

SEQ Combined Human Research Ethics Training Day



Ethical complexities of child co-research

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Overview

- Co-research and claimed benefits
- Child co-research
 - Why it is popular
 - Concerns
- Project
 - Key findings
- Discussion



Quote



“I think our ethics committee had no idea what we were talking about ... in retrospect I think, had no framework for ethical oversight of co-researchers ... all of their feedback and responses and queries were for participants ... I think there were a whole raft of ethical implications for the co-researchers that we didn't really think about and the ethics committee didn't know how to ask us about...I don't think they knew they should have been worried (laughter)”

What is co-research?



- Research participants are 'joint contributors and investigators' (Boylorn, 2008)
 - with an active role in gathering data
 - more than informant, consultant or member of an advisory group.
 - clearest example is interviewing other participants
 - role may also include accessing or recruiting other participants

Claimed benefits of co-research



- Demonstrates respect and inclusiveness
 - *for and by* people, not just *on* or *about* them.
- An 'insider perspective'
- Provides access to hard to reach populations
 - E.g. sex workers, drug users
- Addresses the marginalisation of disadvantaged groups
 - allows a 'less hierarchical relationship'


What is child co-research?

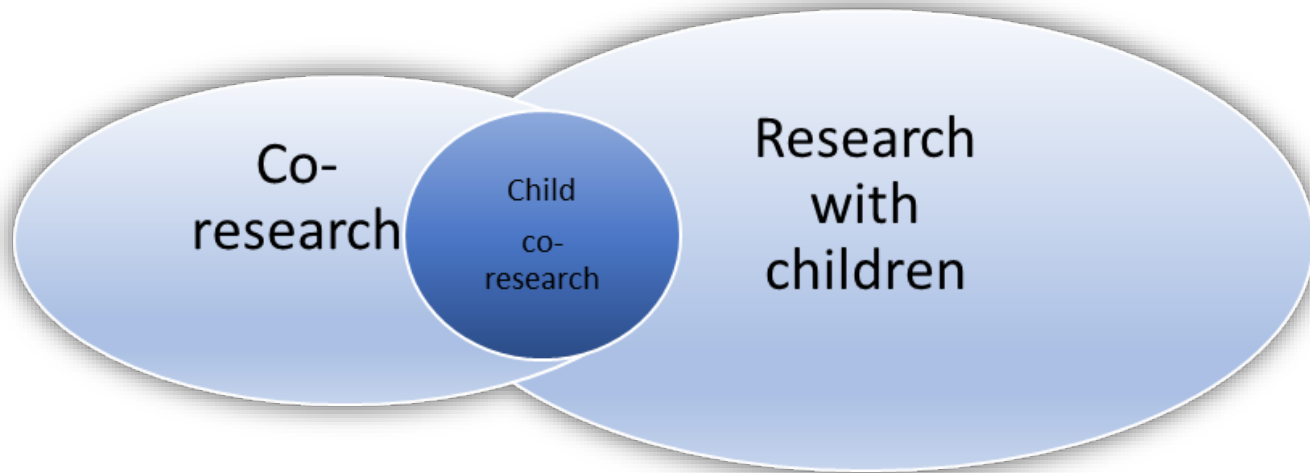


“Child co-research” and “child co-researcher” are not precisely defined. Used interchangeably with descriptive terms:

- “research by children”
- “children doing research”
- “active researchers”
- “participant researchers”
- “peer research”
- “active involvement” in research
- “involving children as researchers”

[Alderson, 2001; Bradbury-Jones & Taylor, 2015; Kellett, 2010; Connolly, 2008]

Where does the child co-researcher fit 
into the literature and into the
research landscape?



The relationship between child co-research and child-led research



Child co-research

Child-led
research

In the existing literature:



Co-research with children

- Promotes children's agency and voice:
 - rescues them from 'silence and exclusion, and from being represented, by default, as passive objects' (Alderson, 2001).
- It is a way of putting into practice the philosophy that children are experts on childhood (Kellett, 2010; Marr and Malone, 2007).
- Advocates claim it is a positive experience for child co-researchers and produces better quality outcomes (Alderson, 2001; Kellett, 2010).

Video Clip:

Do children want to be co-researchers?



Examples

- Children's worries (*11 year old*)
- What do children feel about their faith? (*10 year old*)
- What people in my school and community think about the Police (*10 year old*)
- How are nine to eleven-year-olds affected by the nature of their parents' jobs? A small-scale investigation (*2 x 10 year olds*)



Video clip:

Children's reflections on being a co-researcher



More examples of child co-research



1. 3-8 year olds from a public housing estate using cameras and doing surveys and interviews about children's views on improving their housing estate

- Published an illustrated report, which they discussed with local authority officers.

