



## Ethics Learning from Young Lives: 20 Years On

Gina Crivello and Virginia Morrow

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The views expressed are ultimately the authors' and we take responsibility for any errors. The views are not necessarily those of, or endorsed by, the University of Oxford, Young Lives, the UK government, ESRC or other funders.

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# About Young Lives

Since 2001, Young Lives has studied the development and well-being of 12,000 children growing up in Ethiopia, India (in United Andhra Pradesh),<sup>1</sup> Peru, and Vietnam.<sup>2</sup> The research aims to identify the determinants and outcomes of childhood poverty, and to inform policies and programmes that can benefit marginalised children and their families and promote social justice.

Young Lives is an observational study, meaning it does not carry out interventions or experiments with participants. It is conducted with two cohorts of children born seven years apart – 8,000 in the Younger Cohort born in 2001/2, studied from infancy, and 4,000 in the Older Cohort born in 1994, studied from age 8.

Data collection has so far comprised:

- Five rounds of individual and household survey questionnaires administered along with community questionnaires every three to four years to synchronise the ages at which the two cohorts are interviewed.
- A telephone survey in 2020 during the COVID-19 pandemic, when the Younger Cohort were around 19 years old and the Older Cohort around 25.
- Four waves of nested longitudinal qualitative research over a seven-year period in each country (five in Ethiopia), with a subset of over 200 boys and girls and their caregivers, from the core sample.
- Seventeen qualitative sub-studies covering specific topics, including children's work, children's experiences of violence, and adolescent marriage and parenthood.
- School-based surveys (from 2010) in primary and secondary schools to examine children's learning and school efficacy across a range of contexts and education systems, involving some 30,000 school pupils, 4,377 of whom were from the Younger Cohort, and selected teachers.

Another round of phone surveys in 2021 and a Round 6 household survey are planned, with fundraising underway for further qualitative research and additional surveys. Spanning the first three decades of life, the data can tell us how children's earlier life circumstances affect their later outcomes, and about the nature and dynamics of inequalities across the early life course.

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

2 For profiles of the Young Lives cohorts, see Barnett et al. (2013) and Favara, Crivello, et al. (2021).

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# Young Lives international research partners

Young Lives is a collaborative research programme coordinated by a team in the Department of International Development (ODID) at the University of Oxford, with partners that include research institutes, universities, NGOs and government statistics departments in the four study countries. Young Lives transferred from a UK-based academic consortium to the University of Oxford in 2005, and since then has been managed through a partnership structure underpinned by a collaborative framework agreement. In Ethiopia, the partners are the Policy Studies Institute and Pankhurst Development Research and Consulting plc; in India, the Centre for Economic and Social Studies, Hyderabad (CESS), Sri Padmavati Mahila Visvavidyalam (Women's University), Tirupati (SPMVV), and Young Lives India Research to Policy Centre, New Delhi; in Peru, Grupo de Análisis para el Desarrollo (GRADE) and Instituto de Investigación Nutricional (IIN); and in Vietnam, the Centre for Analysis and Forecast, Vietnam Academy of Social Sciences (CAF-VASS) and the General Statistics Office of Vietnam (GSO).

The team comprises many complementary roles and disciplines: in Oxford and the study countries there are principal investigators, survey and qualitative researchers, data managers, country directors, policy officers, communications staff and programme administrators. Country teams focus on country-level research activities and national policy influencing, while the Oxford team works across the four countries and internationally. The size and make-up of the team have varied over the years, mostly due to funding. Several country researchers have been with Young Lives since the beginning, offering valuable continuity in terms of experience and relationships with the sample communities.

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# 1. Introduction

Many complex ethics questions arise in the conduct of longitudinal research in low- and middle-income countries (LMICs), particularly in studies that involve children and other potentially vulnerable social groups over long periods of time. Agreed ethical standards, to which Young Lives strives to adhere, emphasise principles of justice, respect and informed consent, and of maximising benefits while avoiding doing harm to the people involved (ESRC 2015). There is a well-developed ethics literature on children and youth in social research (Alderson and Morrow 2020), including in development and humanitarian contexts (Berman et al. 2016; Powell et al. 2013; Schenk and Williamson 2005), and in international development research, safeguarding has become prominent (FCDO 2021). However, researcher reflexivity and the publication of lessons learned in navigating research ethics in longitudinal studies are seldom prioritised by researchers; nor are they usually a requirement of research funders or of the institutional ethics boards that give approval for the research to take place.

This report outlines some of the main ethics challenges during the operationalisation of Young Lives, an ongoing longitudinal, mixed-methods study of childhood poverty in four countries that began in 2001.<sup>3</sup> Twenty years on, the 12,000 children who first joined Young Lives are now adolescents and young adults; over this period, they and their families have generously provided detailed information about their changing lives, circumstances, behaviours, relationships, environments, hopes and aspirations – with limited direct benefit to them for their ongoing participation. The study and research teams have also evolved and have met numerous ethical and practical challenges, some planned for, others unexpected, along the way.

## 1.1. Key design features

Some ethics challenges emanate from the key design features of Young Lives, including its longitudinal, mixed-methods, observational and child-focused methodology. The **longitudinal** design entails repeatedly asking questions about poverty and illbeing, which risks re-traumatisation if it reminds participants that their lives have not improved. Yet, repeating questions at each round is a key feature of longitudinal cohort research.

Moreover, longitudinal research requires building and sustaining relationships of trust with the study participants over many years. Research reciprocity, defined as ‘balanced patterns of giving and taking between people’ and ‘giving back’ to research participants, is core to relationship-building and is considered good research ethics practice (Crow 2008: 739), although what constitutes ‘giving back’ and the exact nature of ‘benefits’ can be strongly contested (Molyneux et al. 2012). The ethics of paying participants (Head 2009), including child participants (Wendler et al. 2002), is also disputed among researchers.

Reciprocity 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 (see Section 4 and Section 2).

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3 This ethics report is one of a series of methodological reports and outputs produced as part of the two-year Methodological Lessons and Learning in Young Lives project funded by the Economic and Social Research Council (ESRC). Other reports address data management and governance (Boyden and Walnicki 2020), research design and analysis (Boyden et al. forthcoming) and research leadership and impact (Boyden forthcoming).

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The **mixed-methods** design has implications too, as efforts to arrive at a shared understanding of ethics within the research team requires discussions across differing academic traditions and disciplines (economists, educationalists, social anthropologists, development psychologists, nutritionists, social workers, and sociologists). Not everyone shares the same views on ethics, perceptions of risk, or understandings of children and childhood, reflecting researchers' diverse epistemologies and socio-cultural influences.

Quantitative researchers in Young Lives generally take a positivist approach and emphasise the study's **observational** (non-interventionist) design, such that the research should neither change the lives nor influence the phenomena under investigation. Qualitative researchers tend towards a more interpretivist approach and accept that the research endeavour is a co-production of knowledge and meaning involving researchers and their interlocutors in a complex relationship. Conversations with participants about their experience of being involved in Young Lives research have also been systematically recorded, transcribed, translated and coded in the qualitative research, and this documentation can be analysed for points of learning. It might be that the selection of a small sub-sample of participants in the qualitative research affects their perceptions of and relationship with the study, and in some cases, participation in Young Lives appears to have influenced behaviour change or children's aspirations. Such insights can create tensions within the wider research team since survey research tends to be wary of 'contamination' of data (Boyden and Walnicki 2020). Moreover, the observational design limits the extent to which the empowerment of individuals can be an explicit goal of the research, which may conflict with feminist methodologies espoused by some of the researchers.

Nevertheless, the **child-focused approach** promotes children's participation from early ages in both the survey and qualitative research, along with their parents/caregivers. The conduct of child-focused longitudinal studies is widely recognised as important in the identification of interventions that might contribute to positive outcomes and 'second chances' for disadvantaged, vulnerable, and/or marginalised young people (Auerswald, Piatt, and Mirzazadeh 2017; Crivello and Morrow 2020; Patton et al. 2016). Young Lives' qualitative research aims to bring children's and young people's perspectives and experiences to the fore, at times leading to the research inadvertently uncovering child protection and other concerns that often require an immediate response by local research teams (see Section 3). Children's involvement has also meant greater scrutiny when applying for ethical clearance, as most institutional review boards (IRBs) consider children a vulnerable group on the basis of age (see Section 8).

Relatedly, involving **multiple generations** of children and their caregivers has occasionally created tensions during fieldwork when caregivers were curious to know what their children talked about in the research activities, and asked fieldworkers to tell them. The promise of confidentiality to the children meant that researchers could not disclose the details of their conversations and have had to respond at a more general level, risking upsetting parents.

The **particular methods** for gathering quantitative and qualitative data also have ethics implications, such as in the survey, when children with low levels of numeracy or literacy are asked to take maths and vocabulary tests on which they will inevitably score poorly; or in the use of visual images and written exercises such as timelines and daily diaries in the qualitative research that could breach respondent anonymity if not carefully managed (see Section 7).

Occasionally, the study 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.

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The multitude of ethics challenges experienced by Young Lives do not stem from any one feature of the study design. Rather, it is the combination of features and their intersection within a longitudinal study design that contribute to the experiences highlighted in this report.

## ***1.2. The need for responsive ethics strategies***

According to Neale (2021), longitudinal researchers employ both ‘proactive strategies’ provided by pre-existing ethics protocols, procedures and institutional frameworks, and ‘reactive strategies’ that pertain to the situated and emergent ethical decision-making of daily dilemmas and lived research experience. Both types have been vital in Young Lives experience since 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. Our view is that ethics practices in longitudinal research should be ongoing, iterative, and generative, rather than a one-off ‘tick-box’ exercise. The longitudinal nature of Young Lives has required a flexible approach and oscillation between differing ethical strategies, reflection and learning. Even so, ambiguity, disagreement, and tension in ethical decision-making remain, not least because of the power imbalances and constraints that underpin studies like Young Lives that engage vulnerable cohorts of children and their families over many years.

