powerpoint presentations and question and answer sessions. Stimuli such as statement cards, diamond ranking, timelines, mind mapping and body maps have been used to explore group member's views and develop ideas.

7. Key messages from the young people

The following section presents some of the main themes to emerge from the young people's discussions.

In the first three sessions, probably not surprisingly, regardless of the issues discussed (smoking, obesity and weighing and measuring in schools) the importance of choice, peer pressure, body image and the need for a variety of accessible, low-cost sports and support services were consistent emergent themes. Further information on the outcome of these discussions is included in the January 2007 interim report.

Priority issues identified by the young people

The PHRC was interested in the young people's priorities for public health research. The group first worked on this in October 2006, generating a 'long list' of ideas and issues. The subject was revisited at their April 2007 meeting, with the aim of producing a prioritised list (see table overleaf).

The group revisited their original list of 15 items and decided whether to change, add to or reject any of the items listed. The new set of items were then put into a rough order of priority, set out in the table below (with 'corporate responsibility' as a top priority and 'stress and tiredness' as the lowest of the priorities listed). There was a lot of discussion about the links between many of the items on the list, and – in particular- the influences on young people's behaviour. Also included in the table are some of the specific ideas and issues discussed during this exercise. These issues will be reviewed in the February 2008 meeting in order to inform the PHRC's priority-setting for a new 5 year programme of work starting in 2010.

| | |
|---|--|
| Highest priorities: | |
| Corporate responsibility (Influencing factor) How influential are businesses (including media, advertising) and in what ways? Can be part of the problem or part of the solution (preventative) | |
| Smoking Important because affects children from young age | Alcohol Important because affects children from young age. Ignorance of how dangerous it is Can impact on other issues eg sexual health |
| Education (influencing factor) What age is appropriate for education in issues such as sex and drugs? What kinds of health-related education/activity should go on in schools, and what should happen elsewhere? | Bullying and racism Important to prevent this because it can lead to other problems for victim (eg depression, self-harm, drugs, alcohol, suicide) |
| Obesity and Anorexia Both linked to food/eating habits and behaviour Obesity chronic and growing problem – in the news all the time | Sexual health and teenage pregnancy England is bad compared to other countries |
| High - medium priorities: | |
| Drugs Important, but felt to be more of a priority issue for older teenagers | Self-harm Immediate dangers for young people Links to depression |
| Home environment (influencing factor) Parents are important influences on young people, particularly in terms of their own behaviour (role models) | Work / school environment (influencing factor) Peer pressure (can be positive or negative) |
| Road safety Not always the young person's fault Accidents/deaths impact widely (friends, family, school community etc) | Depression Important as it can lead to many of the other factors/issues in this list |
| Exercise Links to obesity (preventative) | Food Links to obesity/anorexia, corporate responsibility |
| Stress and tiredness While this was agreed to be lowest priority it is still important! | |

Weighing and measuring school children

The main points from the group's discussion on this topic were that they saw positives and negatives in the proposed policy, but worried about confidentiality and support and felt it should be a choice rather than compulsory. They also worried about the potential impact on self-esteem, and felt that it was important for weighing and measuring to be seen as a health issue, not about appearance, and that any programme should be part of a general health interview with school nurse or doctor and linked to support for parents and children.

Involving children and young people in research

During a session with INVOLVE in August 2007 the group discussed how and why they thought children and young people should be involved in public health research.

Involvement in research – what's in it for young people?

- Our views are important!
- Developed interest in research through being research participants/ doing market research – wanted to know more
- A way of getting views across and challenging adult researchers ideas about young people
- Topic (public health) was interesting – in the news a lot and a big issue
- Wanting a chance to make a difference
- Being asked *about* research, as well as being participants and answering someone else's questions
- Gaining an understanding of the research process
- A chance to develop skills (eg getting training) and useful experience
- Important to have something to show for our involvement (eg a report) & to be involved in dissemination (eg at conferences, presenting findings)
- Also important to have a legacy, to feel that what we've been involved in has made a difference

What's in it for researchers?

- More balanced and better quality research
- Better representation of what young people really think
- Reading facts (ie thinking you know what young people think from articles & the media) and talking to people are different!
- Involving young people in developing the research questions and analysing the responses can help to make sure you are asking the right questions and getting the right answers
- Chance for researchers, as well as young people, to learn new skills

Why might researchers not want to involve young people?

- Extra work/ cost/ time
- They don't actually like us!
- They might already think they know what we think ('I'm the expert')
- Losing control

Good ways of involving young people

- Bringing groups together from different backgrounds
- Using good tools and techniques to engage young people
- Having the chance to discuss things in groups, not just be interviewed
- Advisory groups can be mixed (researchers and young people) or separate (group of young people with a rep on researcher advisory group). Types of groups depend on the project, and whether the research is only about children and young people, but on the whole we prefer mixed groups – it can be hard for one or two young people to represent the views of a whole group, and sometimes researchers and other people in advisory groups don't explain things clearly enough. It would be best if

young people, and adults, on advisory groups had training and support. It's also good to have some informal time with adults on equal terms (eg over lunch) before a meeting, so that everyone gets to know each other in a relaxed setting.

