Ethics Learning from Young Lives: 20 Years On

Introduction

Many complex ethics questions arise in the conduct of longitudinal research in low- and middle-income countries (LMICs), particularly in studies, like Young Lives, that involve children and other potentially vulnerable social groups over long periods of time. For the past 20 years, Young Lives has been studying the development and well-being of 12,000 children growing up in Ethiopia, India (in United Andhra Pradesh),[1] Peru, and Vietnam. The research aims to identify the determinants and outcomes of child poverty, and to inform policies and programmes that can benefit marginalised children and their families and promote social justice.

It was not possible to anticipate at the outset all the, often context-specific, ethical issues that would arise over the lifetime of the study nor to put in place all the protocols that would be required to address them. Moreover, the institutional contexts and norms around research ethics have changed significantly in the 20 years that Young Lives has been in operation.

Some of the ethics challenges experienced by Young Lives stem from the study's key design features, including its longitudinal, mixed-methods, observational and child-focused methodology. Occasionally, the study

This summary of the 'Ethics Learning from Young Lives: 20 Years On' report[2] outlines some of the main ethics challenges during the operationalisation of Young Lives, an ongoing longitudinal, mixed-methods, collaborative study of childhood poverty in four countries that began in 2001. Organised around seven themes, the summary distils key learning in relation to: informed consent; safeguarding; research relationships and reciprocity; sensitive questions; maintaining anonymity; using photos and visual images; and institutional research boards (IRBs). Sharing learning aims to contribute to the wider community of practice of longitudinal researchers working in low- and middle-income countries.

This summary was written by Gina Crivello. The full report details acknowledgements, photo credits, quotes, references and the complete list of learning points.

1 United Andhra Pradesh was bifurcated into the states of Andhra Pradesh and Telangana in 2014.

2 Crivello, G., and V. Morrow (2021) 'Ethics Learning from Young Lives: 20 Years On', Oxford: Young Lives.

has introduced new methods, such as using mobile phones for data collection during the COVID-19 pandemic; self-administered questionnaires for collecting sensitive information from adolescents; and visual methods for co-creating short films with a sub-sample of the young participants: each requiring careful consideration of the ethics implications.

The report discusses the main ethics challenges under seven broad themes: informed consent; safeguarding; research relationships and reciprocity; sensitive questions; maintaining anonymity; using photos and visual images; and institutional research boards (IRBs).

Negotiating informed consent over time

> “I am willing.”
>
> (Haftey, 24-year-old participant, Ethiopia

Young Lives' approach to obtaining informed consent has remained consistent over the years, and has emphasised respect for participants' dignity, anonymity, confidentiality, children's views, and voluntary participation. Consent in longitudinal research is an ongoing process, rather than a one-off step at the initial time of recruitment into the study. At each new round of data collection, field researchers convey a core set of information so that those invited to participate understand: the purpose of the research; what they are agreeing to do and how long it will take; how what they say will be used; that they and where they live will remain anonymous; that their participation is voluntary and does not bring them any direct benefit; and they can stop participating at any time.

Respecting children's right to assent

Informed consent is obtained from everyone involved – children, young people, caregivers, and others in the community. It is necessary to go through layers of adults (such as parents and teachers) before children can be approached to be invited to participate in the research. Young Lives has always gained both assent and consent, and children did not participate unless they agreed as well.[3]

> “If the child refuses to participate, he or she can withdraw even if parents have consented. As the children grew older, they started to consent on their own and we secured additional consent from their caregivers/parents.”
>
> (Ethiopia researcher)

However, there are challenges in seeking consent/assent from children in contexts where children are not treated as individuals with rights, or where they are taught from an early age that they must obey adults, which may make it difficult for them to refuse.

Changing layers of consent

Negotiating consent required engaging new participants, including the need to inform (and occasionally get permission from) new family members (for example, husbands of young women or parents-in-law, in some countries), as well as new participants not originally recruited into Young Lives.

As the children grew older, their participation was not so dependent on the willingness of their caregivers to also participate. It was important to acknowledge the evolving capacities of children and adolescents to make informed choices about their involvement in research.

Creating positive conditions for informed consent

One of the central challenges of a study of child poverty is that participants are likely to be poorer, less educated, and less powerful than members of the research teams, so relationships may not be so consensual, given power imbalances between researchers and respondents. Research teams developed tactics, such as the use of body language, that aimed to minimise power imbalances between researchers and participants, thereby contributing positively to the conditions that make informed consent possible.