Moreover, the institutional contexts and norms around research ethics have changed significantly in the 20 years that Young Lives has been in operation. Young Lives’ initial research proposal in 2000 was reviewed by a research ethics committee at the London School of Hygiene and Tropical Medicine, and draft questionnaires were piloted in South Africa in 2001-2002, and then approved by the Rand Afrikaans University (Morrow 2013: 22-3). Save the Children child protection protocols (2003) were used for fieldworkers, as Save the Children was a partner in the early phases.

Initially, Peru was the only study country with a tradition of seeking research ethics approval and an appropriate research ethics committee, but over time, local ethics boards became available in the other countries. When Young Lives transferred to the University of Oxford in 2006, ethics approval was obtained from the university’s Social Science Division Ethics Committee, as well as research ethics committees in Peru and Vietnam.

Research ethics approval has been sought from the University of Oxford at each new round of data collection, and in each study country (see Section 8). However, the shift towards using local IRBs creates the potential for different norms around ethics to be in conflict. Respect for local norms is important but can be complicated and may reduce the comparative nature of the study, for example, when certain survey modules and questions that are judged to be inappropriate are removed for one country, but not for others. For over ten years, a member of staff was embedded in Young Lives to advise/lead on research ethics within the Oxford team and was a point of contact for members of the international team when they had ethics questions. Country teams have shared many ethical difficulties with the senior staff in Oxford, who advised and intervened on a number of occasions, sometimes consulting with the university ethics committee.

In 2020, Young Lives developed new safeguarding and whistleblowing policies that led to safeguarding officers being assigned in each of the country teams and in the UK. 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 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

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systems are poor or non-existent and may even harm participants if local authorities are unable to protect victims against retaliation (see Section 3).

Young Lives' approach to research ethics includes, but is wider than, safeguarding. Documenting and discussing ethical dilemmas in research continues 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.

### ***1.3. Organisation of the report***

The insights in this report come from individual and group interviews about research ethics practice with long-term members of the international research team (principal investigators, researchers, country directors, programme administrators, and policy, communications and data managers), across five countries (Ethiopia, India, Peru, Vietnam, and the UK). We also drew on project documentation, including information from interviews with Young Lives families and fieldworkers' notes.

A review of these data identified seven themes: informed consent; safeguarding; research relationships and reciprocity; sensitive questions; maintaining anonymity; using photos and visual images; and IRBs. For each theme, we offer key points of learning and illustrative examples from Young Lives experience, in particular highlighting aspects of change over time.

Crucially, Young Lives 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. By discussing the struggles as well as the successes, our aim is to contribute to the wider community of practice of longitudinal researchers working in LMICs. It is in this spirit of shared learning that we offer this report.

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## 2. 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 (Morrow 2009). Informed consent is obtained from everyone involved – children, young people, caregivers, and others in the community.

The longitudinal nature of Young Lives has required treating consent as 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; their participation is voluntary and does not bring them any direct benefit; and they can stop participating at any time.

Despite relaying this information over many years, the research team faced numerous challenges in operationalising the principle of informed consent.

### ***2.1. Respecting children's right to assent***

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. 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 (agreement of someone not able to give legal consent to participate in the research) (cf Santelli, Haerizadeh, and McGovern 2017). Many researchers (still) feel that parental consent is enough, but the principle of children's consent (or assent) is important (but contested, see Alderson and Morrow 2020).

Young Lives has always gained both assent and consent, and children did not participate unless they agreed as well. For example, multiple layers of consent and assent were required to conduct the school-based survey, involving the agreement of head teachers, classroom teachers, parents, and children. Even if teachers and parents gave their approval, students still had the option to not join the research and to do a different activity if they wished.

Fieldworkers explained the research in ways that enabled children to understand. Every effort was made to not put pressure on children to participate, and to make it clear that there would be no adverse consequences if they declined. One of the qualitative researchers in Ethiopia explained:

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.

However, there are challenges in seeking consent/assent from children in contexts where children are not treated as individuals with rights. In many societies, children are generally taught from an early age that they must obey adults, which may make it difficult for them to refuse. A senior member of the India team remarked:

What's been important is that our researchers have taken on board that respondents have the right to stop the interview at any point or to not participate in the study. I think it's very well understood by everyone that we have to respect them. In earlier rounds, I would have worried

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about the Older Cohort and Younger Cohort, particularly when they were 8 and 12 years old, as to whether they really exercised their choice ... because of the power dynamic in countries like India, when an adult says, 'do it', then you just do it.

A senior researcher who has been part of the study for many years raised the critical question of 'how consensual is consent, and how informed is informed?' in the contexts where the research takes place:

I'm really not sure given the hierarchical nature of many of these societies, and the fact that children are not normally consulted: they're not normally asked to consent to things. I mean, after all, they don't, in some cases, consent to who they marry, so why would they feel empowered enough to say 'no' in research if they don't feel empowered enough to say no to getting married when they don't want to or to somebody they don't like?

The idea of children being asked to consent/assent is quite alien in many cultures, and some parents did not understand why asking the younger children was necessary if the parents had already given their permission. A qualitative researcher in Peru recollected:

We explained to the mothers that we were also asking their little ones if they wanted to be part of the study, and the mothers were amazed by the idea. They felt like, 'I already said yes, you can talk with him/her'. We said, 'yes ... but we need to ask them'. They were surprised ... but finally they said 'ok ... you ask them whatever you want. I already said yes'.

Further, as the children grew older, their participation was not so dependent on the willingness of their caregivers to also participate. A survey researcher in Peru observed:

There are times when you see, for example, that the mother doesn't want to be involved anymore but the young person might want to, and sometimes the mother will say, 'Well, I'm not really that interested in the project anymore but if my son wants to participate, then let it be'.

Children in many of the Young Lives communities began to take on (what might be considered 'adult') responsibilities from a young age, and in their teenage years, many reported marriage, first-time parenthood, independent migration, full-time work and significant caring responsibilities. This complicated our age-based approach to assent/consent, requiring a stronger relational and contextual lens. It was important to acknowledge the evolving capacities of children and adolescents to make informed choices about their involvement in research (Santelli, Haerizadeh, and McGovern 2017).

## ***2.2. Changing layers of permission***

Although the conventional model of informed consent is based on 'the primacy of the individual', in many contexts where Young Lives research is undertaken, the emphasis on the individual takes less precedence than the collective or community. Negotiating consent requires 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. For instance, the study involves local authorities and government officials, and as one researcher explained, 'the hierarchy keeps changing, so new people fill the role and you need to explain from the very start, since they might be expecting something from the study'.

Moreover, when researchers returned to the study communities, young participants were often found in a different family circumstance than before, requiring flexible approaches to consent. Respect for local cultures demands that some research teams treat male and female participants slightly differently, such that a wider web of consents and courtesies pertain to accessing girls and young women compared to boys and young men. Indeed, even as the cohorts reached 18

years of age, gender-age hierarchies within families and communities warranted sensitive approaches:

For married young women, in addition to the young woman and her husband, we also obtained consent from her parent/caregiver – but more like informing them. (Ethiopia researcher)

For married girls, the consent of the spouse was obtained again, orally, for her to be interviewed. However, the caregiver continued to facilitate the consent. The girls returned to their maternal home and were interviewed there. (India researcher)

The same approach was not applied to married young men (their wives were not asked for permission unless they were invited to be interviewed) because local cultural and power dynamics/logics did not demand this. In some cases, careful explanations were required with new participants or their family members to assuage fears of potential negative repercussions on themselves and their families. One researcher who has been involved in Young Lives since 2008 explained:

[N]ow some of the Young Lives children are married and we may involve their spouses. In that case, you start all over again explaining the nature of the research. So, they're new to the research and there is still some level of expectation from them ... [I]f we're interviewing the wife, sometimes he might raise questions. 'Who are these people?' ... [t]hey might think we're going to take them to court, or there's a legal issue. He may fear that he's married a girl when she's not yet 18 and we have come to sue him. (Ethiopia researcher)