How not to involve young people

- Being tokenistic – only doing it because it looks good
- Not making information easy to understand and accessible
- Exploiting – getting young people to do researchers' work for them and not giving young people credit.

A further session on planning research and developing proposals in October 2007 looked at the different stages of the research process and how young people could be involved as advisors and/or young researchers.

The group said that they thought young people could be involved in a number of ways at different stages of a research project, including:

- Management – representation on steering/advisory group;
- Design – young people working alongside researchers as co-researchers or young advisors. Designing tools (eg questionnaires);
- Recruitment - eg recruiting harder to reach groups through contacts or coming up with creative ways of engaging harder to reach young people. Talking to young people about the research (eg in schools or youth groups);
- Data Collection – Young people may be more willing to talk to another young person rather than an adult, so young researchers could undertake interviews or facilitate focus groups (with an adult to give support/direction if needed);
- Analysis – Work experience (data entry). Young researchers/ advisors informing the analysis (exploring themes and ideas);
- Writing Up – Feed into main report, write a young-people-friendly summary;
- Dissemination – At the dissemination stage the group thought that it was important for young people to be involved in organising a conference and presenting the research findings. Involving young people will also give the research more impact. Could also get involved with writing articles or media work.

Considerations

Being realistic & flexible about time and people's availability. Young people will have other commitments (eg exams, school work), or may leave the project at some stage for planned or unplanned reasons, so researchers need to plan for this. Perhaps have a team of young people who are involved in different ways at different times?

8. Dissemination and publicity

Avenues for publicising the work of the group and for future dissemination continue to be explored. A project sheet explaining the Young People's Reference Group was placed on the NCB website and information included on the PHRC intranet and website. Presentations of progress were made to the PHRC project management meetings in April 2006, May 2007 and November 2007. Information was also sent to 11 Million (formerly the Office of the Children's Commissioner of England).

A paper entitled "Young People's Reference Group on Public Health: Methods and Achievements" was presented at the 5th National INVOLVE "People in Research" conference (6th and 7th Sept 2006). Some of the young people expressed interest in presenting at the conference, however, the date of the conference prevented this as it was the first week of term after the summer break and thus difficult for the young people. It is hoped that a further presentation will be made at the 2008 conference. Following the 2006 conference, links were made with the participation worker of the RCPCH (Royal College of Paediatrics and Child Health) and the involvement officer at the MCRN (Medicines for Children Research Network) both of which bodies are also setting up young people's reference groups.

The summary of the APHO health indicators report that the group produced has been widely disseminated. Copies were sent by APHO to schools and other bodies with an interest across the country, and the summary – and group – were also publicised via NCB and APHO websites and press releases in July 2007. An electronic version of the summary and information was also sent to all NCB members (a multi-agency network of child education, health and social care, youth, early years and other children's services professionals). The UK Public Health Association (UKPHA) has a conference in April 2008 and the group said that they would like to produce a poster based on the APHO summary, so an abstract was successfully submitted and the group will start working on a poster at the next meeting.

9. Evaluation – Section written by Jennifer Gibb

Introduction

This section of the report updates earlier interim findings from the evaluation of the Young People's Reference Group. As before, the evaluation has been conducted by NCB's Research, Evaluation and Evidence Department in collaboration with the project co-ordinator.

The aims of the evaluation remain as originally set out:

- To assess the effectiveness of the Young People's Group in terms of its contribution to the work of PHRC and INVOLVE, and to the wider public health agenda;
- To identify any lessons that can be learned about the way in which the Young People's Group has been set up and coordinated.

Previously reported findings drew upon data from telephone interviews with PHRC and INVOLVE informants (n=3, conducted in May 2006) and on focus group discussion with members of the Young People's Group (n=9, conducted in October 2006). Following a second round of data collection, findings at this stage draw upon additional material gathered using the following methods:

- Semi-structured telephone interviews with 8 key informants from the PHRC, NCB and INVOLVE in October/ November 2007. (Of these, two were project sponsors who had been involved with the project from the start; three were PHRC members who came to work with the group on specific activities relating to their research; and the remaining three were NCB staff who acted as group coordinators during the project.)
- "Follow-up" focus group discussion with six members of the Young People's Group held in October 2007;
- Review of feedback forms completed by young people at the close of meetings throughout the year.

The remainder of this chapter contains the following subsections: a recap of the key issues in October 2006; an update on the views of the young people; the views of stakeholders as expressed in October 2007, and finally a brief conclusion highlighting progress, learning and challenges ahead.

Key issues in October 2006

Issues around young people's involvement

The majority of the young people recruited had become aware of the group at school, whether approached individually by staff or coming across NCB leaflets. Many were (voluntary) participants in other arenas, including school councils, the Diana Memorial Fund, Young NCB and the Anti-Bullying Alliance. For several, experience elsewhere had convinced them that their input could be influential. For the most part, members presented themselves as open to new opportunities and enjoying "this type of thing". For some that meant simply "having a say" or being involved in youth-led activities. For others, a prior interest in health, medicine or research was a motivating factor.

