Involving young people in research: making an impact in public health

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1. Introduction

 In this chapter we discuss the legislative and policy context for children and young people's participation in the United Kingdom (UK), and how this relates to the evidence base for their involvement in research. We then examine a specific project, developed by the NCB (National Children's), Research Centre called 'PEAR (Public health, Education, Awareness, Research): our voices, our health, which supported young people to contribute to public health research. We consider the lessons from this project for the involvement of children and young people (CYP) in research and policy, with contributions from three young people who are members of PEAR.

2. Children and young people's participation

The involvement of CYP in research needs to be placed within the wider context of their participation in other aspects or their lives as well as the international framework of children's rights. Participation[1] can be defined as the process by which individuals and groups of individuals influence decisions which bring about change in them, others, their services and their communities (see Tresder, 1997; Participation Works, 2008). The United Nations Convention on the Rights of the Child (UNCRC) (UN, 1989) was ratified by the UK government in 1989. Article 12 of the UNCRC states that all CYP who are capable of forming their own views, have a right to express those views freely in all matters affecting them.

Since the UNCRC there has been a broad acceptance of children's right to be involved in decisions that affect them, or on behalf of other children (Kirby et al, 2003; Sinclair and Franklin, 2000). The UNCRC was supported in the UK by the introduction of legislation and policy in the UK such as the Children Act (OPSI, 2004), Every Child Matters (HMSO, 2003) and the Children's Plan (DCSF, 2007). Kirby et al (2003) has however concluded there is still work to be done in ensuring that this participation is meaningful to young people, effective in bringing about change and sustained. More recently Davey (2010), in research for the Office of the Children's Commissioner, found that although significant progress has been made in the last few years in relation to children's participation in decision-making, many children continue to be denied opportunities to influence matters affecting their lives. Also, although adults report

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[1] 'Generally 'participation' is the term used in work with CYP, but 'involvement' is more commonly used in the context of participative research.

that services have improved as a result of participation, little progress has been made to evidence at a strategic level *how* children have contributed to this improvement. (Davey, 2010).

There are several rights-based models of CYP's participation, as well as complimentary models for user or 'patient and public' involvement in research. Hanley et al. (2004) identified the different levels of user involvement in research as consultation, collaboration and user control. Arnstein's (1971) ladder of citizen participation was adapted by Hart (1992) to include children and consists of eight rungs: manipulation, therapy, informing, consultation, placation, partnership, delegated power and citizen control. These eight rungs range from non-participation, through tokenism to the last three rungs, which are identified as citizen power or shared decision-making. In 'Building a Culture of Participation', Kirby et al (2003) propose a model which could be seen to sit between these: their model takes as its starting point article 12 of the UNCRC and therefore only includes participation (ie not the lower three rungs of Hart's ladder). This model is non-hierarchical: the appropriate level is determined according to the circumstances and the participating CYP:

- **Children and young people's views are taken into account***: the information children provide is one source, amongst others, that adults use to make a decision;

- **Children and young people are involved in decision-making***: children are directly involved at the point where decisions are made, but adults still hold ultimate responsibility for deciding the course of action;

- **Children and young people share power and responsibility for decision-making:** similar to previous category, but adults make a commitment to share power and to undertake joint decision-making with children;

- **Children and young people make autonomous decisions***: recognising that the implementation of these decisions may be ultimately dependent on adult structures, responsibility and power.

3. Involving children in research

Advances in public and professional attitudes towards children's right to participate have, to some extent, been reflected in increasing interest in CYP's involvement in research (Kirby, 2004; NCB, 2002; Powell and Smith, 2009), both as participants and through their active involvement in the planning and process of research.