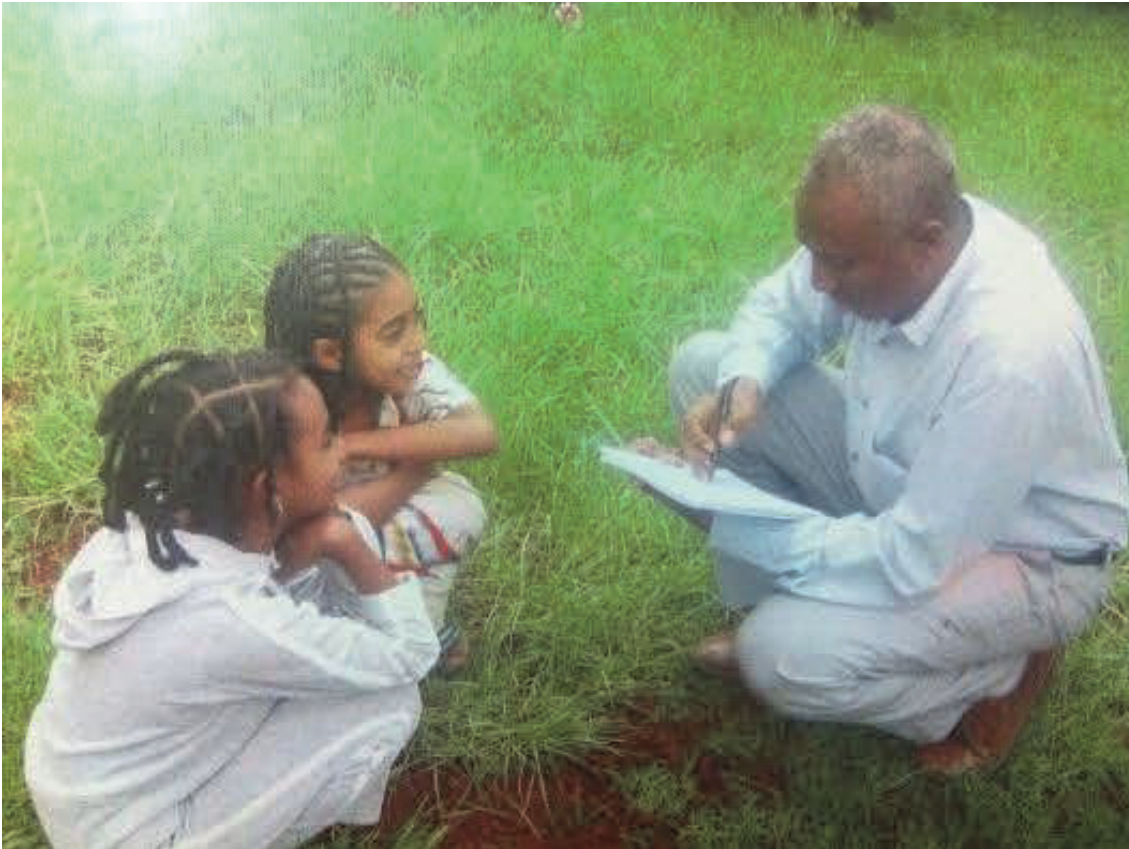
We are aware that such protocols aimed to respect local cultures and to maintain the integrity of the cohort over time not only reflect gender and generational hierarchies but, in some ways, also serve to reproduce them. In India, for example, it was culturally appropriate that senior male field supervisors first approached the girls' families to broker the initial consent process, since they were both familiar to the families and possessed male authority, even though female enumerators were assigned to administer the surveys to female respondents.

### ***2.3. 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 (Morrow 2009). Working with country field researchers who understand the local hierarchies has been invaluable for devising strategies that acknowledged such barriers. For example, Figure 1 was one of a series of images developed for training purposes by the lead qualitative researcher in Ethiopia, with his daughters, ahead of the first wave of qualitative data collection in 2007 when the Young Lives children were between 6 and 13 years old. The images showed the adult researcher (him) in a variety of sitting/standing positions in relation to the child participants (represented by his daughters) to suggest ways researchers might use their body language to make children feel more comfortable talking to them.

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**Figure 1:** Example of images developed for training purposes by the lead qualitative researcher in Ethiopia



Source: Photo courtesy of Mahlet, Eden and Yisak Tafere, 2007.

In a similar vein, the survey coordinator in India said that it was common when there was only one chair available during an interview for families to offer it to the Young Lives researcher; however, training emphasised that in such situations, it was appropriate for the researcher to sit on the floor with the participant or to ask that they sit in the chair instead.

Such tactics, however small or temporary, sought to minimise power imbalances between researchers and participants, thereby contributing positively to the conditions that make informed consent possible. But they had to be managed carefully, so as not to cause offense or risk losing credibility among the community hosts and other research interlocutors.

#### ***2.4. 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. Young Lives has been associated with the government, especially in Vietnam and Ethiopia, since government departments have been involved in data collection; and it has been confused with international NGOs, especially in communities with a heavy NGO presence. Early on, in one country, the research team were transported to the communities in a vehicle branded with the logo of a major international NGO that was a project partner at the time, but they stopped using those vehicles because it understandably caused confusion in the communities (Boyden and Walnicki 2020: 23).

In some cases, researchers' well-intentioned efforts to thoroughly inform participants as part of an ethical commitment backfired, reinforcing rather than mitigating against misunderstandings.

According to one Ethiopian researcher, who has been part of the study since 2008, 'The standards in the UK are strict, but we needed to customise in Ethiopia'. He went on to say:

I think the first challenge is when we try to explain everything in terms of how the study is being run by the University of Oxford in collaboration with the Government of Ethiopia. It raises the hopes and expectations of the respondents.

Young Lives new safeguarding policy requires that each country has a safeguarding lead coordinated by a focal member of staff at Oxford whose contact details are provided (in addition to the usual local contacts) in case participants wish to raise a concern at that level. However, referring to previous experience, one of the researchers pointed out that:

Whenever you name the foreign organisations, they think it's an aid organisation, even if you explain that they're research organisations. So maybe starting with the name of the organisation raises the expectation of the participants. (Ethiopia researcher)

Over the years, Oxford-based Young Lives team members have visited country teams for national and international team meetings, training and data sharing workshops, and for intensive periods of piloting in non-Young Lives field sites. The general rule has been that Oxford-based staff should not visit Young Lives communities, but this has varied between countries, and in some cases, country teams and Oxford team members felt that brief visits to communities could greatly enhance understanding of the contexts of the research. Such visits came with a risk since the visibility of the Oxford-based researchers and association with the field teams potentially disrupted social dynamics, generating misunderstandings about the nature of the study, even though the Oxford researchers were not involved in interviews or survey administration.

In earlier rounds, like Wave 2 [in 2008], in at least two of the communities I was involved in, when they saw foreigners, the families were expecting the children to be taken away, so they hid their children. (Ethiopia researcher)

The picture is more complicated still, as most survey enumerators and field researchers do not reside in the Young Lives communities, in relation to which they can be viewed as 'outsiders'. Their purpose for being in the community may also raise questions among locals, as some earlier examples showed. In one community in India, villagers believed the researchers were part of a film crew for the *Racchabanda* programme (a popular regional television programme in which a famous Tamil and Telugu actress helps families solve marital disputes) when the researchers were caught up in a large-scale commotion caused by a family dispute near their research activity, as one of the senior researchers was mistaken for the programme host.

Examples like these highlight the importance not only of the information that is communicated as part of the informed consent process, but also the social and relational contexts in which this occurs (cf. Dunn 2016). In a study spanning 20 years, it can be difficult for participants to understand why researchers keep coming back and suspicions about researchers' 'real' motives are bound to arise. According to a senior researcher in Peru, involved in the study since 2007:

[A]t the very beginning, [the families] had a lot of questions about 'what is the purpose of this study?', 'are you going to take my son, because you are a bad person?' The next question was, 'are you going to take him later on in order to give him better opportunities in education, please take him' ... that was another request. But we tried again to offer clarity; and that's a question that was raised at each round of fieldwork, despite explaining it.

Such questions were asked in all four study countries. For example, one of the qualitative researchers in Vietnam wrote in his field notes:

The father asked me, 'After the research ends, will you get [my son] a job?' I was quite surprised by his question, so I had to introduce the purposes of the research programme again. It seems

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that every time, the researchers clearly introduced the purposes, but after quite a long time, people still kept a certain hope in the research programme.

On the other hand, according to an Ethiopian researcher, explaining the study ‘over time can get easier, since many details are known, fewer questions [are] asked’. Sometimes researchers asked participants about their understandings of the study’s purpose. One young woman answered:

In my opinion, it is meant to investigate: what kinds of things are harmful to the community? What kinds of activities are being done? What does the educational capacity of students in this area look like? Who are the rich and who are the poor? I think it is about all of this. (Female participant, age 22, Ethiopia)

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. One of the researchers in Vietnam noted that a father of one boy had developed a good grasp of the study through his own efforts:

[The father] said that he had researched and learned fairly well about the Young Lives research programme. He told me clearly, ‘About the Young Lives research programme ... I already read about it in 2009. Children who were born with both parents but could not finish studying or did not have the opportunity to study. Although they really want to study, due to their family circumstances ... like that, their parents do not let them continue going to school; instead, they have to earn a living. I remember that I read from *Family and Population* magazine, and there are five provinces, including [H, L, D, B and P]. There are more than 3,000 children from 7 to 15 years old.

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. In Vietnam, the following exchange took place between a caregiver (an orphaned girl’s aunt) and a qualitative researcher:

Researcher: I mean, do you want Young Lives to do anything differently?

Aunt: Of course, I do.

Researcher: What do you want?

Aunt: I want that she could change her life.

Researcher: But what do you want Young Lives to do differently?

Aunt: To help her with a piece of land, a house, that’s what I wish ...

## **2.5. 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 (see Section 4.6).

Another significant change is being considered in Peru for 2022 as part of a Medical Research Council (MRC) grant to collect biological markers (biomarkers) to study increased rates of overweight and obesity in Young Lives participants in urban areas. If the fully planned study goes ahead, it will involve a questionnaire survey and blood samples from the young people, to understand early predictors of adult obesity and cardiovascular risk. Partial ethics approval was obtained before the pandemic stalled progress and further ethics approvals will be sought in Peru and the UK. Embedding this new component within an existing longitudinal study raises

numerous ethics challenges. Researchers will need to explain to participants that their blood will be genotyped, how it will be stored and other potential uses, and any risks involved. Researchers will emphasise the voluntary nature of participation and that participants will have the option to opt out of the study, but this comes with the risk that they might choose to opt out of Young Lives altogether. If analysis determines that a participant is at specific risk, support and advice will need to be given to individuals worried about their results, and recommendations (e.g. dietary improvements) will be provided. Due to safety and handling requirements, the blood samples will need to be taken at a health clinic. This is a big shift in the context of data collection, since research interactions would normally take place in the young person's home rather than in a clinical setting, and this might affect participants' understandings of Young Lives.