The young people were aware of themselves as a relatively homogenous group and suggested that this was partly due to the way they had been recruited to the project – i.e. via NCB contacts. The young people believed that the project would benefit from attracting participants from a wider range of backgrounds. However, they acknowledged that, as a voluntary activity, the group would inevitably attract a biased membership to some degree.

Perceived aims of the Young People's Group

At the outset, for all three of the adult informants interviewed in May 2006, the Young People's Group was viewed as a pilot project. The intention as they saw it was to learn how to include young people in the work of the consortium and about the contribution such a group could make to the public health agenda more widely. They believed that involvement would have value for the

individuals involved and, if successful, promote participation per se. Both PHRC and INVOLVE informants expressed the purposes of the initiative in aspirational terms; bringing “to life” public health research for children and young people or providing a “reality check” to ivory tower thinking. All felt that the Consortium was open to the young people's ideas for the development of the group itself.

Young people's initial hopes for the group

The young people who had elected to join the group viewed participation as an exploratory project. In general terms, they had anticipated having the chance to express views (on public health), learn new things, try new activities, meet new people and “make a difference”. However, by the end of their second meeting, members had formulated some specific aspirations:

- To develop their own understanding of the research process and findings regarding public health, and of related government action
- To express and discuss their views on public health and research with other young people, with feedback from the project co-ordinator
- To inform PHRC / INVOLVE / Government thinking and policy through the exploration of young people's views on public health issues
- To influence research through dissemination of those views, perhaps at conferences or similar events at which young people were afforded a prominent place alongside researchers and policy-makers
- To gain a more in-depth understanding of research methods.

A research function for the Group

The young people were clearly enthusiastic about getting involved in PHRC research projects. However, they themselves described the membership as London-centric and predominantly white middle class. For the PHRC, this feature of the group was recognised as limiting its capacity to serve some purposes, including piloting of tools for use with other groups. As one interviewee put it, the young people might best be considered consultants advising on their experience.

Adult interviewees stressed that, while the PHRC projects form only a small part of most members' work, they would be able to take account of any learning from the reference group in other spheres of activity, and feed that learning into broader networks. It was felt however that there was a real risk that the young people would not see any direct, practical results of their deliberations. This is discussed further below.

Relationship of the Young People's Group to the PHRC

The adult interviewees felt that the group should be provided with PHRC-related topics to stimulate discussion, but that the emphasis should be on the young people's priorities. It had also been agreed that the project co-ordinator and young people would present at INVOLVE's annual conference (September 2006), providing an opportunity to share any early learning.

At the time of these initial interviews, the ‘mechanics’ of the group's relationship to the PHRC and INVOLVE were in development. One member of the PHRC

was considered key in enabling communication between the group and the Consortium via liaison with NCB staff. Certainly, there was a general perception among those interviewed that NCB would play a pivotal role, both as a conduit for information and as a source of expertise in the involvement of young people. However, more direct lines of communication had not been ruled out; the young people, for instance, had expressed interest in attending a PHRC meeting.

At the focus group in 2006, the young people said that they had appreciated verbal and written feedback from the NCB project co-ordinator and did believe that their views were fed back to and valued by the PHRC. Among group members, there were varied expectations in terms of what influence the group might have. There was some anxiety expressed that their work would be “filed and forgotten” and they expressed a desire to know what would be done with their work, both from individual meetings, and over the course of the project.

The young people evidently had a fair idea of what the PHRC was, in terms of its composition, and understood that initial funding for their group had come from INVOLVE. However, both of these organisations remained a little “faceless” for them. At the time of the focus group, the members were eagerly anticipating visits from PHRC and INVOLVE staff scheduled for subsequent meetings, believing these face-to-face discussions would provide opportunities to clarify plans and options for the future, with a two-way exchange of views. In addition, they were also expecting to receive further information on the developing research programme. As well as raising the possibility of sending representatives to Consortium meetings, the young people hoped to observe PHRC members at work in other contexts.

Feedback on progress by October 2006

Notably, none of the three adult interviewees expected the young people's reference group to have achieved anything of great note by the six-month (interim) stage of the evaluation, other than perhaps increasing their own understanding of public health research. However, they believed that during this period they would begin to firm up the direction of the group's future development, in light of a review of any exploratory activities.

The young people enjoyed simply discussing and generating ideas, particularly where there were conflicts of opinion. This was the case even though they felt discussion of some (but not all) subjects had been limited within the group because of their perceived lack of diversity in terms of social class, ethnicity and life experience.

“I think the best activities are done when we talk about things that aren't clear cut. As in, if you're talking about smoking, we'll all say “yeah – smoking's bad, children smoke because of stress –etc etc – it's all very similar”. But when we did the activity, last time, about “should children be weighed at school?” and that's more of an opinion, and it provoked argument among us because we all had different opinions.”

