Young People in Research: How to involve us
Guidance for researchers from the PEAR young people’s public health group

Who we are
PEAR – which stands for Public health, Education, Awareness, Research – was an NCB Research Centre project supporting young people’s involvement in public health research. The project ran from 2008–2010, supported by the Wellcome Trust. The PEAR group was made up of us – 20 young people, aged 13–18, from London and Leeds. We have:
- worked with lots of public health researchers and policy-makers
- learnt research skills and commissioned our own research project (on cyberbullying and mental health)
- organised a conference
- developed a website to tell researchers and other young people about public health issues and our involvement in research (www.ncb.org.uk/PEAR).

Who these guidelines are for
Because the PEAR group has been involved in quite a few different research projects, lots of adults have asked us for our views on how to involve young people in research. Existing guidance for researchers is often written by adults, so we thought it was important to develop guidelines on how to support young people to get involved in the planning and process of research – giving our perspective on how we would like to be involved. The guidelines may also be useful for other children and young people who want to get involved in research, or adults who work with them.

‘Discussions with the PEAR group provided several really useful insights into the issues we were researching and helped us feel we had got closer to the research problem as young people might see it.’
RESEARCHER

‘We’ve been able to work with researchers and give our opinions. There’s a mutual benefit, we’ve helped them and also gained knowledge ourselves.’
PEAR GROUP MEMBER
Involvement in research – what’s in it for young people?

As young people, we can benefit in many ways. We can use involvement in research as a way to:

- enforce our right to be involved in matters that affect us (Article 12, UN Convention on the Rights of the Child) – our views are important!
- get our views across and challenge adult researchers’ ideas about young people
- become involved in things that are in the news or important in our lives
- get the chance to make a difference
- be asked about what research is done and how, rather than just being participants and answering someone else’s questions
- gain an understanding of the research process and how research projects develop
- get the chance to develop skills and useful experience
- gain something to show for our involvement (for example, a report) and become involved in dissemination (for example, at conferences, presenting findings)
- be reassured that what we’ve been involved in has made a difference.

Ways in which young people can be involved in research

Researchers can choose either, or both, of these options:

- tap into existing groups or networks (NCB Research Centre may be able to help with this)
- consult young people online. Researchers can involve young people on an ongoing basis in a number of ways:
  - as young advisors – working alongside, or as part of, an adult advisory group
  - as young researchers or evaluators – working alongside adult researchers to design tools, collect data, analyse and/or report on findings
  - as co-researchers – being supported to do our own research alongside adult researchers
  - as researcher commissioners – coming up with an idea for a research project and choosing an adult researcher to carry out the work (something PEAR did for our research project).

How not to involve young people

- Being tokenistic – only doing it because it looks good and not being really committed to involving us properly.
- Not making information easy to understand and accessible.
- Exploiting young people by getting us to do your work for you and then not giving us the credit.

Challenges

- In order to get information about involvement in research to young people, you often need to contact us via gatekeepers (parents or carers, schools, youth clubs, etc).
- Young people are not available during the day in term time, so you’ll need to involve us in school holidays, evenings and at weekends. Sometimes times of year may be more difficult too (for example, during exam time).
- If you want young people’s involvement in your project over a year or two, you need to be aware that some people may drop out because their circumstances change or because they are no longer interested in being involved.
- Too wide an age range can be difficult to manage as, while you give explanations, you will find some don’t need it, or get confused, and therefore become bored. Special educational needs or disability and young people’s differing backgrounds should also be given due consideration.
- Keeping in touch can be difficult – you will find face-to-face meetings are often the best way to get our input. Try different things, as some young people prefer social networking sites or instant messaging to email; and text messages or sending things in the post can also be good.

Involving young people at different stages

Young people can be involved in research and evaluation in different ways including:

- MANAGEMENT
  By representing other young people on a project steering or advisory group
- PROPOSALS
  By suggesting search terms or themes, or by commenting on what researchers think the literature is saying
- LITERATURE REVIEWS
  By working alongside researchers to design tools (for example, questionnaires) or commenting on focus group or interview questions
- DESIGN
  By commenting on people’s research ideas and having our views included in proposals
- RECRUITMENT
  By recruiting through our friends and peers, or coming up with creative ways of engaging ‘harder to reach young people’, and by talking to young people about research (for example, in schools or youth groups)
- DATA COLLECTION
  By working alongside adult researchers to design tools, analyse and/or report on findings
- ANALYSIS
  By helping to analyse qualitative (unstructured) data by commenting on graphs and tables and suggesting ways in which researchers could analyse the data further, by doing some basic analysis alongside researchers, by identifying themes for researchers to use when analysing qualitative data (though, or by grouping answers to questions under themes and comparing our interpretation with that of the adult researchers
- WRITING UP
  By helping to give our research more impact by presenting the research findings at conferences, and to young people and adults who work with them, and by getting involved in writing articles or media work
Our checklist for involvement

• Benefits to both research and young people
  There need to be clear benefits for young people from our involvement, but we also think it’s really important to be clear how young people’s involvement will make your research better.

• Plan involvement from the start
  If possible, try and plan how you will involve young people before you start a project or, ideally, involve them in developing your plans or proposal.

• Recruitment
  Think carefully about who you want to involve (that is, in terms of ages or different groups of young people) and how you will recruit them so that as wide a range of young people as possible have an opportunity to be involved.

• Informed choice
  Try and make sure that young people are fully involved in deciding if, when and how they want to be involved – and are given all the information they need to do so in a form that is accessible and interesting to them (that is, not too long or too boring but enough detail so they know what will be involved and what to expect).

• Parental consent
  You’ll need to get consent from parents or carers if you’re recruiting young people aged under 16, but you need our consent too!

• On-going training and support
  Provide the training that young people will need for the things they’re going to be involved in, in a way that’s interesting and accessible. It’s best if the training happens not long before it’s going to be used, so that it is relevant and useful.

• Involvement in as many stages of research as possible
  This means that we can develop our knowledge and skills and also see how things change as the project develops.

• Agree clearly defined roles
  Agree at the start what you will do and what is expected from us. If there are things we can’t get involved in or have a say on, then let us know that too.

• Offer genuine opportunities for meaningful decision-making

• Reward and recognition
  Generally we think that young people working with researchers should be rewarded for their time (for example, in the form of high street vouchers) or get recognition in the form of certificates or other records showing what they have done and skills gained (or both).

• Safe working procedures and ethics
  Make sure that any appropriate safeguarding procedures are in place and that the research, and young people’s involvement, are ethical.

• Staff resources
  Make sure you have allowed enough time and money.

• Evaluation and feedback
  Let young people (and other adults) know what difference their involvement has made and, ideally, let them take part in evaluating their involvement.

• Exit strategy
  Plan for what happens after the project ends. What other opportunities are there?

Further information

NCB Research Centre
www.ncb.org.uk/research

The PEAR project
www.ncb.org.uk/PEAR

INVOLVE
www.involve.org.uk
Includes guides on payment; involving children and young people; and other information including a recent report on the impacts of involvement.

Participation Works
www.participationworks.org.uk