Clearly, many factors influence informed consent and in longitudinal studies these can be dynamic, but the basic principles need to be upheld, for example when child participants grow into adults, and when substantial methodological changes are introduced.

### **Learning points**

- 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.
  - Scripts, in simple language, help field researchers convey a core set of consistent information as part of informed consent; these can be adapted for specific contexts to allow for cultural differences, and need to be reviewed and updated before new data collection.
  - Misunderstandings despite repeated explanations continue to be a challenge to informed consent.
  - Careful consideration of who from within and from outside the research team is permitted to visit the study communities or interact with the research participants, when and for what purpose, is critical to avoid confusion.
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## 3. Safeguarding

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

A vital element of a study of childhood poverty in diverse LMIC contexts has been child protection. From the outset, Save the Children protocols were adhered to and expanded, with a memorandum of understanding for fieldworkers later developed (see Appendix, and Morrow 2009). The context of ethics and safeguarding has changed considerably in the last few years, with numerous implications for Young Lives practice. Young Lives has faced and dealt with many safeguarding challenges over the years, even though the concept of ‘safeguarding’ was not well developed in the early stages of the study. Young Lives has also tried to be attentive to fieldworkers’ well-being. Safeguarding now subsumes child protection, and extends understanding, practices, and requirements in complex ways (see Bond n.d.; UKCDR 2020). New safeguarding rules also require multiple protocols from researchers and project administrators, which impinge on relationships with partners, potentially creating tensions in pre-existing relationships based on mutual trust. Young Lives has tried to adhere to robust and consistent protocols as far as possible.

### 3.1. Child protection

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 that reporting concerns to authorities may make things much worse. In everyday practice, research teams are frequently making assessments and judgements on a case-by-case basis, depending on the context and situation.<sup>4</sup>

In one country, the research team were concerned about a 9-year-old boy who was at home on his own a lot of the time, because his mother was away working. His grandparents had been looking after him, but his grandmother had died, and his grandfather was working nearby. The family could not afford someone to watch the boy when adults were not at home. The researchers asked questions to learn more about the family’s circumstances, and found that they were very aware of the risks: ‘effectively the grandfather came in the afternoon for lunch, at around 3 or 4 pm, and at the end of the day, about 6 pm. So he was alone, but he had his grandfather coming every two hours ... to check [on him]’. Also, the boy could contact him by phone if necessary. The research team were ultimately reassured.

In a second example, during the course of data collection, it became apparent that a girl had been abused by an extended family member:

Her parents tried to protect her, they went to speak with the [abuser’s] family, they went to the police station and everything, but again, like everything here, they tried to follow the process but it was very difficult for them, so they abandoned it.

Her parents supported her and tried to get help, but they felt it had not been effective, and gave up. The research team discussed the situation and found private yet affordable psychological help: they provided the information to the mother, who was grateful.

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<sup>4</sup> The new safeguarding policy provides a framework for safeguarding leads to come together to discuss each instance and ensure support for those at risk.

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The consent script instructs research teams to advise the children that the researchers may need to respond to child protection concerns, that ‘If you say something that makes me worried about your safety, I will talk to you about it first, then I may talk to my boss/team leader’. A qualitative researcher in Ethiopia was concerned about a 15-year-old boy who was being poorly treated by his caregiver/aunt, who tried to prevent him from going to school (his mother was working in the Middle East, his father was absent). The researcher spoke with the boy to understand his existing support system and possible actions to improve his situation: go live with his grandparents; wait a few months for his mother’s planned return; or go and talk to the authorities. The researcher told the boy he would ‘support him from behind’, meaning he would not force him into a course of action but would accompany him in the next step. The boy preferred to wait until his mother returned. The researcher spoke to one of the boy’s trusted teachers about his situation, and the teacher agreed with the boy’s preference and to keep an eye on him.

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. Further, there is a risk of retaliation and revenge, or making things worse if researchers try to investigate further or make the information public, and that justice systems might be too weak to respond appropriately. In some localities, some staff expressed the view that ‘there’s a feeling that you cannot do anything really’. Such predicaments demand that Young Lives continues to adapt and strengthen its safeguarding strategies to reflect on-the-ground realities.

### **3.2. 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. Some researchers felt bad about this:

At a personal level, I feel a lot of pity. They’ve been involved in the research for so long and don’t receive a direct benefit and they keep asking. Sometimes you can also feel sympathetic, but as a researcher you must be professional and ethical ... [A]t least having the freedom [for researchers] to make some kind of support can be necessary, because you want to give the respondents something, but you may not be allowed. So, you’re in between ethics and humanity. (Country researcher)

Research teams have intervened in emergency situations, such as in 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. A senior member of one country research team said it was easier to respond to clear ‘emergency’ situations, but less straightforward when it came to everyday suffering.

[W]e are an observational study, and we are also humans. So ... 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 ... [W]hen an accident happens, it is pretty clear, especially if you are in the field ... Sometimes we have donated money among the researchers for specific cases; we do that at a personal level.

Such personal efforts were not part of, nor endorsed by, the official protocol, neither were personal donations a substitute for referring cases of serious concern. An important ethics question arises due to the unlikelihood that families could differentiate researchers’ personal donations from the Young Lives project they otherwise represented. Nor should the personal onus rest on individual staff members, rather such instances signal the need to strengthen internal safeguarding procedures and mapping of referral networks.

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### 3.3. Seeking advice

In an observational study, there is a fine balance between ethical conduct, and influencing the findings of the research unduly. 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. Increasingly, families sought advice from the researchers with whom they had contact. One Ethiopian father said: '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.'

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. However, in the moment, some field researchers felt they did not know how best to respond in accordance with their role. This was the case for a male qualitative researcher in Vietnam, who was asked by a family to talk to their son who had left school and with whom they had been struggling to communicate.

[His father] asked me to call ... and 'advise him to go back to school' ... I really thought that his requests for me were quite difficult because according to the [project] rules, I should not and would not be allowed to give any personal advice to the children. Therefore, in this situation, I did not know what I should do for the best. I decided to explain the basic principles of the research programme to him ... I would be willing to help him if it did not violate the principles not to interfere the child's life.

### 3.4. Protecting fieldworkers

Young Lives is a pro-poor sample, it's a constant struggle of psychological and emotional things that come up in the research process. The economic problems are easy to spot and for the researcher to give some amount of money for such cases, for the sake of your own sanity ... Maybe emotional therapy may be a strong term to put here, because it's not a battleground, but there must be consideration of the experiences of the researchers in the field.  
(Ethiopia researcher)

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. 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. For example, in one country, a psychologist convened two online workshops with the survey enumerators involved in administering the COVID-19 phone survey. COVID-19 had directly affected several of the enumerators and their families, and the team anticipated that topics related to illness and death were likely to emerge in survey discussions with Young Lives participants.

The workshops provided the enumerators with a safe space in which to share their experiences and they were taught practical tips and given tools for protecting their emotional and psychological well-being. During the data collection, weekly online meetings with the research team sustained communication and encouraged collegial support. Indeed, including in the context of in-person fieldwork, there has been an increasing focus on strengthening peer support systems, such as expectations among the fieldwork teams of very frequent communication, knowing where each other is, accompanying each other, and not being alone. Many county teams maintain WhatsApp groups with their research team members to encourage open communication.

**Safety concerns:** Field managers and supervisors play important roles, and in some contexts the principal investigators carry a heavy burden of responsibility for looking out for fieldworkers' safety and well-being during data collection, visiting the teams to check up on them. When laptops and tablets were introduced, this increased the physical risks of thefts for fieldworkers. In one country where the risk of theft was high, fieldworkers were instructed during training to give up their equipment and to not resist should they be threatened.

In one country, qualitative researchers trying to avoid high costs when travelling within the city to conduct interviews with the families opted for the less expensive moto-taxi option. However, after two researchers were involved in a moto-taxi accident, the research team was instructed to prioritise safety and to use the more costly auto-taxi option. In all countries, safety measures have been put in place to limit staff travelling alone and to ensure interviews are conducted during daylight hours. Some fieldwork requires travelling to areas where there are not hotels locally, and in one country, qualitative researchers stayed with Young Lives families in the rural areas. However, this was unusual in the context of Young Lives research, although local teams advised that this was culturally appropriate in their context and has been common practice among ethnographers (see Bonnin 2010). Ahead of future fieldwork, it will be important to review whether it is appropriate for team members to stay with local families and the safeguarding risks this may present.

**Gender:** Safeguarding of fieldworkers has a gender dimension too. In some countries, gender-matching of researcher and participant was introduced, partly because of sensitive questions (Boyden and Walnicki 2020) but also for the safety of female researchers. In one country, three women were assigned to each field team in case one of the women fell ill during fieldwork or had to return home, so that those that remained would not be on their own.

### ***3.5. 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 be conducted remotely, including the drafting of instruments, field guides and ethical and safeguarding protocols, programming for computer-assisted personal interviewing (CAPI), training of enumerators, pre-piloting and piloting,<sup>5</sup> survey administration, research reciprocity, data management, and stakeholder engagement. The research team developed a systematic way for survey enumerators to record cases of concern to discuss in case follow-up was required. Enumerator well-being was also a concern and supported through regular (telephone/online) debriefings.

#### **Learning points**

- 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.
- There will always be an element of risk in social research, which is why informed consent and robust ethical frameworks are so critical (cf Wiles 2012).
- Ensuring each person involved in the research has a way to communicate concerns is important.

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<sup>5</sup> The surveys are pre-piloted and piloted remotely in the four study countries with children and young people from outside the Young Lives sample who are the same age and from similar communities as their Young Lives counterparts.