Involving those who are the focus of research can have a positive impact on what is researched, how research is conducted and the impact of research findings (e.g. Staley, 2009; INVOLVE[2]). In recent years there has been a theoretical and methodological shift amongst social researchers away from traditional approaches which saw CYP mainly as objects of enquiry, and towards a view that CYP are social actors, with their own unique views and insight into their own reality (Grieg et al, 2007; Prout, 2002). There is also increasing acknowledgement of their competence to contribute such insights and the power of the 'child voice' in research (Alderson, 2001; Hill, 1997; Powell and Smith, 2009; Sinclair, 2004). Although there is less of an evidence base in relation to children and young people's involvement in research practice compared to adults (Brownlie, 2009), the case for their involvement has been explored in a number of publications (e.g. Alderson, 2001; Kirby 2003; Kellett, 2005). The main arguments for involvement of adults in the research process are all valid to the involvement of children and young people:

- the functional benefits to the research (validity - e.g. better understanding of young people's worlds, impact)

- the benefits to those who get involved (e.g. skills, experience, recognition)

- the ethics of participation (rights, inclusion and empowerment)

CYP can be involved in research at different stages (from developing a proposal to dissemination) and in different roles (from being part of a reference group for adult-led projects, to undertaking peer-led research). The degree to which CYP are involved in research will vary depending on the availability and interests of the individuals themselves, the nature of the research, and the available resources (Alderson, 2001; Kirby, 2003; Powell and Smith, 2009). Although this can involve CYP as research participants (i.e. sources of data), the concept of involvement discussed here is focused on their active involvement in research planning and processes.

Some of the specific challenges to children's involvement in research include: availability (many children are not available during term time and often have other commitments outside school or college) (McLaughlin, 2006); age and accrual (children grow older and, as well as interests and availability changing rapidly over time, also cease to be 'young researchers' when they reach adulthood); informed consent and the role of 'gatekeepers' (parents, teachers or staff in services) (Alderson, 2000, Powell and Smith, 2009); and ethical issues regarding safeguarding and child protection, which need to be balanced against rights to participate. Children who are perceived to be vulnerable, or at risk of social exclusion can be denied opportunities to

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[2] www.invo.org.uk

participate in research (Cahill, 2007; Powell and Smith, 2009). Along with issues of diversity and accessibility common to much adult user involvement in research (e.g. Steel, 2005; Staley, 2009), CYP who choose to get involved in research tend to be older and the voices of younger children can be excluded. Involvement of CYP in can have resource implications for research projects in terms of both costs and researcher time and involvement needs to be planned with this in mind as well as considering issues of availability, safeguarding requirements and lack of experience (McLaughlin, 2006).

Adult researchers also need to consider the extent to which they hold ultimate responsibility for maintaining quality standards, managing technical aspects of the research and ethical and legal issues. In the authors' experience these are areas of the research process in which CYP rarely want to get involved but nonetheless the limits of CYPs involvement and influence should also be agreed with them at the outset and consulted on and updated as appropriate.

4. The PEAR project – involving young people in public health

The Young People's Public Health Reference Group (YPPHRG) was run by NCB Research Centre from November 2005 to February 2008, with support from the Public Health Research Consortium (PHRC)[3] and INVOLVE, as a pilot project to explore how young people could contribute to public health research in the UK (Brady et al, 2008). Funding from the Wellcome Trust enabled NCB to expand and extend the work of the pilot, and members of the group renamed the project 'PEAR (Public health, Education, Awareness, Research): our voices, our health'. The PEAR project supported young people to contribute to the UK public health agenda from 2008-2010 by:

- Helping young people to learn about, inform and influence public health research and policy (e.g. contributing to setting of priorities for public health research; involvement in research projects at proposal-writing, design, literature review, analysis and dissemination stages; advising public health research bodies on how they could involve young people in their work; responding to government consultations).

- Developing links between young people and public health researchers, research bodies and policy makers.

- Producing and distributing information about public health issues and research to other young people (primarily through the website and conference – discussed later).

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[3] http://www.york.ac.uk/phrc/

- Seeking to demonstrate the impact of young people's involvement in public health research, and how this can be applied to policy and practice.