Ongoing questions and misunderstandings about the study

Another main challenge has been ensuring participants are sufficiently informed to consent/assent. Consistent and repeated messaging about the purpose of Young Lives and the nature of participation has been vital in efforts to inform participants and to manage their expectations over the years. Yet misunderstandings remained.

With access to the internet increasing over the years, participants have accessed information about the study from other sources, including the Young Lives websites and social media, though this might only be a minority of the sample. Lack of information was not always the reason why some participants queried the purpose of the study or were hesitant to continue, since they might have understood the nature of the study, yet not agreed with certain aspects.

Introducing substantial changes to data collection

Occasionally, significant changes in methods have required altering and obtaining new consent from participants. For example, switching from in-person to phone-based surveys during the COVID-19 pandemic necessitated obtaining permission from participants to ask about new topics and to record the discussions, and to explain the amount of compensation provided for participating.

3 The ethics literature draws a distinction between consent (that can only be provided by individuals who have reached the legal age of consent) and assent (the agreement of someone not able to give legal consent to participate in the research).

Learning points on negotiating consent

- Informed consent within longitudinal research is an ongoing process, rather than a one-off step at the beginning of a study, and some aspects of the consent process may need to be adapted over time.
- Attention to social context and being prepared to involve a wider set of participants (spouses, in-laws, etc.) is important when seeking permissions, depending on local etiquette and power relations which need to be respected.
- Misunderstandings despite repeated explanations continue to be a challenge to informed consent.

Safeguarding

> "What is the right thing to do? We can't just hear that information and then do nothing."
>
> (Peru researcher)

The context of ethics and safeguarding has changed considerably in the last few years, with numerous implications for Young Lives practice. The concept of safeguarding in international development, focused on protecting individuals from harm or abuse, did not exist in its current form at the beginning of Young Lives, when such concerns were viewed through a 'child protection' lens within a broader understanding of research ethics that included a commitment to 'do no harm'. Safeguarding now subsumes child protection.

Safeguarding requires that referrals for formal support are available, which can make it difficult to research topics with vulnerable social groups in places where referral systems and services are weak. Indeed, in many Young Lives communities, referral systems are poor or non-existent and may even harm participants if local authorities are unable to protect victims against revenge or retaliation. The research teams have tried to adhere to robust and consistent protocols as far as possible.

Researchers are increasingly expected to (and in some countries are legally required to) report instances of abuse to local authorities, or to offer support to children who they suspect are neglected. But often no such support is available locally, and sometimes there is a risk of making things much worse if researchers try to investigate further or make the information public, and that justice systems might be too weak to respond appropriately. Decisions to report illegal activities, such as underage marriage or clandestine migration, that have already happened, have to be balanced with the need to adhere to confidentiality. Such predicaments demand that Young Lives continues to adapt and strengthen its safeguarding strategies to reflect on-the-ground realities.

Trying to solve problems

Researchers who interacted closely with the families often felt their hands were tied to help since they were unable to solve their problems or provide aid, unless in emergency situations. Young Lives had no (or very limited) financial resources to provide direct help to participants.

Research teams have intervened in emergency situations, such as a family health crisis, or in child protection concerns, which they discussed as a team on a case-by-case basis to determine whether and what course of action was appropriate and necessary, including referrals.

Seeking advice

Increasingly, families sought advice from the researchers with whom they had contact. However, in a longitudinal observational study, providing advice about support risks influencing findings or changing young people's outcomes; for some academic disciplines, this may invalidate the research. Many researchers maintained that offering advice when asked was an ethical response, even if there was a chance that it might alter a young person's pathway.

Protecting fieldworkers

Young Lives' experience underscores the importance of considering protection not only as a concern about children's well-being, but one that applies to everyone involved, including fieldworkers. Young Lives safeguarding policy, for example, includes an important focus on fieldworkers' well-being and safety. Safeguarding of fieldworkers also includes a gender dimension.

Psychological screening of fieldworkers was introduced in some countries but was difficult to sustain due to the high cost. Some teams hired psychologists to support fieldworkers in times of difficulty, and maintain WhatsApp groups with their research team members to encourage open communication and peer support.

