Patient and Public Involvement in systematic reviews: opportunities and challenges

Kristin Liabo
Kate Boddy
PenCLAHRC Patient and Public Involvement Team
What we will cover today

- Quick re-cap of PPI
- Benefits and challenges of PPI in systematic reviews
- Past and current examples of PPI in reviews
- Discussion
What is PPI in Research?

INVOLVE definition:
“…research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

Patients and members of the public provide a different way of looking at things that can ground the discussion in practical experience.
Benefits and Challenges...

Less interest in review involvement

Little scope for involvement

Managing the process

Address public concerns

Burden on researchers and public

Improve relevance

Improve utility of findings

Improve dissemination
Improving the mental health of children and young people with long term conditions

Project team

- Jo Thompson-Coon – Exeter
- Darren Moore – Exeter
- Michael Nunns – Exeter
- Liz Shaw – Exeter
- Sophie Bennett – UCL
- Tamsin Ford – Exeter
- Ruth Garside – Exeter
- Morwenna Rogers – Exeter
- Roz Shafran – UCL
- Penny Titman – GOSH
- Isobel Heyman – GOSH
- Rob Anderson – Exeter
- Chris Dickens – Exeter
- Obioha Ukoumunne – Exeter
- Russell Viner – UCL
- Erin Walker – GOSH
- Stuart Logan – Exeter
- Fiona Lockhart
- Paula Lavis – Children and People’s Mental Health Foundation
- Children & Young People Advisory Group
Project

REVIEW 1: synthesis of **effectiveness** research.

REVIEW 2: synthesis of **qualitative** research.

Overarching synthesis: quantitative and qualitative research.

Consultation with stakeholders
Darren Moore

Non-pharmacological interventions for ADHD delivered in school settings
Systematic reviews of quantitative and qualitative research

Michelle Richardson, Darren A Moore, Ruth Gwernan-Jones, Jo Thompson-Coon, Obioha Ukoumunne, Morwenna Rogers, Rebecca Whear, Tamsin V Newlove-Delgado, Stuart Logan, Christopher Morris, Eric Taylor, Paul Cooper, Ken Stein, Ruth Garside and Tamsin J Ford
The story of a systematic review: Interventions to support looked after children stay in school

Authors: Members of the Children's Active Involvement Service, Islington and Kristin Liabo, National Institute for Health Research Trainee

This is the story of a systematic review, and how a group of young people who had or were looked after, worked with a researcher to produce it.

1. The group first met up and talked about which issues are important to looked after children's health. We touched on a lot of different areas including illegal drugs, mental health, bullying, placement moves and offending.

2. We then voted on which topics were the most important ones to us, and came up with three priority areas: alcohol and illegal drugs, lack of motivation to go to school, and positive things about being in care.

3. We then debated which of these was the most important topic, and tested other people to task what they thought.

4. We decided to focus our review on education.

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All stages of the review process...

- Setting the review topic and question
- Writing the review protocol
- Searching for studies
- Screening abstracts
- Critically appraise included studies
- Synthesise the results
- Write up the review

- Consumer-led
- Collaboration
- Consultation
Involvement is...

- Dialogue

- Patient and public involvement (PPI) is often meant to mean the facilitation of this dialogue about research, between researchers and people with relevant lived experience

- How can we facilitate this dialogue? E.g. bridging languages
- How can we evidence this dialogue? E.g. it did actually happen!
- Does it make a difference?
3.2 Types of participants
3.2 Types of participants

- Children aged 10-13, or in years 5 and 6 at school.
- Children with behaviour problems

Should we include studies with children who are not in care?

Yes [ ]  No [ ]  I don’t have a view on that [ ]

3.3 Types of outcomes

How do we know whether the intervention is successful in making looked after children stay in school?
3.2 Types of participants

- Children aged 10-15, or in years 5-8 at school.
- Children who have been subject to a full care order and placed by the authorities to live outside of their family setting. This means that we are interested in interventions for children who have been placed with someone they did not know from before.

- We will not exclude studies where some of the sample included children placed in kinship care, but we will exclude studies where this group formed the full sample.

Yes ☐ No ☐

- Non-disabled children. We will exclude studies of interventions aimed at disabled children.
- We will not exclude studies with mixed samples of disabled and non-disabled children in care.

Yes ☐ No ☐
2.3 Types of participants

Because of our review title and the kinds of interventions we will include, the participants of some studies may include social workers and carers. We are interested in interventions which are targeted at:

- Boys and girls, aged 10-15, or in years 6 - 11 at UK schools.

- Children and young people in mainstream schools.

- Children who have been subject to a full care order and placed by the authorities to live outside of their family setting. This means that we are interested in interventions for children who have been placed with someone they did not know from before, excluding kinship care.

- We will exclude studies of interventions aimed at children with a learning disability. This is because we want the focus of the review to be on mainstream children in care, and for whom the main issue in regards to their education is being in care rather than having a learning disability.

- We will exclude studies of interventions aimed at young offenders, because a lot of young offenders are living at home, and this is a sub-group of the larger population of looked after children, and one with specific needs.

- We will not include interventions for homeless children.
What links education and health????????

Research has shown that you live a longer life if you’ve got a good education

Education helps with your mental and physical development

Education is important to health because it is likely to give you a better job, and therefore more money

Education comes first. It prevents crime, drug use, alcohol use and therefore improves your health.
The case against education:

There is no direct relationship between education and health

Education is useful but not essential

I disagree with the choice of topic but I still want to be part of the review, and to make a contribution
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<td>Shifting group membership</td>
<td>Good relationships</td>
<td>Review topic and question</td>
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<td>Researcher’s lack of experience</td>
<td>Initiative from all involved</td>
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<td>Different experiences within the group</td>
<td>Opportunities for skills development, travel and earnings</td>
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Reviewer bias
Comment on a piece of research reported in a paper....

“[Name] made the point that the article itself states that more research is needed … Kristin then asked her what kind of study she would trust. She said she would want parents’ point of view, a proper comparison and explanation about the dummy [intervention] and the real one. She would want to see the protocol and the methods”

From Kristin’s research diary (audio recording not consented at this meeting)
So what’s the benefit of the control group?

“Because we’ve got nothing to compare it to, we’re not able to compare someone else who hasn’t had the intervention, like because you, if you’ve got just one person and you just give it to one person, or you just do it to one group and you give them it all and just look at after, it could be something that has got no bearing to the intervention, it could be that their placement has changed or their schooling’s changed or, their emotional wellbeing has changed, or their mental health has changed, so it could just be something else…”
“…. Obviously if you’ve got 20 people that all have the same intervention all change in the same way, that’s positive you would find, I think it’s a massive coincidence if every single one of them had something else other than the intervention that changed in their life that made them better, or that made them…”
Why did you stay on in the research group?

I was enjoying learning about research and searching the topic we were exploring. And by the time it was getting mentally challenging I felt that I had invested so much time and effort in this review that I wanted to see it through to the end.

… we had really good lively debates which I really enjoyed as it was a good opportunity to hear what other people had to say. I also really liked arguing my points … and because I had started something I wanted to see it through to the finish.

I wanted to complete my PhD.