<div align="right">(Brady and Ghosh, 2009).</div>

The PEAR project included regular meetings of 20 young people in groups based in Leeds and London. Group members worked with public health researchers and received training in research skills and public health, helped develop a website[4]and organise a conference, as well as commissioning their own research project on the impact of cyber-bullying on young people's mental health.

4.1 Successes of the project

In the evaluation of the pilot project (Brady et al, 2008) the young group members felt that they had been able to influence public health research, and both those young people who were interested in 'having a say' and those with a specific interest in public health and/or research said that they had benefited from their involvement in the project. Adults involved felt that the group had 'brought to life' public health research for young people, provided a reality check to academic views and that methods of engaging young people had been tested and tangible outputs produced. The concrete outputs of the project (in particular research summaries) were really valued, both by young people and adults, and it was felt that the group's work has reached and generated interest among a wide audience.

PEAR group members - the views of young people:

The key successes of the project for group members included opportunities to learn about public health, gain research skills and have something to put on our CVs; having our voices heard by researchers and policymakers; helping to make research and policy more relevant to young people; commissioning our own research project, developing the website and planning the conference; and letting other young people know about public health issues that affect them:

"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"

"There's lots of research about young people and public health – we deserve to have our voices heard"

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[4] www.ncb.org.uk/PEAR

"The views of adults and young people are different – hearing what we have to say makes it [public health research and policy] more valid and useful"

"It's important that…our opinions are heard not assumed"

4.2 Challenges

Challenges faced by the pilot (Brady et al, 2008) included recruiting a diverse range of CYP to something quite academic and involving a long-term commitment. This was something the subsequent PEAR project sought to address (discussed in the next section). It was also hard to maintain attendance through the two years of the project, but recruit new members was difficult as understanding of public health and research developed amongst the group. There were also challenges in balancing group members and researchers' expectations. Researchers often wanted input from young people at particular stages of their project (eg when developing research tools or emerging findings), but group members were more interested in on-going involvement and shaping researchers ideas and thinking from the start of a project. There was also initial scepticism from some researchers about how young people could usefully contribute to research. Time and resource constraints limited how often the groups could meet (four one-day meetings a year during school holidays), and because of the need to link in with research timetables and researcher availability the agenda was often adult-led. The fact that group members had school or college and other commitments, and that the age group interested in being involved tended to be in exam years had implications for availability, as did the fact that availability and interests were likely to change over the course of the project.

PEAR group members – young peoples views:

Group members felt that it was really important to get feedback on the impact of their involvement:

"I think researchers we have helped should 'drop us a note' about what they did with the information we provided"

"It's important that we're involved in evaluating the project as well as being part of the group. We think the group should have met more often – as otherwise it's hard to stay engaged and to remember things we've learned…As some people have left, or don't attend very often it means that the meeting is smaller, and we think it would be better if there were more people at the meetings. It would also be good to have a wider range of young people in the groups".

5. Children and young people's involvement in research – making an impact

PEAR group members – young people's views:

Amrita Ghosh

"Involving young people in research has benefits for both young people and adults: we are taught new skills that we can put into action as we grow up and know that we are making a difference to public health research; and adult researchers get to see their research from our perspective, understand what our priorities are for public health and how our involvement can improve their research. In the group I have discovered that the adults and the young people often have different ideas on the same subjects, so involving us in planning research about young people's public health helps makes sure researchers are asking the right questions in the right way. The PEAR group has helped us to bridge the gap between young people and researchers. Since we've received feedback from researchers who have spoken to us I've realized the impact of our opinions and it has also made me more aware of public health systems and government policies".

Ellie Davis

"It's very good to see some of [the research and policy process] done for young people as we only usually get to see the end result, and also to take part in some of the decision-making processes that have an effect on our lives. Through taking part in the group I have an increased awareness of just how much support is available for young people on public health issues".

Bhavika Surti

" As a member of PEAR I feel like we have really achieved something and shown that it isn't just adults who are researchers but that young people can also be involved. As young people we have picked up on public health ideas that researchers haven't thought about, as we see things from a different perspective. I've learnt a lot and feel privileged that I could help researchers with their projects and I feel like I have made a difference. It's fascinating to see the difference in opinions from adults and children and it goes to show that involving children in projects like PEAR is beneficial".