[Alderson P. 2001]

2. Girls (12-15 years, who have been excluded from school) interviewing peers in a study focusing on the biographies of socially excluded girls.

Why this method?:

- Participants will be more open than with adult researcher.
- Deeper insight into young people's worlds giving better quality outcomes.
- Gains for co-researchers in confidence and vocational skills.

[Based on Conolly, A. 2008]

Concerns about child co-research



- The need for children to be protected and not exploited.
 - i. The emphasis on a child's right to participate comes at the expense of other considerations e.g. their right to refuse (Willumsen et al. 2014)
 - i. Researchers' competing interests and lack of reflexivity
 - E.g. career advancement
 - ii. Little attention is being paid to ethical difficulties faced by child co-researchers in the conduct of child co-research.

Lack of guidance



- **HRECs** - on the questions they should be asking when faced with projects involving child co-researchers.
- **Researchers** - on things to reflect on in their interactions with child co-researchers and other participants.

Definition of child co-researcher



Two key features:

- a) The child meets the criteria for participating in a study or is a peer of the participant population, and
- b) Actively collects data from other participants (their peers).

- The child may also recruit other participants.
- Co-researchers are not the initiators of or responsible for the research project.

Project: Using research participants as co-researchers



- **Aim:** To help facilitate research involving co-researchers in a way that does no harm to co-researchers or other participants
- **Method:** Key informant interviews with researchers and HREC Chairs
- **Main project outcome:** Set of questions HRECs should ask when reviewing research using co-researchers
- **Main questions:** **HREC Chairs:** What kind of projects they have seen using co-researchers and what are the issues? **Researchers:** Why do you use co-researchers? What are the challenges? What works well and what does not work well? When would you not use this method?



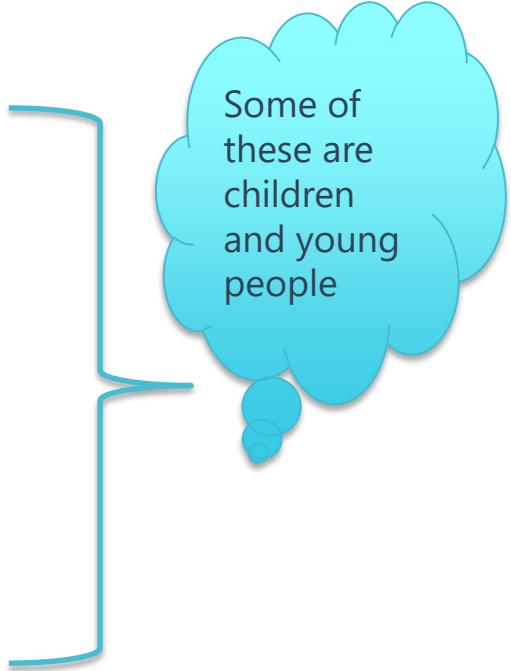
RESULTS

Merle Spriggs & Lynn Gillam. 2017. Ethical complexities in child co-research. *Research Ethics*. In press

Groups reported as being used as co-researchers



- **Children and young people**
- Indigenous people
- People from disadvantaged or disaster contexts
- Sex workers
- Drug users
- Refugees
- People with disabilities
- People with a psychiatric illness or disorder
- Victims of domestic violence



Some of these are children and young people

Participants



- 10 researchers
- 6 did co-research with children and young people.
 - Settings: indigenous people, disadvantaged or disaster contexts.
- 3 talked exclusively about co-research with children and young people
- 3 - co-research with young people amongst other participant groups
 - e.g. sex workers, refugee backgrounds, disadvantaged communities.

Why researchers use co-researcher methodology



- *'important', 'inclusive', gives children 'the opportunity to self-determine'* (1R)
- Supports *'recognition of children as being competent and capable of contributing to decisions that affect them'* (19R).
- **Aboriginal children - a culturally appropriate method, compatible with a 'yarning approach'** (16R)
- Gives *'a more holistic view'* of what's going on in the world, not just for *'a proportion'* of society:
 - ... provides a really valuable set of data that can be used sometimes on its own but that's also not very useful just like any set of data on its own is limiting, but it's a set of data that we can put together with data that's constructed by adults ...*(1R).

Practical benefits for recruitment



- Co-researchers can access other participants because they are trusted (15R).



Ethical complexities

1. A hidden rationale: taking advantage of children's relationships / networks



- In a 'very knowing way' researchers are taking advantage of co-researchers' relationships:

... that's partly why you do it... you think that peers are much more likely to say yes ... so it's funny that we then pretend that that's not going on ... that's part of the benefit of using co-researchers ... we are mining relationships ... (11R)

Two problems:

1. Researchers are not being honest with themselves about what is a significant reason for using co-researchers
2. The child's relationships can be disrupted.