As well as enjoying the sessions, the young people had appreciated the research training they had had so far, finding it interesting in itself, and also as a means of stimulating ideas for possible research topics.

Regardless of the direction of the group's development, in terms of their enjoyment and commitment, there was a general consensus about the importance of their influence over the agenda for meetings, choosing, for example, to focus on sexual health as opposed to smoking.

“At the last meeting... we were asked what we thought were also the important topics and sexual health came up as one of the most popular topics that we felt we needed to know more about, or give our opinions on – and that was a way for us to take control of what we'd like to say.”

Developing a shared sense of purpose

At the interim stage of the evaluation a core group of enthusiastic young people had been created and there was evidence to suggest that the PHRC had begun to think strategically as to how this group could be put to work.

However, it appeared that a clearer sense of purpose could be beneficial.

Clarity over aims and objectives

In October 2006, there was a lack of clarity over the short- and medium-term aims of the group and the scope for its involvement in Consortium work. Several factors seemed to have been important. The multi-stage nature of the PHRC programme meant that there was not full information available about the nature of forthcoming projects. The fact that the Consortium was very much a virtual group; with projects taking place in individual, geographically separate, university sites, meant that Consortium members did not necessarily know a great deal about the methodology of other researchers' projects, their relevance to young people or the scope for reference group involvement.

Representation and membership

In considering the future of the group, the young people suggested additional ways in which its representation could be improved, such as strengthening links with other schools, and approaching young people who were less used to putting themselves forward for this type of activity, and who perhaps had more personal experience of some of the relevant issues.

None of the members thought having a larger group was a good idea. However, there was strong support for setting up more groups in different areas; accessible to those outside London, and without the deterrent provided by travelling long distances.

Responsibility and stakeholder commitment

Initially, there was some uncertainty regarding responsibility for development of the group, the mechanics of its relationships with the PHRC, and funding to sustain its activities. To some extent, the exploratory nature of the project appeared to have prevented longer-term planning.

Looking to the future, interviewees in 2006 recognised the PHRC as only one of many potential stakeholders with an interest in the young people's group. In particular, there was a belief that closer links to the Department of Health could be beneficial.

Young people's indicators of success in October 2006

Asked to imagine *they* were evaluating the project, the young people reiterated some of their key concerns as indicators of achievement:

1. *Feedback.* If the group is “just talking” and hearing nothing back, that would be disillusioning and threaten their interest. Recognition from the PHRC of their views (that they listen and value them) would, they felt, be crucial.
2. *Direct input into research activities.* The group very much wanted to “make a difference” by helping to develop research projects – their own and other people's. Clarification from the PHRC about any such possibilities would be welcomed.
3. *Attendance, membership and structured growth.* The young people ideally would like to see an increase in the number of groups and numbers attending.

Update on young people's views: October 2007

Since the first round of evaluation activity, members of the group had been involved in a variety of activities, described elsewhere by the group coordinator. In October 2007, six young people took part in a “follow-up” focus group discussion. By their own account – confirmed by the coordinator – they were regular attenders; while their experience might differ from other members', they were well placed to reflect on the activity of the group over the past year. Key points made by the young people are outlined in this section.

Activities to date

Reflecting back on their early experience, group members generally felt that while the initiative had got off to a slow start, it did now have more direction; notwithstanding uncertainties around funding it was increasingly involving concrete projects with evident benefits.

“I think this time last year we didn't have much of an idea where these meetings were taking us, but now we have got more of an idea.”

The young people spoke enthusiastically of enjoying discussing issues amongst themselves. While still conscious of what they had in common, they were aware of differences; highlighting that they came from different areas of London and had different groups of friends. This meant that they felt they brought quite different experiences and opinions to the group. Discussions, they said, had on occasion challenged their own views. Within the setting of the group they felt comfortable delving into the reasoning behind each others' positions, which was not necessarily the case in other “real life” contexts, where an opposing stance might simply be dismissed. In this sense, the group had stimulated creative thinking, within and outside the group.

“We debated whether children should be weighed in school and I think that provoked one of the most thoughtful discussions we've had.”

Several members described being pleasantly surprised by the range of opportunities arising through the group and the number of researchers who had taken an interest. They had expected activity to focus on Consortium projects - links with members' academic departments were a definite bonus.

"I think our expectations have broadened a bit – I mean, the ones we had in October last year were quite broad, but we didn't really appreciate that it would involve the range of organisations that we're dealing with, and the number of people who are interested in us. Today threw up quite a lot of interesting opportunities as well."

As stressed elsewhere, adult stakeholders had predicted that the *impact* of the group on PHRC members would not be measurable purely in terms of PHRC-funded activity. Nevertheless, the involvement of the group in these "external" activities had evolved rather than been planned at the start. One activity of this type mentioned by the young people entailed focus group discussion on self-harm led by a PhD student whose supervisor, a Consortium member, had recognised the relevance of the topic.

Some of the group's contact with PHRC staff had been less "active", yet given them a more in-depth understanding of the work of the consortium. A couple of the young people stressed that simply thinking about public health – "health beyond the NHS" was interesting - and something pupils were rarely encouraged to do.