Safety in a pandemic

The need to safeguard the health and well-being of Young Lives respondents and staff in light of the risks posed by COVID-19 required that survey development and administration be conducted remotely. Survey enumerators recorded cases of concern among the respondents to discuss in case follow-up was required. Enumerator well-being was also a concern and supported through regular telephone and online debriefings.

Learning points on safeguarding

- Safeguarding pertains to everyone involved in research and encompasses, but is not limited to, child protection.
- Referral systems are core to safeguarding, but in reality, may be poor; this may affect the research topics that can be addressed.
- Attention to field workers' psychological well-being is critical but often overlooked.

Relationships and reciprocity

> "We're like family now …"
>
> (Young Lives mother, Ethiopia)

Longitudinal research requires building and sustaining relationships of trust with the study participants over many years. Reciprocity, defined as 'balanced patterns of giving and taking between people' and 'giving back' to research participants, is a principal feature of Young Lives' ethics approach that helps to counter the potentially extractive nature of data collection and to minimise attrition. However, balanced reciprocity is complicated by the power differentials between researchers and participants, and by conflicting expectations among those involved regarding the nature of reciprocity and the research relationship.

Maintaining relationships is key to minimising attrition

Keeping participants in the study is crucial, but not at any cost. Preserving the cohort for future data rounds and taking steps to minimise respondent attrition and respondent fatigue over long periods is a methodological priority requiring practical steps such as intermittent tracking of respondents by telephone or in person, retaining the same field researchers, communicating the relevance of the study, and offering appropriate compensation to participants. At the same time, supporting respondents to exercise their choice to leave a long-term study (with the option to remove any or all of the information they provided over the years) without fear of retribution needs to be part of the ethical practice of managing research relationships.

Compensation and 'giving back' to families

Young Lives strives to compensate participants fairly and reasonably within the study constraints for the time, experiences and knowledge they contribute to inform and shape the research. It avoids incentivising with payments that might distort the consent process. Small amounts of cash, school supplies for the children, gifts to their schools, calendars, books, refreshments, and photos are some of the items that have been provided as compensation and gestures of thanks, at different times.

Research findings and information

Reciprocity has also taken the form of reporting research findings to the families, communities, local authorities, and government officials. Some research teams held discussions in the communities and with Young Lives families about the research findings. Participants were pleased when study findings based on their inputs were used in reports and were shared with government, but many also wanted to see improvements in their localities and households, or for their children to be provided with opportunities.

Unintended benefits

Even though Young Lives is not designed to offer direct benefits, some participants have described being 'helped' or having 'benefited' from the study:

> "I believe that I have acquired better knowledge compared to other children who are not part of the study. I was telling them the things you have been doing."
>
> (Older Cohort boy, Ethiopia)

Eliciting information from children about decision-making, their likes and dislikes, and aspirations, encouraged self-reflection and, in some cases, grew their confidence to express their opinions.

Familiarity and boundaries

The long-term nature of the study certainly influenced participants' views of the research relationship and the expectations they had. Several mothers who were part of the longitudinal qualitative study said they valued having someone to tell their life stories to and that they would miss this when the study came to an end. Personal bonds established over the years had to be balanced against the requirement to maintain professional boundaries. It is therefore a fine balance between ethical conduct and influencing the findings unduly.

COVID-19 amplifying challenges

The context of COVID-19 intensified many of the relationship and reciprocity challenges, and it has been necessary to maintain high ethical standards rather than to relax them. Equally, a flexible and practical approach was required as new challenges emerged.

The international survey team responsible for the COVID-19 phone survey devised several strategies for navigating sensitive questions, ensuring safety and privacy, and being able to respond appropriately to requests for help from research participants.

Learning points on relationships and reciprocity

- Develop strategies to understand and manage participants' expectations of the study and their involvement in it, since their expectations and circumstances can change over time.
- Avoid incentivising participants with payments that might distort the consent process, but it is important to provide fair compensation. Taking photographs of the children and families and giving them photos as thanks was widely appreciated and cost-effective.
- Maintaining professional boundaries can be a challenge in longitudinal research. Researchers who interact closely with families or participants over many years might feel compelled to act in a personal capacity, but this should be avoided.

