Young people’s involvement in a systematic review

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“Interventions to support looked after children to stay in school”

David Mulcahy and Kerry Gray were involved from start to finish, and in all stages of the review.

Witana Woldai and Helen screened 12.5% of all abstracts (N=817).

20 young people came to one or more meetings.
Involving looked after young people in a systematic review relevant to their health
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
Deciding on review title and question

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<th>Type of voting</th>
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Looked after children’s academic attainment falls short of their peers:

7% of looked after children gained 5 or more A-C GCSEs compared with 17% in the group with free school meals and the national average of 69.7% (2009).

Losing out on education can impact negatively on current and long-term physical and mental health.
Protocol development

4 meetings
4, 8, 3 and 4 young people at each meeting
9 young people contributed in total

• Ongoing research training
• Ongoing reminder about research concepts
• Protocol worksheet
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.
Protocol development

- The question changed while we were discussing aspects of the protocol
- All study designs to be included
- The young people liked to see how the protocol grew from time to time, and to see their contributions in print
- In hindsight: examples of studies and abstracts would have helped at this stage
Searching

- Search workshops over two evenings at the university
- Young people worked on search terms
- Young people searched google for relevant studies
- 1 young person searched websites of relevant organisations
- Researcher designed the search terms and strings and carried out all searches on electronic databases

Consultation
Screening

- 3 meetings fine-tuning the screening tool
- 2 young people double screened 817 (12.5%) studies
- 3 meetings consolidating disagreements
- 6 young people were involved in the screening
- After the screening numbers started to fall and only 2 young people stayed on from previous stages of the review
Critical appraisal and synthesis

• 2 young people remained from previous groups
• 4 new young people joined for one meeting but did not come back
• 1 young person wanted to be involved but could not due to deportation order (subsequently changed on appeal)

• Discussions about research quality
• Personal educational histories
• Reflections on interventions
“[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…”
Review results

- 6502 studies identified through database searches, hand searching and contacting authors
- 11 studies relevant to the review question and meeting inclusion criteria
- No RCTs, 1 comparison study (with unequal comparison group), 8 before-after studies, 2 studies using official local authority figures to track changes
- 6 different interventions

Disappointing
And the outcomes …

• All bar one study had attainment-related outcomes
• Our focus was ‘staying in school’, meaning levels of attendance, exclusions, drop outs
• Two studies addresses young people’s motivations and attitudes to school – the young people concluded that these are the most important outcomes
Involvement versus quality?

Choosing the research
- Problems
- Priorities

Doing the research
- Research design
- Methods

Using the research
- Context
- Funding

Service users: patients, citizens, the public, practitioners...

Researchers: skilled in research design, conduct etc

Decision-makers: politicians, PCT leads, head-teachers...
Involvement in systematic reviews

- **Challenges:** reading research language, inaccessible studies, technicality
- **Levers:** searching is a transferable skill, much is decided in the protocol – the protocol is a guidance
- **Consumer fatigue:** other sources of views
- **Main question:** which areas of your review are in most need of consumer input?