A few examples of their work highlighted by the young people are described below.

- *Website and survey review (Dr Maria Maynard – Glasgow)*. The group had tried out and commented on a website designed to give feedback to young research participants, and the content of a survey planned for schools. According to Dr Maynard, the young people made many helpful comments about the site; relating to the number of clicks, links and navigation; colour-scheme and fonts, as well as providing reassurance that the content itself was not patronising. Although it was not possible to implement all of the suggested changes there and then, the young people were given a provisional timeline. They looked forward to receiving progress updates via the NCB coordinator.
- *Focus Group discussion on self-harm (Dr Steve Platt – Edinburgh)*. As mentioned above, the young people had shared their views and understandings of self-harm among young people with Steve Platt and his PhD student. They had valued the feedback they had had; essentially that their views had been very helpful for the researcher in helping formulate her ideas at an early stage of her work.

"In his email afterwards he said that he found it really useful, and that there were certain aspects of it which he and his PhD student could go on with and different ideas to explore that they wouldn't have had if we hadn't thought them up. So seeing that our input is useful – I think it's important for us."

- *Young people's summary of research report (Professor Brian Ferguson – Yorkshire and Humber Public Health Observatory)* The group had produced a summary of the Association of Public Health Observatories' (APHO) Child Health Indicators Report which presented key information in a format suitable for young people.

"We weren't really responsible for the actual design although we did come up with ideas – it was more about what should go in; how it should be presented and in what language – picking out the right bits....I think it was sent around secondary schools as well."

- *Working with INVOLVE.* The group had discussed ways of involving young people in research. They also produced a concise statement summarising the role and activities of their own group for an INVOLVE public information pack (Getting Involved in Research).

The young people also mentioned opportunities that, unfortunately, they had been unable to take up. These had included presenting at an INVOLVE conference. As the event fell immediately *after* the start of a new school term, none had felt able to attend – nevertheless, they appreciated that the NCB coordinator had taken part, and had spoken about their work to a large audience. Other "optional extras", such as roles in the 11 Million Takeover Day at NCB continued to be highlighted to them. Those taking part in the focus group said that they were keen to become involved in additional activities, where feasible. Hypothetically speaking, if an opportunity was offered which they were not drawn to, they believed they would be able to express reservations to the NCB group co-ordinator.

Success indicators – looking back and looking forward

Turning to their success criteria as listed the previous year, group members were positive about progress. Below, their points are summarised under the *original* headings, followed by their suggestions for measuring gains in future.

Feedback from the PHRC / INVOLVE.

The group were confident that their work had been useful to PHRC members, and in some cases a wider audience. They knew that their summary of the (APHO) Child Health Indicators Report had been distributed to schools – and publicised via a vast mailing list. They had had positive feedback from other researchers and students involved with the group via emails forwarded by the NCB coordinator. Invariably, researchers described how they had enjoyed the sessions and made use of the material and ideas generated. This reassurance about the value of their work was important to the young people.

"The reasons why we joined this group, I think... it's not purely personal reasons. But recognition is important. I think we like to see – more for the group than ourselves – that if we are useful, then we're recognised for that."

“For me, it’s important to know that something concrete’s being done with it, and that people are benefiting.”

Direct input into research activities

The young people were pleased that routinely, one or more researchers would attend their meetings. This had not always entailed their involvement in projects; some sessions had been “information only”. These were not dismissed, however; members felt they had benefited from contact with the range of individuals from the PHRC and INVOLVE. Some researchers had sought their views on research tools, processes and potential priorities for young people. During one session they had been asked to set out their priorities for public health research; their views had been fed directly to the PHRC and discussed. They understood that this was to happen again, at a time when key PHRC members were beginning to focus on potential areas for future research.

Group attendance, membership & growth.

The young people remained convinced that including members from different backgrounds and regions would benefit the initiative. They had developed their ideas for involving a wider range of young people, but, as before, were in favour of there being additional, parallel, groups elsewhere in the country.

New success indicators for October 2008

By October 2007, the group had revised their ambitions for the year to come, stressing additional or revised milestones as listed below:

Developing involvement in research

Group members aspired to involvement in research at a level further up the ladder of participation. This could mean involvement at the design stage of a project and in writing more than simply summaries of existing findings. They were keen to share ideas and shape researchers’ thinking at an earlier stage, as well as approving, summarising and communicating already well-developed ideas or findings. In short, they would welcome being involved earlier - and for longer - in research led by PHRC members or colleagues.

“Being more involved in research. Because we’ve been talking a lot about how children and young people should get more say.”

“More direct input into projects. Not just the participation stage at the start – a bit further up the ladder! Being part of the design. Being involved from the start to the end, including some of the translation and promotion so it’s suitable for our age range, but not just limited to that.”

The young people remained keen to undertake research themselves, with input and support from professionals, while recognising that personal commitments could make this very challenging. Whatever the nature of their involvement, they were keen to see it have an impact.

“Something that shows we’ve done something... and taken our ideas further - not just giving ideas to other people... Maybe managing a project – one of our own or one given to us.”