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- Attention to field workers' psychological well-being is critical but often overlooked; training is vital to address and mitigate the psychological and physical risks of fieldwork (cf Penny, Oré, and Madrid 2012).
  - Teamwork and constant communication are vital during fieldwork and processes need to be put in place to debrief and support researchers after fieldwork.
  - Consider appointing a safeguarding advisor in each country to work with teams (possibly as part of country advisory boards) – as norms differ between contexts.
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## 4. Relationships and reciprocity

‘We’re like family now ...’ (Young Lives mother, Ethiopia)

Longitudinal cohort studies rely heavily on the quality of the relationships between researchers and respondents to sustain the viability of the research endeavour over many years. Young Lives has two decades’ experience of managing long-term research relationships. Many of the field supervisors and researchers have become known to the families after return visits. Young Lives aims to maintain relationships built on trust, fairness and respect, and is committed to the fundamental principle of ‘do not harm’.

### ***4.1. 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 (Boyden and Walnicki 2020).

Good recruitment practices and staff training are vital to the inculcation of respectful attitudes in Young Lives. From an ethics lens, attrition might affect some social groups more than others, potentially excluding certain views, such as those who migrate; it may also introduce bias, thereby undermining the quality of research findings unless sufficiently controlled for in analysis. 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 (Morrow 2009).

### ***4.2. Compensation and ‘giving back’ to families***

Research reciprocity has been a key strategy to reduce attrition and an ethical commitment to ‘giving back’, but one complicated by imbalanced power relations, the realities of poverty, multiple understandings of reciprocal relations, and the study’s observational research design. The principal investigators in each country propose reciprocity activities and appropriate compensation within their contexts, which are factored into budgets and work plans. 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.

**Photos have been widely appreciated:** Research teams took photographs of the families and children and later gave them copies to thank them for their continued participation. Families appeared to cherish the photos as they were sometimes among the only photographs of the child that they possessed. A long-standing member of the Peru survey team explained:

Every time we go [to the family], we take a photo and the next time ... we come back with a photo in a frame. Sometimes, they are waiting for that photo and they show us, ‘Look, I’m going to put this photo with the other ones ... all together.’

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In 2014, the qualitative research teams prepared photo albums (Figure 2) for each of the children involved in the seven-year stream of qualitative longitudinal research, as a ‘thank you’ and ‘goodbye’ since it was unclear at the time whether Young Lives would continue beyond 2015. One of the researchers in Vietnam described in her field notes the reaction of 19-year-old Nga’s family when she presented the photo album to Nga:

The whole family gathered to see the photo album I brought. Everyone said, ‘This is our old house’ (referring to the house prior to being renovated), and ‘Our father’. Nga’s youngest brother almost sprawled on the album, blocking other people’s views. He attentively looked at the photos and joyfully screamed whenever seeing himself in any photos. He pointed at me [the researcher] in the photo and said, ‘Our house’.

**Figure 2:** A study participant in India receives a photo album in 2014



Such photographs created a valuable family record, but sometimes also provoked emotional responses when particular photos evoked good or bad memories.

### 4.3. Research findings and information

Reciprocity also took the form of reporting research findings to the families, communities, local authorities, and government officials (Figure 3).

**Figure 3:** Findings leaflet for adolescents in Telugu language, India



In Peru, in response to requests by caregivers to learn about what the study had found about their children, the country team developed themed findings leaflets which they distributed to all participating families. In some communities, they held discussions about nutrition (Figure 4), and they organised a travelling photo exhibition to communicate findings at the community level.

**Figure 4:** Young Lives researcher discussing nutrition with families in Peru.



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.

[I] told you about my sorrows, I told you my situation, [I] thought you would help me ... all that we are telling you, if not now at least in future [will] you do something for us? (Indian mother)

#### **4.4. 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.

By asking so many questions, you bring to mind so many things. It is like sharpening the mind ... With this study I became aware of my own thoughts ... Usually, I don't think about myself. (Older Cohort girl, India)

The qualitative research found that children's initial hesitancy to open up often gave way in subsequent research visits to increasing levels of trust and sharing.

## 4.5. Familiarity and boundaries

The long-term nature of the study certainly influenced participants' views of the research relationship and the expectations they had (Morrow 2009). A qualitative researcher in Peru reflected on her experience in Young Lives between 2007 and 2014:

I was able to establish very intense relationships with the families because I was able to participate in the study from the beginning and ... get to know the families a little better. The mothers and young people always treated me with a lot of familiarity: when they saw me, they recognised me, and they remembered my name. This made me feel good.

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. One mother in Vietnam explained, 'Sometimes talking to the husband and children is not as easy as talking to another woman'.

The line between what was acceptable and unacceptable, and the malleability of the boundaries of the research relationship, has not always been easy to define. In all the countries, there were many instances of Young Lives families demonstrating hospitality towards researchers with offerings of food and drink; familiarity with invitations to weddings and family celebrations; and in some cases, conferring honour through symbolic gift-giving and invitations to ritual kinship (e.g. to become a godparent or ritual brother). Some researchers were uncomfortable accepting gifts in light of the families' economic circumstances, but also worried that refusal might damage the relationship.

These examples reflect the importance of interpersonal familiarity and rapport established between researchers and participants over many years, which has helped sustain Young Lives; however, experiences varied, and personal bonds had to be balanced against the requirement to maintain professional boundaries. Moreover, in a long-term study, providing advice and becoming too familiar risks influencing findings and changing young people's outcomes, which some researchers might say invalidates the research. It is therefore a fine balance between ethical conduct and influencing the findings unduly.

## 4.6. COVID-19 amplifying challenges

At the time of writing, the global coronavirus pandemic is still underway and has affected each of the Young Lives study countries in different ways (Cueto et al. 2021). 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 (Crivello and Favara 2021). Equally, a flexible and practical approach was required as new challenges emerged.

In this context, the major shift from in-person to remote interviewing with phone surveys required strategies for navigating sensitive questions, ensuring safety and privacy, and being able to respond appropriately to requests for help from research participants (Young Lives 2020). For example, early on in the pandemic, one team started to receive requests from families for financial help due to their worsening situations. It became imperative to ensure a systematic and equitable response to such requests, since initially members of the team gave small donations out of their own pockets, a situation which was not sustainable.

The international survey team responsible for the COVID-19 phone survey devised the following strategies for the four study countries:

- Breaking the survey into three short calls conducted over several months to reduce respondent burden.

- Ensuring participants are compensated for their time and effort, in the form of phone credit or bank transfer (equivalent to amount provided in the past).<sup>6</sup>
- Distributing a participant resource guide containing information about COVID-19 and details of country-specific services, including for emotional support, sent via online messenger or email and made available on the international and country Young Lives websites.
- Updating the study's safeguarding protocol and the system for enumerators to record cases of concern that can be followed up.
- Debriefings with survey enumerators to support their emotional well-being and discuss concerns.

Learning on the effect of the pandemic on research relations and reciprocity is still being drawn out and will be important for informing a fourth phone survey in 2021 and the next round of face-to-face surveys in 2022. Other examples of learning are integrated elsewhere in the report.

### **Learning points**

- 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. Respect that not everyone wants their photo taken.
- Many participants and local authorities want to know about research findings. Providing feedback in different formats for a variety of audiences is an important aspect of research reciprocity.
- 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.
- COVID-19 and the difficulties faced by families during lockdown required Young Lives to review and adapt some aspects of its protocols.

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6 The phone survey manual (Young Lives 2020) instructs enumerators to explain to participants: You will remember that whenever we have visited you, at the end of the interview, in gratitude for the time that you have given us to answer all the questions, we have given you a [Peru: a small present, e.g. backpack, watch, mini radio; Ethiopia: a small amount of money or transferred mobile card; India: money purse, vanity bag, etc; Vietnam: a small amount of money], right? This time, as it is not possible to visit the participants in their homes, we will not be able to personally carry and deliver any presents. So, as we did last year, at the end of the survey, all participants will be given [Peru: S/. 50 soles, the approximate equivalent to the cost of the present], [India: Rs. 600, the approximate equivalent to the cost of the present] [Ethiopia: Birr 100 or a mobile card, the approximate equivalent to the value of the money] [Vietnam: VND 50,000 or a mobile card, the approximate equivalent to the value of the money].

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## 5. 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 (Powell et al. 2018). Sometimes, our assumptions have been wrong, and questions that seemed innocuous brought up unexpected feelings or reactions.

### 5.1. Challenges

Details of some of the most difficult topics are outlined below.

**Income:** As a poverty study, Young Lives obviously needed to explore the effects of low income. However, in one country, 'people were really upset by the income questions, so that's why they were dropped, because they felt they were invasive'. Participants were asked about expenditure and consumption (these are considered to be more reliable indicators of wealth, especially in LMICs):

If you ask the question about how much somebody earns, immediately they won't answer that way ... you talk about what they do, what they've been spending on, how they got the income for it, sort of the roundabout ways of building up a dialogue, conversation, so they volunteer the information without feeling it's being extracted from them, like a juicer. (Ethiopia researcher)

Continuously asking about families' economic circumstances when lives have not improved can contribute to ethical unease in longitudinal research:

In general, asking children from poor families about poverty does not feel good. Even in a longitudinal study, it is much harder to talk of 'poverty' repeatedly, knowing that the life of the person has not changed. (Ethiopia researcher)

**Well-being questions:** A seemingly simple subjective well-being question can upset people, for example, 'where would you place yourself on a ladder compared to other children [where the rungs represent different levels of well-being]?:'

You think it's just a question, but it's a very sensitive question, because you are making them think, 'how am I compared to my neighbour?' and it evokes a whole lot of emotions. (India team member)

However, changes made to questions in a longitudinal survey require careful consideration since introducing changes can affect the comparability of variables across rounds. For example, the wording of one of the survey questions asking children whether they felt ashamed about their shoes was changed so that it asked about pride, but this meant that the answers were no longer comparable.