Laura Wilson

"Prior to being a member of PEAR, as a young person I was often aware of the vast amounts of research on people of my age by 'experts' who didn't seem to have come into contact with a diverse range of 'real' young people, which I think can help create and promote stereotypes. But by being a member of the PEAR group and participating in research about and by young people, working alongside researchers and professionals, I feel that our voices are being heard more coherently. It has also allowed us to expand our knowledge and understanding of research as well as discovering the importance of public health. I feel we have also enabled researchers to understand young people's perspectives more fully, allowing their research and projects to become more accessible and relevant to young people."

Evidence of impact emerged as a key issue in the pilot project, as group members wanted to see the impact of their work and evidence of how they were 'making a difference'. They wanted to see direct, practical results soon after their input into a project, but this was not always possible or did not always happen as quickly as they would have liked. There was also an issue of how to measure broader impact – i.e. beyond the researchers the group worked with.

NCB attempted to address these various challenges in the PEAR project, for example through establishing a second group in Leeds and a wider recruitment base. Young people were involved in overall management of the project through representation on the project advisory group and, as well as working with adult researchers on their projects, the group also had areas of responsibility which they controlled with support from NCB staff (the website, conference and commissioning their own research project). As well as providing information from researchers on what the group can offer, there were clear expectations on what is expected in return, in particular on-going involvement or timely feedback on impact and outcomes. The project team tried to do more to involve group members in between meetings. As you can see from the co-authors' views mentioned earlier, seeing clear evidence of the impact of their involvement is really important for those involved as well as researchers and funders. So group members were also involved in the evaluation of the project, including defining objectives and outcomes and collecting data.

Nevertheless there are clearly limitations to an advisory group model for involving CYP in research, particularly one that meets infrequently: it is difficult to keep some CYP engaged with the project in between meetings, for access to the group to be available for researchers at the time they need it for their research, as well as the issues of recruitment and retention as

previously discussed. Obviously there are significant cost implications to more regular meetings, but these could to some degree be offset by writing the cost of input from the group into research projects at the planning stage – as the costs would still be considerably less than setting up a specific CYP's reference group for an individual project. We would therefore suggest that a better model may be a flexible approach with slightly more frequent meetings (e.g. every six to eight weeks, at weekends as well as during school holidays) combined with a secure online forum for discussion in between meetings and a network of organisations and CYP's groups with specific interests or needs (e.g. those who may not want to be part of a regular group or have an interest in a specific project or type of project) who can be called on when needed. So, for example, if researchers working on mental health wanted input from CYP it would be possible to set up a meeting with a group of young mental health service users as well as with an established group of young researchers. This would give two different, but equally valid sets of CYP's perspectives.

6. What makes involvement meaningful?

CYP's involvement in research has benefits for researchers, research bodies, policymakers and for CYP who are both involved in and affected by research. The author's therefore propose that for CYP's involvement in research and policy to be meaningful for all involved it needs to:

- Be planned from the outset

- Carefully considerof who should be involved, how, where and when and addressing issues of gatekeepers and parental or carer consent

- Provide genuine opportunities for meaningful decision-making

- Have benefits for the research as well as the CYP involved

- Involve CYP in as many stages of the research project and process as possible

- Involve CYP in deciding if, when and how they want to be involved – and give them all the information they need to do so in appropriate and accessible formats, and clearly defined roles

- Be flexible and creative about models and methods of involvement, seeking to ensure accessibility to a wide range of children and young people

- Provide appropriate and on-going training and support

- Consider appropriate methods of reward and recognition

- Recruit, train, support and reward CYP appropriately

- Ensure safe and ethical working procedures

- Be properly resourced

- Have a clear exit strategy

- Build in systematic evaluation of, and feedback on impacts and outcomes related to CYP's participation in research.

Author information:

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