An online presence (website) for the group.

This suggestion was put forward not simply to reach more young people, but also to publicise their achievements and “advertise” their services to other researchers who might be interested in working with the group.

“A few more groups... But they wouldn’t all have to be physical groups – there could be a virtual group, through the website.”

“If we were to have our own website, if we were to get funding for that it would be an indicator of success - that we were established as a group. Because we don’t really have a presence as such, and if we did then maybe more people would be interested in coming to talk to us.”

Communication, administration and agendas

Communication

All of the group members described communication as good; the only “blip” they recalled was during a strike by Royal Mail. In any case, they had all received the relevant material via email in advance. Email also allowed updates in between meetings, should additional opportunities arise – and had also allowed their receiving feedback from PHRC researchers.

Setting the agenda

The young people stressed that although they had not greatly shaped the agendas in advance, they did believe the door was always open - if they felt strongly about something or had an idea. They had recently suggested some issues as of interest; mental health, health economics and ethics. Nevertheless, the agendas they felt had been pretty full – with good topics and activities.

As noted above, members were regularly offered opportunities to be involved in activities; to date, they had said “yes” to many during meetings, and also to some outwith them where this fitted personal schedules. Potential dates could be unsuitable because they fell within school term, particularly at important exam periods. February and October half-terms were more convenient - however, they recognised that where other organisations were involved, accommodating their preferences might not be feasible.

Feedback forms and participation in evaluation

Members are encouraged to take part in monitoring the initiative, not only through the focus groups held each year, but through completing simple feedback forms after each meeting. As is evident from their written comments, they have appreciated this involvement in the evaluation and in wider

discussions about the future direction of the group. As one member wrote, in October, the best thing about the meeting was:

“The evaluation of the group – giving us a chance to talk about what we want for the future.”

Often, feedback forms recorded comments such as “*Guest speakers were good!*” and indicated how much the young people had enjoyed dialogue with visitors or “professionals” from the various stakeholder organisations. As before, they registered their enjoyment of debate per se, with a “best thing” for one member being “*Discussing the differences between self-harm and self-injury*”. However, several suggested that they had preferred activities in which they were accorded an active rather than passive part. Indeed, much of the time, highlights of the meetings for members seemed to reflect their having *some* role, not necessarily a huge one, but one which involved a contribution to valuable pieces of research, and learning in the process.

The comments below give a flavour of what members’ have valued about their involvement.

“Being given the opportunity to become involved in real research projects which will hopefully bring about real change in public health policy.”

“Developing and improving the research methods into young people’s drinking habits and discussing ways in which young people would be more willing to participate in focus groups.”

“Feeding in about the [DASH] website, knowing it’ll make a difference.”

“Getting an insight into the direction our work goes and stages in the research projects (and the opportunity to work at different levels in them).”

The feedback forms encourage members to outline “What could have been better, and why” in relation to each session. Some replies, replete with exclamation marks and smiley faces, referred to accommodation or food. Frequently, the young people suggested that “nothing” could have been better, but this comment typifies one recurring theme:

“If there were more people who had attended then we could have gained more opinions and further insight into the topic.”

Other wishes communicated in this way reinforced those expressed within the focus group setting; enthusiasm for more research training and the chance to use it; and opportunities to present their work to a wider audience through events, a website or other media.

Comments made by two young people during the October discussion sum up well how the group felt about their experience:

“I just think the main thing is that we’re making an impact. And that we’re all interested in what we’re doing.”

“It’s having the chance to give our own opinions, rather than being told what we think or what we ought to do. We can say what we think ought to be happening, or what might help to change the situation.”

Finally, exemplifying their belief in the vitality of their work and young people’s participation per se, one member of the group insisted, to nods from others:

“I think it’s important to get young people involved at an early stage. I mean, if you want to make a difference – if you want to make a lasting difference - then it’s important that they do that. You can’t just say ‘this is something designed for young people and we’ll just force it down your throats’. To kind make them more receptive towards it, and accept it, you need to give them a chance to form it in the first place.”

Points raised by PHRC/ INVOLVE/ NCB stakeholders

For the most part, those interviewed in October 2007 outlined the aims of the group in similar ways as did the original three interviewees a year earlier. All were keen that the group continue, and were confident that the young people involved benefited in numerous ways, gaining skills, confidence, contacts and knowledge – as one pointed out, in line with the “empowerment” philosophy at the heart of the public health agenda. Stakeholders were also able to reflect on what *they* had learned from their work with the group, and on questions raised in the process.

Administration and organisation

Among adults interviewed for the evaluation, those involved with the group as researchers all stated that their contact with the young people had been facilitated smoothly by NCB staff.

