

Ethics learning from Young Lives: 20 years on

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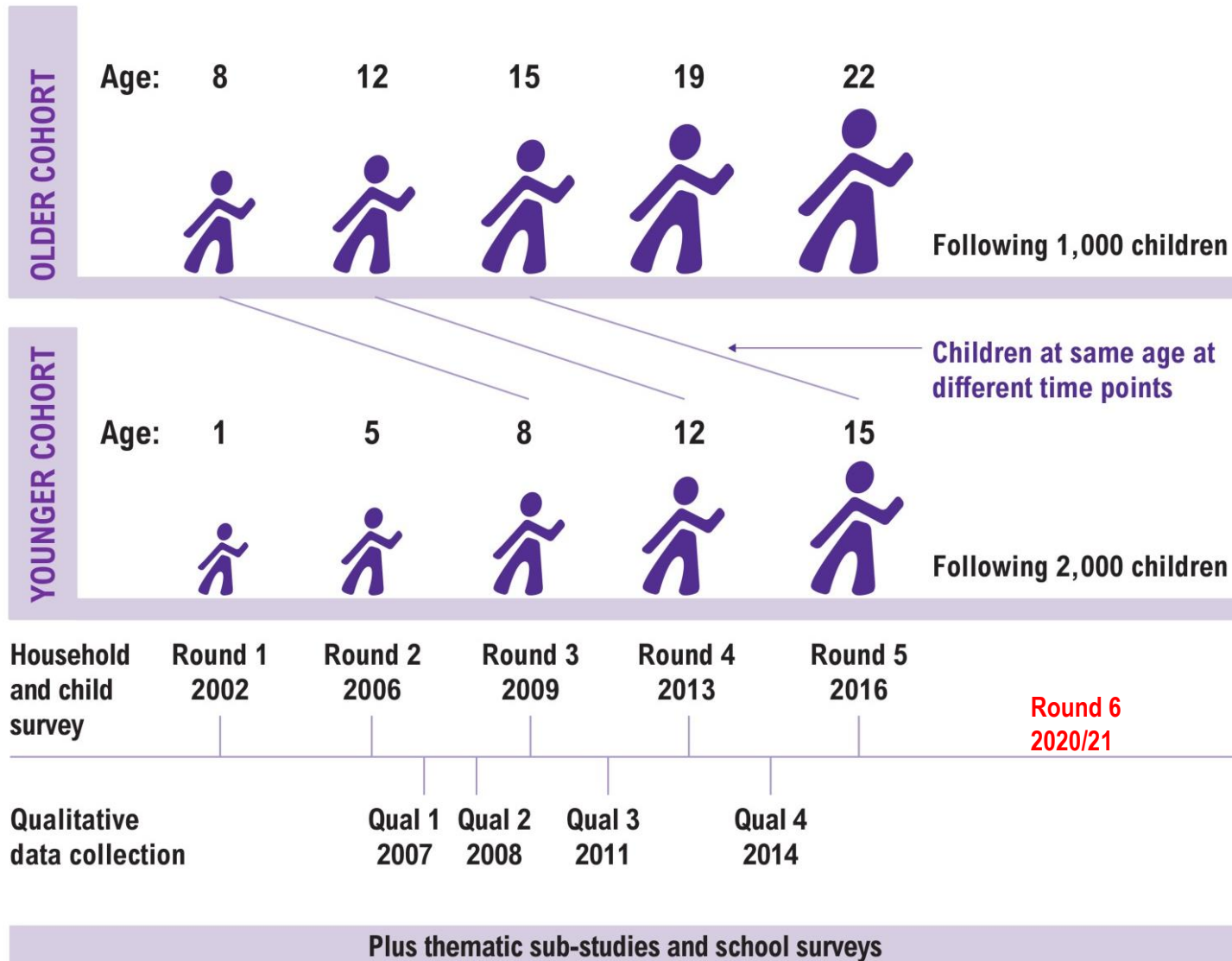
Learning from longitudinal studies in LMICs

Day 3, 13th May 2021

Doing and adapting longitudinal research: What have we learned?



Young Lives: 2001- 2024



Learning from Young Lives - ongoing ethics project

Young Lives has a robust ongoing and practical approach to research ethics, maintaining basic principles of trust, respect and reciprocity

Ethics covers all aspects - design, data-gathering (survey and qualitative research), dissemination, communications, and policy implications.

Together with Gina Crivello, we've been revisiting with our research teams their experiences, focusing on:

- Informed consent over time
- Relationships and reciprocity
- Child protection and safeguarding
- Maintaining anonymity
- Using photos and other visuals
- Experiences of RECs/IRBs

Research relationships and reciprocity

The success of the study depends on sustaining research relationships over long periods of time:

- Managing expectations of participants
- Try to avoid 'NGO' label
- 'Scripts' carefully developed with researchers and in training to explain the nature of the research
- Researchers negotiate professional boundaries – increasingly asked for their advice (school, work); drawn closer into families (asked to be godparents)

*At a personal level, I feel a lot of pity. They've been involved in the research for so long... [y]ou want to give the respondents something, but you may not be allowed. So, you're in between ethics and humanity.
(Researcher, Ethiopia)*

- Teams sometimes intervened in emergencies, such as in family health crises, or in child protection concerns, dealt with as a team on a case-by-case basis.

We are an observational study, and we are also humans. So, basically, when you see someone in need you need to find some way to help. On the other hand, Young Lives is not an intervention study and we don't have the resources to help families, so the difficult thing is to say when we should help and when we shouldn't... (Researcher, Peru)

Informed consent

- Power relationships and hierarchies - children generally taught from an early age that they must obey adults, which may make it difficult for them to refuse.
- Informed consent sought at each new round, and needed adapting - involving new participants (spouses, mothers-in-law, babies, etc)
- Young people increasingly ask questions about the study and their participation in it; can be challenging

Heightened expectations

- “After all these years...”

Why hasn't there been any change? (in my household, in the community?)

- “What advice do you have for my child and for my family?”

*You studied a lot about the children. You are like their family. I'd be happy if you gave us guidance on how they can grow and improve their lives.
(Habtamu's father, Ethiopia)*

- “When the study ends, will you help my son/daughter ...”

find a job, study, migrate, with dowry, to purchase land or housing, etc.

Concluding thoughts

Collaborative approach - co-producing ethics guidance, training, developing strategies, and creating spaces and time for shared problem-solving and learning.

Some challenges reflect the long-term nature of Young Lives, but may also be shared by shorter-term studies working in similar contexts/ with vulnerable populations.

It's impossible to predict all ethics questions that will arise, and it's vital to treat research ethics as an ongoing process (not a one-off tick-box exercise).

Need to simultaneously maintain basic ethics principles of trust, respect and reciprocity that underpin research relationships

References

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