Sensitive questions

> “I asked myself if I would have agreed to share this information if I was to be interviewed.”
>
> (India researcher)

It is well-recognised in research that questions we expect participants to respond to can be upsetting, though what counts as sensitive cannot always be predicted. Sometimes, our assumptions have been wrong, and questions that seemed innocuous brought up unexpected feelings or reactions.

Challenges and strategies

Some of the most difficult topics to talk about included: income; well-being; violence; sexuality, fertility and contraception use; marital conflict; and death, loss and bereavement.

Research teams employed a variety of strategies to help them navigate these, and other, sensitive topics, including exploring sensitive questions indirectly/subtly; taking time to listen carefully; understanding the local context; and avoiding asking certain questions.

Learning points on sensitive questions

- Anticipate and prepare for sensitive information to emerge in interviews, even if field questions do not elicit this information directly.
- Pilot questions and methods carefully in each context and be prepared to adapt (or drop) sensitive questions even if this means compromising comparability across settings.
- In line with current requirements relating to safeguarding approaches, identify and locate local potential sources of support on sensitive issues. If no support is available on particular issues, consider dropping any direct questions on these altogether.

Maintaining anonymity

> “… you can’t control everything.”
>
> (Peru researcher)

Maintaining participants’ anonymity is a cornerstone of ethical research practice. Young Lives protocol for protecting personal data/identities/locations has focused on protecting participants from outsiders (rather than protecting their confidentiality and anonymity from other people living within their communities, although this was also an important consideration). All data that identify respondents and their locations are personal data and are not put into the public domain.

Anonymising individuals

Breaches of anonymity are seen as a challenge by some Young Lives team members. In particular, it is difficult to keep secret who the Young Lives families are in smaller communities, although efforts to do so are also important.

Participants were not always aware of the risks of their anonymity being breached, and these risks could be explained to them by the researchers. In some cases, children and adults indicated they would prefer to be named rather than anonymised as point of pride, or because they felt they should be entitled to some help. However, this was not allowed.

Anonymising communities and locations

There were differing views and some debate within Young Lives teams about anonymising communities, with some team members thinking it would be acceptable and even preferable to name communities, to help introduce development programmes, and to allow other researchers to access the communities. On the other hand, principal investigators, who are responsible for maintaining the sample cohorts, are adamant that they want to prevent other researchers identifying and accessing the localities. Over the years, several journalists have requested access to the Young Lives communities or children, but these requests have been declined.

New social media

New social media (such as Facebook) has raised further challenges that meant that protocols had to be established to ensure that fieldworkers were not posting inappropriately. It has been difficult to anticipate or control how our social media and web platforms have been used, including by Young Lives participants.

Learning points on maintaining anonymity

- Maintaining participants’ anonymity and confidentiality is key to Young Lives ethical research practice, even though not everyone agreed and some might have preferred to name individuals and communities.
- Breaches of anonymity are a challenge and must be monitored and swiftly addressed.
- New technologies might increase the risk of breaches by external researchers and by participants themselves.

Using photos and other visual images

> “Photos and visual images are vital to help audiences understand the lived realities of the young people in our study – after all, a picture tells a thousand stories. We use images very carefully to ensure that we portray the reality of poverty without depicting powerlessness.”
>
> (Communications Manager)

Young Lives has used photos and visuals in three main ways: to elicit data from children and young people; as a form of research reciprocity; and to communicate the study findings. Anonymity, respect, and informed consent underpin the approach to using visual images for these purposes. However, their use in social research with vulnerable children and families invokes many ethical and safeguarding considerations.

Digital stories

In 2019, Young Lives experimented with digital stories as part of a qualitative sub-study on young marriage and parenthood in Ethiopia. The intention was for the young person to identify images that could serve as symbols within their story, so as to maintain anonymity. However, there were some challenges. For example, not all the images were anonymous and heavy cropping and editing was required when photos featured individuals/places/license plates/street names. Also, the young people influenced the photos used and the storyline, but the final scripts were ultimately crafted by Young Lives staff.

Reciprocity

Country research teams took photos of the families who participated in the study and gave them printed copies when they returned to their communities, as part of the approach to research reciprocity. Most families appeared to appreciate the photos.

Communicating research findings

The commitment to maintain participants' anonymity prevented the use of images of the children, young people, families or communities involved in Young Lives. Instead, Young Lives commissioned local photographers in the four countries to create photos with parallel samples. Some members of Young Lives research teams did not agree with the decision to use photos of individuals not involved in the study, and would have preferred to use drawings instead.