A number of those who had observed meetings volunteered that what seemed quite a formal or structured approach had worked well. However, NCB staff themselves claimed that funding uncertainty and staff changes had had some negative impact on the group’s activities. Certainly, the group had had to deal with three different coordinators owing to the original coordinator leaving and the Acting Director of Research stepping in until a replacement was recruited. While the NCB staff had shared learning, each one had had to build relationships with the young people as well as PHRC and INVOLVE staff. This was not necessarily a bad thing – and the young people seemed to have enjoyed working with all those taking on the role. However, during a short period in between meetings where there had been no member of staff able to devote time to planning this had – according to regretful NCB staff - resulted in one “missed opportunity” in that a good discussion on weighing of children in schools might otherwise have been written up in a letter to the BMJ. However, the discussion alone had been valued by the young people.

Representativeness

As one PHRC researcher stressed, challenges around representativeness arise for groups engaging *adult* members of the public or service users. Even where groups are mixed in terms of gender or ethnicity, they may consist of “professional” lay people. All of those interviewed, while keen that efforts be

made to engage a wider range of young people in terms of age and region, acknowledged that participants were likely to be articulate and able – and to become more so through that involvement. Several pointed out that *no* such group could be fully representative of all children and young people.

As a couple of “visiting” researchers noted, attendance had not been high, with only six or seven young people at some meetings. However, those who had been involved with the group for longer held that there were 8-10 core, active members. Given the enthusiasm of those who *did* come regularly and *their* preference for larger group discussions, stakeholders were keen to refresh and extend membership.

Links or parallels with other initiatives

Several of those interviewed across all three organisations knew of other relevant initiatives involving children and young people. Four were identified:

- A young people's reference group established by the MCRN (Medicines for Children Research Network);
- A young people's panel set up by the Royal College of Paediatrics and Child Health;
- The Young People's Health Advisory Group set up by NHS Education for Scotland;
- The National Youth Agency's Young Researcher Network (NCB is a member and the group coordinator sits on the steering group)

Most of those *aware* of the groups knew little about them, other than that they were at an early stage of development. A few PHRC members, however, suggested that NCB use existing links with the MCRN (the group coordinator advises MCRN on the running of this group and other activity around the participation of children and young people) to explore and disseminate potential learning across the groups.

Experience with the group

From the point of view of the various stakeholders, methods of engagement had been tested and tangible outputs produced. That it had proved possible to set up the group and sustain interest was itself seen as an achievement. Some argued that it would always be the case that the group's influence is wider than is demonstrable – but that this is true of many valuable initiatives in the public health field.

A few interviewees admitted to a degree of scepticism, initially, about what the initiative could achieve, but claimed to have found their own contact with the group revelatory and anticipated that the same would hold for other researchers. Without exception, those who worked with the group found them engaging, hard-working and stimulating. The group had reportedly provided an interesting forum for testing out Consortium ideas at an early stage and discussing communication of public health messages.

Looking to the future, researchers generally considered that the obvious ability and enthusiasm of the group for learning about research methods argued for opening up opportunities in that direction, where possible.

Limitations, concerns and issues raised by October 2007

Among those interviewed, several were keen to point out limitations on what the reference group could achieve – some factors being internal and others external to the group. One simple constraint should not be forgotten – namely that the group meets on a relatively infrequent basis. While there may be opportunities for activity outwith these sessions, the young people lead busy lives and cannot be expected to commit more of their time.

Some indicated that they were unclear about the relationship of the young people's work to the Consortium. One researcher who had worked with the group once (and been complimentary concerning their input) nevertheless suggested that, given the size of the group, its recruitment, and the artificiality of the situation, the salience of what the young people said to Consortium thinking or decisions could be questioned, alongside the generalisability of the ideas they developed. Similarly, several stakeholders were keen to stress that for many purposes, the group's views would need to be tested out with samples recruited through other channels.

It seemed that, for some interviewees, there was a need to clarify further what the Consortium's response to the group's stated priorities could and should be. For example, one PHRC member wondered whether the young people's agreement with existing PHRC priorities strengthened the validity of those priorities – and if so, for whom? Conversely, where there was a clash, what was the appropriate response? The clear impression given by the young people during focus group discussions was that they valued feedback; conceivably, as long as the group's conclusions are discussed by the PHRC and responded to in a considered way, this in itself may prove satisfying for the group and stimulating for the Consortium.

To many of those interviewed, the group appeared to run more in parallel to the Consortium, rather than as an integral part of the (virtual) whole. Some suggested that with another round of research studies yet to be finalised the young people's (new) priorities could be taken into account and/or their involvement planned in at an earlier stage. However, potential tensions were acknowledged between researchers' desire for help – for example, focus group discussion – at particular stages of a project, and the group's interest in being involved in more depth at all or several stages. Moreover, all those interviewed recognised that the number of PHRC projects for which the group's input was feasible would remain limited by the nature of those projects. While their involvement in "non-PHRC" projects was universally welcomed, some interviewees cautioned that the kudos (not to mention rationale) for the group had originally stemmed from its links with the Consortium, and that it was important to demonstrate meaningful links with and integration into its work – and/or that of other research bodies.

Finally, a number of interviewees pointed out that the broader impact of the group - beyond involvement with individual researchers or projects - was unclear at this stage. Perhaps understandably, it was difficult to identify gains for children and young people in the wider population from what was conceived as a pilot project and still very much in development.