**Violence:** While some questions on the use of corporal punishment were included in the survey, the qualitative research did not ask directly about experiences of violence. However, the topic came up from the start when children and parents discussed well-being: 'mothers and children told us about their own experiences, but in a very natural way ... it compelled us to think, what are we going to do with that?' In Peru, the team discussed such cases, and unless the child was perceived to be in immediate danger or said, 'I am suffering', it was addressed less directly – with community-based workshops, conveying the message about treating children well:

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One session for the community, including the parents of the children, was about nutritional aspects, the other was about violence in homes and in school. [We gave general] information on how to treat children well, the importance of controlling ourselves, what studies say about the consequences of punishing children. And we did that with teachers, health workers, and also with mothers and authorities from the locality. (Peru researcher)

In the COVID-19 phone survey, an innovative list randomisation method was introduced to measure the percentage of young people in the sample experiencing an increase in physical domestic violence (from any family member) during lockdowns (Porter et al. 2021). The listing method is a way to gain insight into the incidence of domestic violence without directly asking about individual experiences, since the latter raised ethical concerns. Nevertheless, managing the sensitivity of such questions was entwined with wider safeguarding, and a system for enumerators to document individual cases of concern during the surveys was put in place should follow-up or referrals be required.

**Sexuality, fertility, contraception use:** These are highly sensitive topics in most countries. For example, in India:

In the process of interviewing young mothers about reproductive health, sexual relationships, conception and child-bearing, several sensitive questions had to be asked, which was not easy, not only because they were sensitive but also there was a feeling that it might be intruding. Some of them broke down during the interviews; we allowed time and continued the interview, if they wanted. For some ... it was a chance to ventilate [speak out], because no one ever asked them for their views or decisions. (India researcher)

**Marital conflict:** Participants unsurprisingly tended not to want to talk about difficulties in their relationships:

We had interviews with both the husband and the wife, for some cases, and they often don't tell you the same stories – so one might be much more candid than the other about challenges in the relationship. (Ethiopia researcher)

**Death, loss and bereavement** are always difficult to talk about:

Every time research teams visit the families, they collect information about household changes, and naturally, we would expect reports of deaths and loss to be part of this. 'Updating the household roster' might sound like a technical exercise but there's a potentially sensitive and emotional aspect too which the fieldworkers who come face-to-face with the families must carefully navigate. (Oxford researcher)

Participants sometimes asked researchers personal questions, for example, for their phone numbers and addresses, and how much they earned. This was uncomfortable:

Sometimes they were very curious about our work, 'so you work by asking questions, how much do you earn? Why is that?' So they have a lot of questions about earnings ... [which] was very difficult for the team to answer. (Peru researcher)

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

Our longitudinal methodological approach (triangulating, asking the same questions over and over again) may have engendered a sense of mistrust for some participants.

This can be tiring and repetitive – in fact, if the experience was a bad one, we risk retraumatising the individual. This is a problem when we have to hire new researchers and of course they want to ask [the participants] about their stories and lives; but when it's the same researchers, they don't need to ask in detail, there is a starting point already. (Ethiopia researcher)

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## 5.2. Strategies

**Explore sensitive questions indirectly/subtly:** One good example of this was the COVID-19 phone survey list randomisation questions on violence. Moreover, the semi-structured and narrative nature of the qualitative research meant that potentially sensitive topics could be explored indirectly:

I think the main thing is that our researchers are very skilled at going round these questions, and not asking them head on, asking them in different ways, or moving to another topic before coming back to it, they're very experienced with that. (Ethiopia researcher)

**Taking time to listen carefully:** In one country, a psychologist was brought in to advise on training qualitative fieldworkers, including how to be empathetic, and dealing with sensitive questions and difficult moments. Other teams developed their own training sessions on listening, avoiding leading questions, and managing difficult topics and emotional moments during interviews:

Mothers became emotional when reflecting on aspects of their past experience and difficult relationships. For example, when we did the timeline exercise with mothers, we asked questions about their childhood experiences, how old they were when they became mothers, how was their relationship with their husbands ... and sometimes they spoke about violence. Mothers became very emotional in those conversations, and we had to comfort them, speak with them, stop the interview, try to understand them ... We searched for psychologists located in the nearest hospitals or medical posts and made a point to give the mothers information about the days and times they see patients, and we offered to accompany them if they wanted. Where helplines were available, we shared that information with them too. (Peru researcher)

**Context:** Social contexts vary in relation to expectations of and attitudes towards young people – these change radically post-puberty, especially for girls, and raise new challenges for researchers trying to work with young people. Gender-matching fieldworkers to respondents and organising separate focus group discussions for male and female participants was important in some contexts, for adults and after children reached 12 years old.

There are some sensitive questions, about pregnancy and about adolescent behaviour changes [in the survey] that men cannot ask women, or that women will not be comfortable talking about with the men. In that age group, questions on sexual behaviour are there, knowledge, services, and practices ... so only by talking to women will you get the correct/good information. (India team member)

**Avoidance:** The school survey chose to not ask sensitive questions, for example, about corporal punishment, on account of the large-scale nature of the survey and lack of capacity to gather information to make sense of these questions in each context. Where children and parents described experiences of violence, the research team tried to analyse these data as effectively as possible, in collaboration with other funders and with international NGOs with closer links to programmes, campaigns and policymakers.

### Learning points

- 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.

- Allow time during the interview process to stop, move on, offer support, if people become upset.
  - Discuss the nuance of each research question within research teams: 'it's about how you phrase the question, and how you end the whole thing'. Avoid sounding judgemental in asking questions.
  - Researchers should ask themselves whether they would be willing to answer the questions they expect participants to respond to. Would it be acceptable to ask this in your own country?
  - Consider gender-matching participants and research team members.
  - Researchers should be prepared to answer questions about themselves.
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## 6. 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). The assumption has been that the main threats are from journalists, other researchers, and government officials. One major risk is that external researchers want to match Young Lives data with other datasets and to do this, they need access to personal data, such as GPS coordinates or national ID numbers, which raises many ethics questions. Young Lives has developed a protocol to address this risk (Boyden and Walnicki 2020). However, there are also risks when Young Lives researchers undertake data-matching exercises using participants’ personal data, since such efforts can also breach confidentiality and consent agreements, if not carefully managed.

All data that identify respondents and their locations are personal data and are not put into the public domain. Young Lives follows conventional guidance, and all participants (children, young people and adults) are reassured that data will be anonymous – in other words, names ‘will not be used so we can describe what you think without anyone knowing that it is you’. The names of communities are also disguised, and locations are identified only at the regional level, and not precisely plotted on maps (Boyden and Walnicki 2020).

Yes, I think they understand [anonymity], because we explained it in a very easy way; for example, we told them ‘your name is going to be replaced by a code’, and we showed them [their code] ... ‘and your mother is going to be [this code] ... and someone reading your information is going to read that ...’, and actually they don’t have any trouble with that ... They became more trusting with that explanation, ‘your name is not going to be there’. (Peru researcher)

### 6.1. Anonymising individuals

However, 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:

We say it’s all confidential and it’s true, and usually we’re in the porch of a house, and the rest of the family may well be listening, and the neighbours. I mean people know who are Young Lives families and we keep going back and visiting, so it is not entirely anonymous – the information is – but the fact that you participate in Young Lives, I don’t think we can really claim it can be completely anonymous, when it is evident that we are in the community and who we are talking to. (Peru researcher)

In some cases, children and adults indicated they would prefer to be named rather than anonymised as a point of pride, or because they felt they should be entitled to some help:

The main thing that people found difficult was why what they were doing as individuals couldn’t be mentioned, and in what ways this was actually going to help them. (Ethiopia team member)

Participants were not always aware of the risks of their anonymity being breached, and these risks could be explained to them by the researchers.

## **6.2. Anonymising communities and locations**

There were differing views and some debate within Young Lives teams about anonymising communities, but Young Lives adheres to its anonymity/confidentiality protocol regardless of individual opinions and of participants' wishes. In one country, ethics boards questioned the need to anonymise communities and thought it was better to be able to name them. Not everyone involved in Young Lives agreed with the strong anonymity approach. Some team members:

... were not very happy about anonymity, in the sense of us not being able to say where the communities are, beyond the regional level. They felt one should be able to say at a lower level without that compromising anonymity. (Country researcher)

Some team members think it would be acceptable and even preferable to name communities, to help introduce development programmes, and to allow other researchers to access the communities:

I mean obviously there's the risk of research fatigue and so on, but I am more of the camp that believes that openness about what you are doing, as long as you are not reporting on illegal activities, or on things that might get people into trouble, or portray them in a bad light. (Ethiopian researcher)

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.

## **6.3. Change over time**

As Young Lives evolved, measures were taken to ensure that anonymity, confidentiality and security procedures were maintained, during gaps in leadership, and between research and funding phases:

One of the things that's been very difficult in this [leadership and funding] transition period for the relationships between Oxford and its partners, is that in order to be sure that you are conserving the anonymity and confidentiality of study participants, you have to delegate all these security procedures. They are received as quite draconian, harsh and non-trusting – and that's how they've been experienced by [partners] ... It looks like you're imposing ... It's not because you don't trust them ... but you are [legally] the controller which means that ultimately the buck stops with you, if there's a breach of personal data ... and it's really important that you don't allow them to be shared, and that is so hard in a multi-institutional, multi-country, multi-round large study of the nature of Young Lives ... But in a partnership study, securing data invokes protocols and regulations ... and I think that's really tough when you are trying to stay in a good relationship of partnership. (Oxford researcher)

## **6.4. New social media**

New social media (such as Facebook) has raised further challenges that meant that protocols had to be established to ensure fieldworkers were not posting inappropriately. For example, the team in Peru developed clear guidelines about what is and is not acceptable to post during field visits (such as tagging locations and selfies).

