

INVENTIVE INVOLVEMENT | WITH PATIENTS & THE PUBLIC

Children & Young People (under 18s)

What this involves

As with adults, young people can be involved in any element of the research cycle and there is no restriction on how this involvement occurs. However, in working with people under 18 you will inevitably need to take a different approach or style.

- In addition there are some practical variations;
- You will need to get parental consent for working with anyone under 16.
- When paying travel expenses you may need to pay the parent who is providing the transport etc.
- You may want to pay for the young people's time with high street vouchers as they may not have a bank account – ask them what suits them.
- You will need to ensure that any appropriate safeguarding procedures are in place.
- Provide certificates of attendance or opportunities to learn new things & skills or other benefits to enhance their CV

What are the benefits of working children and young people?

The benefits will be obvious if the research that you are doing affects the lives of young people. You cannot assume that parents know everything about the condition or the young person's experience of it.

As a researcher you are in a unique position to engage young people with a world they may not otherwise encounter or consider, which can often have far reaching impacts. Engaging young people with your research is an exciting experience which can also help to encourage and stimulate the next generation of researchers.

When this might be a useful/appropriate approach:

In any research that relates to a young person's health condition specifically.

How can you work with PPI Contributors who are under 18?

You could begin by checking if research has already been done in your field with young people by our Health Experiences Research Group: www.healthtalk.org/young-peoples-experiences

One option would be to make contact with Generation R. This is a National Young Persons' Advisory Group funded by NIHR, made up of local groups across the UK. It includes one group who specialise in mental health. <http://generationr.org.uk/about/> There is currently no group in Oxford.

You could contact the PPI Officer for the School for Primary Care Research who is developing a young person's advisory group.

Another option would be to work with Science Oxford <https://scienceoxford.com/schools/membership/>

What are the drawbacks of this approach?

- You will need to work with the young people when they are not in school (evenings, weekends and school holidays) unless you are able to establish a working relationship with a school – see example below. You will need to be sensitive to some times of the year being difficult such as exam time. Often parents have to be free as well if providing transport is involved.
- Young people grow up fast and their circumstances change. This may mean that you have to work more on refreshing your recruitment.
- Too wide an age range can be difficult to manage. What you will do with a 6 year old will be very different to what you do with a 16 year old.

Resources:

- INVOLVE resources at www.invo.org.uk/find-out-more/how-to-involve-people/involving-children-and-young-people/resources-for-involving-children-and-young-people : <http://www.invo.org.uk/find-out-more/involving-children-and-young-people/>
- National Children's Bureau have young Research Advisers and are also able to provide guidance on how they work: <https://www.ncb.org.uk/what-we-do/what-we-do/research-policy/involving-children-young-people-research>
- Guidelines for research with children and young people: <http://www.participationworks.org.uk/resources/guidelines-for-research-with-children-and-young-people/>

The secondary school based Young People's Advisory Group had been run from the Centre for Child and Adolescent Health (CAAH) to provide researchers with access to first-hand knowledge of being a young person. Now managed by the CLAHRC West researchers teach the young people about research each week over a couple of terms and then the students do their own research project. Alongside this researchers can seek input from the group.

It runs on a weekly basis during school term time from October to Easter enabling quick access for researchers, with a new cohort recruited each academic year. The school is Redland Green Post 16 Centre, Bristol. The participants are volunteers from Year 12 who provide advice and critical analysis on all aspects of research with children and young people. In 2017 there were 15 students taking part.

In return, they receive a taught programme on research and research methods provided by a core team of researchers from CLAHRC West.

References cont.

During the first part of the programme (from October to December) students are taught about research by professional researchers. Lessons include different types of research, analysing data, ethics and questionnaire design.

Following this, the students are encouraged to design their own research project. Once they have made a decision, they have to fill in a research proposal and ethics submission before undertaking the research (usually within the school). The results are analysed and presented to the CCAH and CLAHRC staff around Easter and the students receive a certificate to show they have taken part.

The sessions run from midday to 1pm and drinks & snacks are provided.

Topics taught include;

- What is research?
- Looking at different types of research- qualitative and quantitative.
- Understanding evidence - Making sense of data, drawing conclusions. Deciding whether correlations are meaningful or coincidental. Proving cause and effect.
- Experimental Research- is it always ethical? The need for Ethics. When research “goes wrong” - examples of unethical research
- Practical statistics - a practical session of using and interpreting data.

Contact: Michael Bell (mike.bell@bristol.ac.uk) for more information.

ARCHIE is a study at the Dept of Primary Care Health Sciences in Oxford looking at the early use of antibiotics for ‘at risk’ children with influenza (www.phc.ox.ac.uk/phctrials/trial-portfolio/archie). Some early PPI with young people and parents in the study transformed the branding (logo) of the study and gave valuable advice on how best to recruit to the study.

Contact Tricia Carver (tricia.carver@phc.ox.ac.uk) for more information.