Increasingly, Young Lives has used or commissioned infographics and illustrations to communicate messages around particular research themes (rather than to represent individual participants). These are easy to anonymise; however, they can be relatively costly to produce and are more limited in their range of uses compared to using photographs.

Maps are also used in papers and presentations, and it is important that any geographic maps including Young Lives research sites be indicative rather than precise, so that they cannot be identified. Monitoring for potential breaches in anonymity is continuous.

Learning points on using photos and other visual images

- Maintaining Young Lives' commitment to anonymity is crucial, even if this has limited the storytelling power of the photos used.
- Photo-based methods have been effective in eliciting information from children and young people about their everyday environments (homes, schools, neighbourhoods), and children enjoyed taking part in these.
- The children and their families greatly appreciated the photos they were given by the study, which were an important aspect of research reciprocity.

Institutional research boards (IRBs)/ research ethics committees (RECs)

> “It was always up to us to report back problems.”
>
> (Oxford researcher)

Over the lifetime of Young Lives, international and national approaches to research ethics approval have changed. Initially, approval was only sought from the University of Oxford REC, but with the expansion of global research ethics awareness and necessity for ethics approval, approval has been sought in each country (for both survey and qualitative research), and country-level approval now runs in parallel with Oxford University's approval process. Some of the decisions of local IRBs may be in conflict with the comparative research design, but the decisions have to be respected. In some countries, it has taken time to identify appropriate IRBs, and some ethics committees seem more rigorous than others, depending on previous experience.

In one country, researchers are invited to attend the IRB meetings to explain their approach (e.g. oral versus written consent) and to report any cases recorded during fieldwork that raised ethics questions and how they responded to these. Such iterative processes contributing to shared ethical learning are not part of the institutional ethics requirements in Oxford, nor in the other Young Lives countries, although we see these processes as extremely valuable.

Learning points on IRBs

- National and local ethics committees tend to be focused on clinical or medical research, especially clinical trials. However, broad social science RECs are increasingly available in LMICs, and ethics clearance should be obtained in the study country where this is possible.
- With multi-partner north-south collaborations, a collaborative approach is necessary and useful. Avoid the temptation to seek approval from an IRB in a study country where ethics governance is presumed to be less stringent than in others, and/or to settle with one ethics approval for the whole of the study when this is allowed.
- If possible, report back learning to ethics boards, so that it is not just a bureaucratic process, perhaps by using anonymised case examples, local knowledge, and concepts that might not be reflected in formal applications.

Conclusion

Young Lives has navigated numerous ethics challenges since it began two decades ago. The longitudinal nature of the research has required a flexible approach and oscillation between differing ethical strategies, reflection and learning. Young Lives has tried to be as consistent and robust as possible, while at the same time acknowledging the situated and emergent ethical decision-making of daily dilemmas and lived research experience that often escape documentation and debate. It takes a positive approach to research ethics as central to the study's continued successful execution, and to the production of trustworthy and high-quality data.

Some ethics challenges can be amplified in long-term research, such as negotiating informed consent, maintaining anonymity, managing participants' expectations, and ensuring reciprocity in imbalanced power relationships between researchers and participants. Involving children and families from disadvantaged social and economic groups over many years in such studies can further compound these challenges.

Ethical practice within longitudinal research should therefore be ongoing and iterative, rather than a one-off 'tick-box' exercise, and every member of the research team has a responsibility for ethical conduct in their role. Documenting and discussing ethical dilemmas in research continue to be encouraged across the Young Lives team, as the need for ethical conduct and for awareness of the power imbalances between Young Lives staff and respondents spans the whole study, from design to implementation to data governance to policy and communications, over many cycles.

Young Lives is an international study of childhood poverty and transitions to adulthood, following the lives of 12,000 children in four countries (Ethiopia, India, Peru and Vietnam) since 2001. Young Lives is a collaborative research programme led by a team in the Department of International Development at the University of Oxford in association with research and policy partners in the four study counties. This report has been funded by the Economic and Social Research Council.

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Young Lives, Oxford Department of International Development (ODID)
University of Oxford, 3 Mansfield Road, Oxford OX1 3TB, UK

www.younglives.org.uk
Tel: +44 (0)1865 281751 • Email: younglives@qeh.ox.ac.uk • Twitter: @yloxford