However, it has been difficult to anticipate or control how our social media and web platforms have been used. In recent years, several Young Lives participants have posted comments on the project webpages, often enthusiastically identifying themselves as participants, which other users can see. The research team discussed how best to address these posts which breached

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anonymity, without offending or dampening the pride of the participant. In one country, the research team created a protocol and a script for such cases, ultimately asking participants to remove their public comments, but inviting them to join a new private group open only to Young Lives participants in that country.

**Learning points**

- 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 committees.
  - 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.
  - In complex multi-partner research teams, it is important to establish who has access to and is responsible for securely storing confidential data (Boyden and Walnicki 2020).
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## 7. Using photos and other visual images

Photos and visual images are vital to help audiences understand the lived realities of the children and young people in our study – after all, a picture tells a thousand stories. We use images very carefully to ensure we portray the reality of poverty without depicting powerlessness, and we maintain the anonymity of our participants at all times. Over the course of the study, we have developed many innovative visual communications, informed by guidelines, to bring participants' stories to life. We have also used images in the research process to prompt participants to share stories and to thank them for taking part in Young Lives. (Communications Manager)

Photos and visual images are a cogent way to convey and humanise complex research findings. However, their use in social research with vulnerable children and families invokes many ethical and safeguarding considerations.

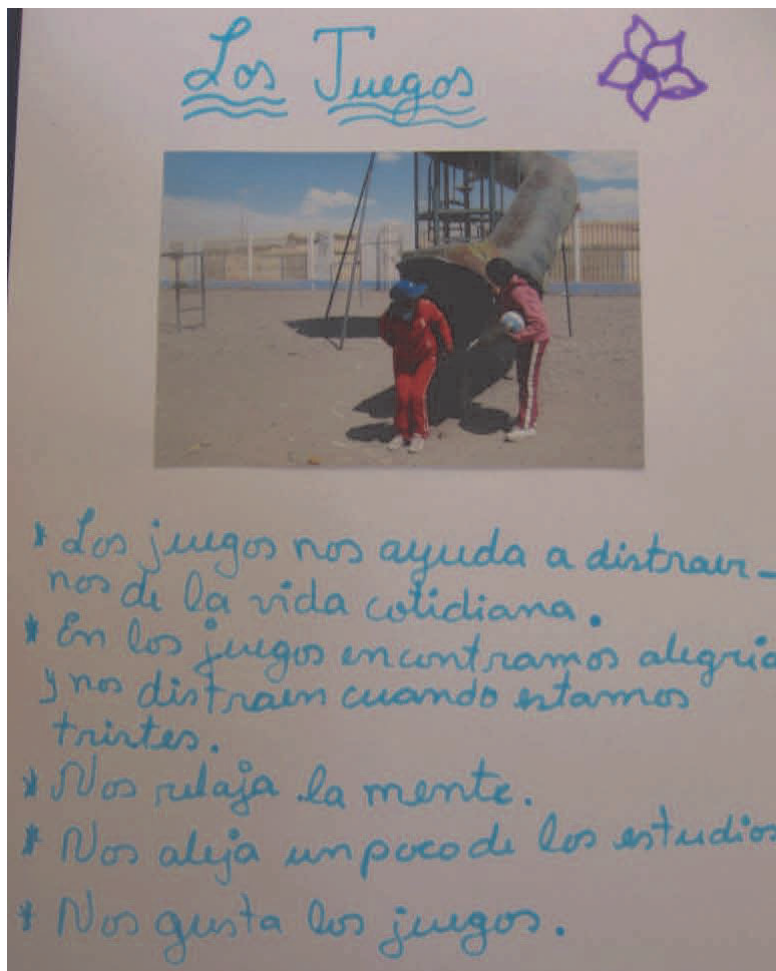
Young Lives has used photos and visuals in three main ways: to elicit data from children and young people; as a form of research reciprocity; and to communicate the study findings. Anonymity, respect, and informed consent underpin the approach to using visual images for these purposes.

Initially, Young Lives drew on Save the Children guidelines as it built up a photo bank of images depicting children in the four study countries for use in the new project website and in reports, presentations, and other project materials. Child protection was a main concern at that time, but it has been necessary to adapt, as the children grew older, their contexts changed, and the field of research communications evolved.

### ***7.1. Visual methods to elicit data***

Young Lives qualitative researchers incorporated photos and visuals into the methods toolkit they developed to engage children and young people in different research activities (Crivello 2017; Crivello, Morrow, and Wilson 2013). For example, children were given disposable cameras and asked to take photos of images that represented aspects of their daily lives, with the photos later forming the basis of in-depth individual discussions with researchers or used as prompts in focus group discussions which were audio-recorded and written-up for analysis. 'Child-led tours' involved children showing researchers around their neighbourhoods or preschools, filming or photographing the places children wanted to film and later talk about. For example, older children worked together in groups to map their communities, deciding which places they wanted to photograph, and later creating a scrapbook with photo captions aimed at newcomers to their community, which was then gifted to a local school. In Peru, children included a photograph of the local playground in their scrapbook (Figure 5), explaining that games helped distract them from the troubles of daily life.

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**Figure 5:** The playground (Peru)

A number of ethical considerations surrounded these photo/video exercises, requiring mitigating strategies.

- Children sometimes identified dangerous places or sad images that could be distressing.
- Some children reported that elder siblings had used the disposable cameras to take photos for themselves rather than for the intended research purpose.
- There were difficulties in ensuring informed consent when children took photos of other people not directly involved in the research.
- Difficulties in anonymising the images meant they could not be used in publications or presentations.

## 7.2. Digital stories

In 2019, Young Lives experimented with digital stories as part of a qualitative sub-study on young marriage and parenthood in Ethiopia.<sup>7</sup> Six young women and young men were invited to visually narrate their experiences through captioned photos co-produced over the course of a day with researchers. The use of digital cameras and portable printers meant the young people could select the photos they wanted to represent their story of young marriage and parenthood. The intention was for the young person to identify images that could serve as symbols within their

7 A blog (Chuta et al. 2019) reflects on lessons learned.

story (e.g. a baby blanket or a cooking pot) and that this would maintain anonymity. However, there were some challenges:

- Not all the images were anonymous and heavy cropping and editing was required when photos featured individuals/places/license plates/street names.
- One young man told the researcher there was nothing worth photographing in his home.
- A young mother only captured images inside her home to avoid unwanted attention and scrutiny from her neighbours.
- The young people influenced the photos used and the storyline, but the final scripts were ultimately crafted by Young Lives staff.
- Lack of time, budget and security concerns meant the research team was unable to share the stories with the young people prior to publishing them.

Many more photographs were taken than were used in the stories, including photos of the young people and their families which were printed on the day and given to them as a keepsake.

### **7.3. 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. However, local research teams needed to be sensitive to families' wishes when taking photographs for this purpose; for example, some urban families in India did not want photos taken of unmarried adolescent girls in their households. 'We have to follow their wishes,' explained a senior member of the field team.

### **7.4. Communicating research findings**

*Commissioning photos:* 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, as explained on its website:

The photos we use on this website are of children and young people living in similar circumstances in similar communities but are not the study children themselves. We ask website users to respect their confidentiality and not try to identify the children, their families, or communities.

Careful planning underpinned the commissioning process with respect to the photographers, site and participant selection, informed consent, compensation, and topics. Emphasis was on capturing images of children and young people in their everyday environments, relationships, and activities.

However, the decision to work outside Young Lives communities did not eliminate ethical challenges. For example, in a recent photo commission, the local photographer reported some of the concerns from young people invited to participate, including that:

- the photographer/project would sell their photos for profit
  - the photographer/project would claim to be helping/aiding them
  - they did not want to be associated with poverty
  - they preferred to be named rather than anonymised, as a point of pride.
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Consent procedures were important to ensure that young people knew what they were signing up to if they agreed to be photographed. The photographer was encouraged to show examples of earlier photos commissioned by Young Lives and explain how they had been used.

*Illustrations:* 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:

Of course, we don't use any pictures of our children and I think we are very careful about that ... this creates challenges because often people will say, 'but these are not your Young Lives children, whose pictures are you showing?', which is true, they aren't. We'll give a case study of a child and we'll have somebody else's picture there which is not quite right. Ideally, we should not be using photographs. We should be using sketches. I would not use photos in those reports.

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 (Figure 6).

**Figure 6:** Illustration on educational trajectories in Young Lives (2020)



*Maps:* It is important that any geographic maps used in publications or websites are indicative rather than precise, so that the names and locations of the research communities cannot be identified. Young Lives created maps, skewing site locations, for wider use. However, it transpired that an earlier map had been published with precise locations that enabled an external researcher to overlay an actual map and identify the site locations. The team quickly mobilised to remove the map from the public domain and contacted the researcher to explain the potential ethical breach.

**Learning points**

- Maintaining Young Lives' commitment to anonymity is crucial, even if this has limited the storytelling power of the photos used.
  - Updating the photo bank was necessary every few years to reflect the changing ages of the children and research themes, and should be budgeted for in advance.
  - 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 logistics of using photos in research needs careful planning and potential cultural sensitivities need to be taken into account.
  - The children and their families greatly appreciated the photos they were given by the study, which were an important aspect of research reciprocity.
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## 8. 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.