Hopes, ideas and suggestions for the future

At their October meeting, the group had discussed a number of forthcoming opportunities including a piece of work on food branding. They had also talked about hopes for further financial backing for the group, up to 2010 – indeed many ideas supported by PHRC members were contingent upon continued funds. At the time of the interviews, it was felt that a successful outcome for the bid to the Wellcome Trust submitted in Summer 2007, would allow the group to develop its membership and the parameters of its activity along the lines envisaged both by PHRC members and the young people themselves. Key suggestions supported by stakeholders across the three organisations are listed below.

- *Increase, refresh and widen membership*

Representativeness will remain an issue, as discussed above, regarding any such voluntary activity. However, the age range has been skewed (to older participants) and there are more young men than young women; it should be possible to address these issues and target young people through more diverse routes.

- *Establish a “sister” group in the North*

Based closely on the London model, this would be a feasible step to addressing “London-centric” bias.

- *Diversify means of communication with the Consortium*

Updating Consortium PIs (and perhaps other PHRC researchers) on the group's activities in an accessible way could further integrate the group; perhaps through an email after each meeting, summarising discussion. (There appeared to be limited awareness – although definite curiosity - among PHRC members who had engaged with the group about the experience and aims of other colleagues attempting the same. This suggests that within as well as outwith the Consortium, feedback about the group's activities could be better disseminated).

- *Seek opportunities for press exposure*

The INVOLVE newsletter, for example, could provide one means of the group reaching a wider audience.

- *Develop a website*

This was supported by stakeholders as a means to enabling dialogue with more young people and forge links with the wider research community.

- *Plan a varied and stretching programme of future meetings*

A number of those interviewed with more experience of the group's meetings emphasised the need to vary their focus; aware that with public health, the same underlying issues, particularly poverty and choice, arose regularly.

- *Extend involvement in PHRC projects*

On the basis of their interaction with the young people, researchers were in favour of their being offered opportunities to become more involved in future

projects. All of those interviewed were in favour of their using research skills developed through the meetings and prolonging contact beyond the standard one-off sessions or piece of work if this could be planned to the satisfaction of everyone involved.

- *Support young people-led research*

One way in which the group could follow up their own identified priorities, suggested by interviewees, would be for them to develop and commission or complete a new piece of research, with support from NCB and other interested researchers in the PHRC and elsewhere. Interested members could be enabled to join a Young Researchers Network.

- *Increase young people's role in setting the agenda*

In line with the above ideas, stakeholders were keen that within the remit of the group, young people were able to set their *own* agenda in terms of meetings and activities; whether this meant choosing between proffered opportunities or creating entirely new items. Either way, longer-term planning should be helpful as the process would not be inclusive if reliant on between-meeting planning.

- *Hold a residential conference*

NCB and PHRC stakeholders felt that, while present arrangements worked well, a residential conference for young people could allow more extended activities than would ever be possible in a one-day meeting bounded by travel at either end.

Conclusions

Stakeholders across the three organisations - as well as the young people themselves - testified to the learning enabled through the pilot initiative. While the group's activities have been limited by time and resource constraints, what was always an exploratory project has already demonstrated development in line with young people's aspirations. As well as more intangible gains, concrete outputs have been produced and tasks completed to the satisfaction of all concerned, and already some of the group's work has reached and generated interest among a wider audience. It is encouraging to see that members' aspirations for the future of the group are shared by its supporters in the PHRC and INVOLVE, and that with the likelihood of funding from the Wellcome Foundation, there is every reason to anticipate their making a growing contribution to the public health agenda.

10. The future

In July 2007 a proposal was submitted to the Wellcome Trust by NCB and the UCL Institute of Child Health, with support from the PHRC. In December we were told that a conditional award had been made, subject to amendments currently under negotiation. The proposed project is an opportunity to expand and extend the work of the YPPHRG and it is hoped will support children and young people to contribute to the UK public health agenda by:

- Providing opportunities for children and young people to learn about the current public health research and policy agenda
- Enabling children and young people to feed their views and priorities into current public health policy and the research agenda
- Supporting children and young people to translate and disseminate research findings to their peers
- Enabling children and young people to contribute to the translation of public health research for policy and practice

These aims will be achieved by building on the work of the YPPHRG by setting up a number of young people's reference groups, development of a related website and other activity (including conferences, training and other young person-led activities/outputs) so that public health research can be communicated by, to and between children and young people. The proposed activities emerged from the recommendations of the interim evaluation and group members' views.

As well as continuing to build on the links between NCB and the PHRC and INVOLVE, the project will encourage dialogue between children and young people and the wider public health research and policy community. Through NCB's established links with young people's networks, and research and policy networks in public health, the project will create genuine communication between public health researchers, policy-makers and practitioners and children and young people. The desired long-term outcome is that both the research and policy agendas in respect of public health and young people are better informed, more relevant and therefore more likely to be successfully applied because of the inclusion of young people's perspectives within the process.

Louca-Mai Brady, Senior Research Officer (NCB)