2. Child co-researchers may gain access to knowledge they would not otherwise have



- A co-researcher is not a stranger who comes and then leaves.
- Can find themselves with competing loyalties and obligations

... interviewing people who they have a past or a future with ... hearing something that might have implications for family or other community members that they, in a normal circumstance, would act on ... Are they a researcher or are they a community member or family member in that context and how do they negotiate that? I think that's quite difficult ... (11R)

3. Child co-researchers pressuring participants to take part



- The child co-researcher's relationship with other children means that they could pressure potential participants to take part (11R).
 - Surprisingly, not in the literature
 - Connected to the pretence that goes on around the reason for using co-researchers
 - The pressure that comes from using children's relationships, is not something that can be addressed by training.

4. Participants pressuring child co-researchers



- Participants (peers) could also put pressure on the child co-researcher.
- An adult researcher can easily say no
‘for young people who are members of that community, that’s a really difficult thing’ (11R).
- Again - may change the co-researcher’s relationship with peers or community.

5. Child co-researchers' exposure to distressing information



- Can cause difficulties
 - May feel unsafe after hearing other people's stories (14R).
 - May lead to stress and worry
 - worry about participants
 - feeling responsible for helping participants (R6;15R).

6. Possible burdens for child co-researchers



- The time-consuming nature of children's involvement
- Being a child co-researcher may not be a priority for the child
- Unspoken adult expectations

*... we put a lot of time and effort into this group of children and young people and they absolutely enjoyed it and did some great research. I guess **our expectation** as a service and as adults was **that they would then just go on and forever be researchers now that we've imparted all of this knowledge**. I've continued to stay in touch with many of them and **some of them just went "you know, that was a great experience and I learnt so much and it was really great and yeah, I might do it again, but actually not right now ... there are other things happening in my life"** ... (1R).*

The nature of children



- Child-co-researchers may regard their involvement in research merely as an interesting and enjoyable activity.
- Researchers may fail to respect the limited extent of children's insight beyond the enjoyable activity of a specific project.
- Expecting otherwise is potentially coercive.

The burden of unspoken adult expectations



- In the literature but as something that is not widely recognised or articulated (Michail and Kellett, 2015).
 - E.g. child co-researchers asking an adult researcher if they 'would be asked to present on their research and experience indefinitely' (Michail and Kellett, 2015).
- Important to give children opportunities to exit the research.

Researchers need strategies in place so children do not feel under pressure by real or perceived adult expectations.

How to address challenges



- Support

- ‘Careful planning’ (5R) ; close supervision (15R)
- Without access to support and resources, the research should not be done because it will not be ‘done well’ and it will be ‘open to criticism (1R)

- Training

- Using ethics scenarios (11R, 14R, 6R, 15R).
- Role playing e.g. anticipating situations where co-researchers have competing loyalties (11R, 15R).



Reflexivity



- Researchers need to reflect on how their research may affect child co-researchers before the research commences
 - Researchers' scrutiny of themselves and their role should include scrutiny of the research context, participants and co-researchers.

Questions for HRECs * added after feedback



from SEQ training day

Is there funding and resources to make sure child co-researchers are well trained and supported?

What strategies are in place should child co-researchers encounter something they cannot manage? *(i.e. need to identify and manage)

Can a child co-researcher leave the research project?

- What strategies are in place to allow this?

* What is the involvement of parent/guardian?

* Does this project have research merit?

* Have researchers demonstrated a need for child co-researcher/s in this project?

Questions reflexive researchers can ask



Does the use of child co-researchers in this project benefit children in general?	
How would using child co-researcher methodology lead to more beneficial outcomes for children generally, than not using it?	
Will child co-researcher methodology benefit children generally by producing better quality outcomes?	
In what ways will using child co-research enhance the project?	<ul style="list-style-type: none">- Improve the project?- Collect better data?- Other?
What difficulties might child co-researchers encounter in this project?	
How are child co-researchers going to be trained and supported to deal with these difficulties?	

For discussion: Research study: Supporting children and young people in out of home care



- **Aim:** To contribute to the evidence base to improve decision making about how best to support young people in out of home care.
- **Method:** Longitudinal, mixed methods, collecting information from multiple sources.
 - This phase uses co-researchers (ages 14-17 yo) who are part of a reference group, who access potential participants and conduct interviews with children & yp in OOHC.
- **Why this method?:**
 - Shared understandings / makes it safer for young people to talk
 - Authentic voice / deeper insight into the young people's worlds / better quality outcomes
 - Gain in confidence and vocational skills for co-researcher
- Do our questions bring up all the ethical issues?
- Does the project have research merit and integrity?

Questions – Child co-research



- When research is described as research **by** children, is it really research **about** children i.e. what is the focus, the children or the topic they are researching?
- What, if any difference, does the answers to this questions make?

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