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Category Research		
PRESENTATION DETAILS		
Authors Dr Sarah Mitchell Prof Jeremy Dale Acorns Sibling Council Birmingham Children's Hospital Young Person's Advisory Group		Title of Study Patient and public involvement in palliative care research: An ethical approach to working with young people
<p>What's the problem you are tackling? Patient and public involvement (PPI) in research is important to add relevance and context. For research about children and young people in an area such as palliative care, the approach to PPI requires careful consideration of potential ethical issues.</p> <p>This presentation outlines how an ethical approach was devised in order to recruit a group of young people to provide PPI to a palliative care research study, "The Journey through Care". The work is ongoing, with plans being made for use of social media.</p>		
<p>How did/will you do it?</p> <p>An ethical approach to PPI was developed, and young people from local groups from Acorns Children's Hospice and Birmingham Children's Hospital were approached. Presentations of project plans and resources were given at existing meetings and verbal and written feedback sought. Additional dialogue has taken place via email.</p>		

What did you find?

Considering potential ethical issues systematically before approaching groups has allowed for processes to be developed in case of problems occurring through the PPI work, including for example minimising the possibility that the PPI work causes any distress to the young people involved.

Approaching existing groups has the advantage of being able to take part in meetings. It is exciting to work with young people who and are prepared to offer honest constructive feedback on the project.

The PPI has progressed to working with three young people as co-authors on literature reviews. Consideration of other methods of PPI, including the use of social media is necessary, in order that the PPI fits with other commitments that young people have.

Why does this matter?

PPI is an integral part of research. Involving young people as peers provides the benefit of being able to develop and design research from their perspective. Researchers must be mindful of ensuring that their approach to PPI is accessible, appropriate and ethically sound taking into consideration their PPI group and research plans.