



Research Summary

Tips to involve disabled young people as partners in health research

Key messages

- A small number of examples describe how disabled children and disabled young people have been involved in research, and provide helpful good practice recommendations to guide researchers.
- Investing adequate resources, planning activities tailored to people's ages and abilities, offering choices, and supporting people who use non-verbal communication are important.
- Involving disabled children and disabled young people in research can have positive impacts when done well, but can potentially have negative impacts if done poorly.
- Methods to involve disabled children and disabled young people meaningfully in research should be further developed, and reported so that the research community can share good practices.

In this summary:

- Being '**involved as a partner in research**' means being part of the research team, not being someone who is having research done 'on them', or 'to them'.
- **DCYP** means disabled children and disabled young people up to the age of 25 years old.
- By '**disabled**' we mean someone who has any chronic health condition and difficulties carrying out normal day-to-day activities. The definition we used in this study comes from the [Equality and Human Rights Commission](#).

Who carried out this research and why?

The research was led by the team at Peninsula Cerebra Research Unit (PenCRU), a childhood disability research unit at the University of Exeter Medical School.

PenCRU have gained experience involving parent carers of disabled children in research through a [Family Faculty](#). Parents in the PenCRU Family Faculty have been involved in various ways in our research projects.

Their involvement has improved the research and they have enjoyed being treated as experts in their own lives. As a next step, we wanted to involve disabled children and disabled young people as experts too.

Background

The organisation [INVOLVE](#) defines public involvement in research as "research being carried out 'with' or 'by' the public rather than 'to', 'about' or 'for' them".

Involving patients and carers in research is likely to produce findings that are more useful and relevant, and can have positive impacts on those involved.

There are various issues to consider when seeking to involve DCYP as partners in research. Some of the issues we had thought about were:

- How to advertise the opportunity?
- Practical issues - where to hold meetings, and how to engage DCYP of different ages and abilities?
- Whether being involved had any impacts on DCYP?
- Whether involving DCYP improved the research?

What did we do?

This type of research is called a [systematic review](#). Systematic reviews bring together the results of all studies addressing a particular research question. They provide a comprehensive and impartial summary of existing research evidence.

How did we involve families as partners?

Six parents from the PenCRU Family Faculty met with researchers at various stages. They helped to develop the research questions, decide which information we would include and exclude. Parents identified and examined relevant websites, and interpreted the findings. They also helped to write this summary.

How did we search for evidence?

We searched several online libraries that catalogue published research papers, e.g. [Cochrane Library](#). We also looked at websites, such as the [Council for Disabled Children](#) and [CanChild](#), for information that might not have been published as academic papers. At least two people checked each source to avoid missing anything important.

What types of study were included?

We were looking specifically for information about how DCYP had been involved as partners in health research. We did not include research about schools and education. DCYP had to be less than 25 years old and be identified as having a chronic health condition.

What did we find?

We looked at a huge number of potentially relevant references. Only 22 documents were found that fully met our criteria for being included in the review.

Nine documents were examples where DCYP had been engaged as partners in a research project. The health conditions of these DCYP included autism, diabetes, asthma and HIV. They were involved in activities at various stages of the research, including designing the project, interviewing, data analysis, and producing reports, policies and presentations.

The other 13 documents we found described researcher's experiences, or opinions, of how to involve DCYP as partners in research.

Having identified articles that met our criteria, we examined the information regarding our objectives, and brought the findings together.

Access and recruitment

- DCYP had been recruited through schools, hospitals, and community groups.
- Opportunities had also been advertised using online forums, websites and in newsletters.
- Partner organisations, youth workers, school and hospital staff, and parents had helped to advertise the opportunity to DCYP.
- Adverts should use language appropriate for the age and abilities of the target DCYP, and to explain clearly what was being asked of them in terms of commitment, likely activities and any flexibility.

Selection

- Some DCYP had volunteered themselves, whereas other DCYP had been nominated by their parents.
- One study used a structured recruitment and selection process similar to applying for a job. In other examples it was less formal, or not stated.

Practical issues

- Accessible venues, regular rest periods, and refreshments were identified as important.
- Providing individual support for some DCYP may enable them to be more fully involved.
- Various means exist to support DCYP who use non-verbal communication, such as picture cards.
- Activities likely to engage and include DCYP need to be tailored to their age and abilities.
- Building trust and confidence, through honesty and providing positive feedback is likely to prolong participation.

Overcoming challenges

- Adequate time, budget and resources are needed to provide support and build relationships.
- Research staff may need additional training
- Offering DCYP opportunities to choose and define their own roles enables them to take control.
- Parents, carers and professionals can be a barrier to DCYP expressing their own views.
- A familiar communicator or carer will sometimes be necessary to enable DCYP to be fully involved.
- Organisers should take steps to minimise adult influences on children expressing their own views.
- Building an organisational culture and commitment to involve DCYP can overcome misconceptions of their competence and the value of their contributions.

Impacts of involvement for DCYP

- Positive impacts on DCYP that have been reported include increased confidence and self-esteem, learning new skills, building independence, and a sense of responsibility.
- Social benefits of involvement for DCYP included the opportunity for them to socialise with peers, meet new people, and make new friends.
- Researchers need to be aware that negative impacts can occur if DCYP think their involvement is not valued, or if there are not strategies in place to manage distress.

Impacts of DCYP involvement on research

- Involving DCYP has been reported to improve research by bringing their unique understanding and views to enrich the findings.
- Not including the perspectives of DCYP may mean research is not relevant to their lives.

Limitations of this review of evidence

- Our findings are limited by small number of studies, the quality of the evidence we gathered, and where in the world they were carried out.
- Some of the data we included is 'expert opinion' rather than evidence from studies.
- It was difficult to find relevant information, and key details were often not well described.
- DCYP were not involved in this review!

Who reviewed our research?

The systematic review is published in a journal called *Child: Care, Health and Development*. Before the journal accepted the paper to be published the editor asked two independent academics to look at the paper and decide whether the research had been carried out properly, reported clearly, and whether it was important enough to publish.

What next?

- This review has identified examples of how DCYP have or can be involved as partners in research, and provides helpful guidance for researchers.
- More complete and transparent reporting of how DCYP are involved as partners in research in future will help share good practices and tips.
- Researchers can use the recommendations to involve DCYP with a wide range of abilities.

How is the review influencing PenCRU?

- PenCRU carried out a pilot project with DCYP to find out more about their ideas for research.
- We are working to involve DCYP in various PenCRU activities as standard practice.
- The methods for doing so will be informed from what we have learnt from this review and from our pilot project.
- A Steering Group with parent carers, teachers and researchers are guiding the involvement of DCYP.
- The next milestone is to involve disabled children and young people on the Steering Group!

The full version of the structured review and qualitative synthesis is published in the journal [Child: Care Health and Development](#). If you would like a copy please contact pen cru@exeter.ac.uk

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