Researchers have reflected on changes over time, and experiences of research ethics review (such as the where, who, cost, timing, and nature of concerns raised by committees). For ethics approval in Oxford, when children in the sample were aged under 18, specific considerations and assumptions about vulnerability and protections were required. When they became of 'adult' age, participants were no longer considered a vulnerable group on the basis of age, so a straightforward ethics application could be submitted, unless the topic or sub-sample signalled additional risks.

Some Young Lives team members felt that ethics review committees reflected medical or health approaches rather than social scientific approaches, so that some of the committees' comments were not seen as particularly relevant or useful. Existing ethics committees in LMICs may have little experience in observational research, that is, non-clinical research that does not involve an intervention, randomisation and placebos; or in minimal risk research – research that involves activities that are no more risky than everyday activities. Social science research often falls into these latter categories.

Nevertheless, applying for ethics approval was generally seen as useful:

For one, having to have ethics clearance means you have to think about it, so you can't just barge into a study. And second, thinking through the consent form is a useful exercise. Then you have to train people, as to how to use the consent form, because it is not – and it shouldn't be – just a matter of 'please sign here'. (Peru researcher)

**At the University of Oxford:** Young Lives had to comply with the university's well-developed ethics procedures. Prior to Young Lives transferring to the University of Oxford, social anthropologists in the Department of International Development (ODID) that houses Young Lives Oxford had argued effectively for a different approach to ethics at the university that better reflected the realities of poor and illiterate populations in different cultural contexts. Young Lives argued, for example, that in cases where written consent from participants was inappropriate, oral consent (audio recorded) should be an option, to which the ethics committee agreed.

**In study countries:** In some countries, it has taken time to identify appropriate IRBs, which can mean using different ethics committees for survey and qualitative research. 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.

**Country IRBs:** The general view is that in-house committees and social science applications are more straightforward than applying to health RECs.

Some of the decisions of local IRBs may be in conflict with the comparative research design, but the decisions have to be respected. For example, in one country, one of the methods designed to assess attitudes towards 'risk-taking' was not approved in the survey. In another case, the committee rejected questions related to 'dating', 'romantic relationships', and sexual activities in a self-administered questionnaire (SAQ) that were felt to be too sensitive and culturally inappropriate to ask of 15-year-olds and unmarried young people. In this case, the ethics committee and indeed the research teams were understandably concerned that asking culturally inappropriate questions could potentially damage long-term relationships within communities and with respondents. The questions were dropped.

The application of some methods, such as filming, give rise to specific ethics concerns. In the school survey, teachers were filmed in order to identify good practice in the classroom. However, this was perceived as potentially very threatening for teachers who might fear that the data would be used to evaluate their work, with the possibility that they may be punished or even sacked.

The ethics approval process for the classroom observation sub-study was slightly more complicated, as it involved filming teachers (i.e. they could not be anonymous). Based on feedback from the IRBs (Oxford and in country) we reframed the purpose of the video clips so they focused on 'good practices' rather than potentially negative examples where the teacher could be identified. (Oxford researcher)

### Learning points

- 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.
  - Young Lives has had some positive experiences and good critical questions and comments from some country IRBs.
  - 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 (see Schroeder et al. (2018) on the risks of 'ethics dumping').
  - It takes time for ethics committees to meet and make decisions, so it is advisable to allow a minimum of at least three months.
  - Research ethics reviews need to be budgeted for, because many IRBs charge large sums to review research proposals.
  - Be prepared to reframe research questions and methods to avoid stigmatising poor practice (for example, by filming teachers who may be identifiable).
  - 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.
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## 9. Concluding reflections

Young Lives has navigated numerous ethics challenges since it began two decades ago. This report has discussed some of the main challenges, considering both continuity and change. Building and sustaining research relationships and reciprocity have proven to be persistent aspects of ethical practice, and in large part reflect the talents and skills of the frontline researchers who interact directly with the participants. The report also highlighted changes in ethics questions over the years, for example, as the child participants grew into adults, as new methods for collecting data were introduced, and as the institutional frameworks governing research ethics evolved. Young Lives has tried to be as consistent and robust as possible through these changes, while at the same time developing a shared approach to ethics that allowed for flexibility and for adaptation to local context. The requirement for flexibility needed to be balanced with continuity throughout.

Many of the ethics questions raised in this report are not exclusive to longitudinal research nor to LMICs and will therefore resonate with cross-sectional/single-visit research with shared concerns. However, 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. We argue that ethical practice within longitudinal research should therefore be ongoing and iterative, rather than a one-off 'tick-box' exercise, and that every member of the research team has a responsibility for ethical conduct in their role. There is a need for robust ethics protocols, 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.

This report comes at a crucial time in international development, when research funders have encouraged large-scale, multi-year, collaborative, north-south research partnerships, like Young Lives, in their efforts to address global development challenges. Openness to share learning – warts and all – is necessary in contributing to a wider community of practice. Yet reflexive accounts of the challenges and lessons in the conduct of complex studies of this type are very limited. Moreover, the knock-on effects of the COVID-19 pandemic on the UK economy have resulted in drastic cuts to overseas research funding, creating uncertainty and/or early closure of many collaborative international studies.

At the time of writing, the world is still in the throes of the global pandemic which has affected all aspects of Young Lives research, including significant budget cuts, with implications for staffing. Plans for a new round of face-to-face data collection in 2020 were disrupted, and alternative online strategies swiftly implemented. School closures, job losses and food insecurity have affected many of the young people (Favara, Freund, et al. 2021). It remains unclear what the longer-term impacts will be on Young Lives, if the research relationships and collaborations can be sustained, what new ethics challenges will arise, and whether the ethics strategies developed so far will be up to the task of addressing them.

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# Appendix

## **Memorandum of Understanding for Young Lives Field Researchers (2006)**

Key points: respecting children in research

**Note:** *The form of wording below is directed to children, and may need to be adapted for different respondent groups. This is a protocol, to be translated into relevant languages using locally relevant examples and forms of expression.*

1. **Introduce yourself.** Be sensitive to local concerns about children (parental fears of child abduction, for example: *Young Lives aims to learn about the lives of children within their families, Young Lives will never take children away without consent*).

### Consent

2. You must obtain informed consent from children, their parents or carers, and community members. To do this you must explain the following:

- **Who you are:** For example, explain to children: *Young Lives is a study of children growing up in four countries (Ethiopia, India, Peru, Vietnam) taking place over 15 years. We are trying to find out about children's everyday lives: the things you do, and the important people in your life, and how these things affect how you feel. Bits of what you say/write/draw will be used in reports that we write that we hope will be helpful to local and national governments when making plans/planning services for children in the future. Our research may not change things in the short term, because that depends on local and national governments.*
- **Archiving:** *The information you give us will be stored on a computer. We are sharing the information that we collect now, and that we collected on our previous visits, with other trusted researchers (people like us) in Ethiopia/India/Peru/Vietnam and internationally.*
- Take particular care not to raise expectations about the impact of the research: *We are here to learn from you, but we cannot promise to improve your life.*
- The details of our work:
  - How long you will be in the community on this visit.
  - What you are asking them to do and how long this might take.
  - Why you are asking them to undertake activities (whether talking individually, in groups, drawing, body-mapping, etc).
  - How the data (including photos and videos) might be used.
  - If you are doing group activities, and other adults are present, politely suggest they leave (if appropriate). For individual interviews, explain that if a child wants another person to be there, such as a sibling, friend or parent/carer, this is ok, but emphasise that you are interested in the child's answers.
- **Anonymity:** *Data will be anonymous: e.g. your name will not be used so we can describe what you think without anyone knowing that it is you. We will also disguise the name of the community where you live.* If children want to put their name on material they produce, let them, but disguise it before the materials are digitally photographed.

- **Confidentiality:** *e.g. I will treat what you tell me as confidential. This means what you say will be shared with other members of the research team, but I am not going to tell your family or anybody in the community what you tell me. Your name will not be used when we tell people what we have found.*
- **Child protection:** *If you say something that makes me worried about your safety, I will talk to you about it first, then I may talk to my boss/supervisor.*
- Explain to children/caregivers that they may **opt out** at any time – they may ask for all the information/data they have given to be removed from the project, or records destroyed, at any point.

### Respecting children's views and feelings

3. Emphasise that you are interested in children's descriptions in their own words and that there are no right or wrong answers. They can leave an activity if they don't want to carry on. They don't have to answer all the questions or participate in all the activities.
4. Be respectful that a child may be reluctant to speak about a sensitive topic. If you feel that children are unwilling to speak for any reason, move on to the next question. This is especially important in a group so they don't feel embarrassed in front of other children. Be sensitive to children's body language and tone of voice. Do not put words into their mouths, though you may need to probe, in which case avoid leading questions. Some examples of leading questions are: *School is good, isn't it? Healthcare workers treat people in your community badly, don't they?* Use open questions, not closed questions that lead to yes/no answers. For example: *Tell me how you feel about school. How do healthcare workers treat people in your community?*
5. Ask children for permission to audio record, and explain why (if they ask, let them hear themselves for a short while.) Ask children for permission to take photos or video, and to photograph their drawings or other material they produce. Leave their drawings with them to keep.

### Conduct in the field

6. Be punctual, organised, and listen. Keep appointments, find the room, set out chairs and materials in advance. Turn off your mobile phone. Offer refreshments. Keep a flexible timetable and be prepared to have a break between activities, especially when children appear to be unmotivated or struggling to focus on certain tasks.
  7. As a representative of Young Lives, under no circumstances should you hit/strike a child, even if this is acceptable within local practices. Do not speak to children in a rude or insulting way. Avoid raising your voice throughout the sessions. Try not to have a school-like atmosphere where discipline is valued, but a place where children can communicate freely and spontaneously. Avoid guiding or directing children, for example when drawing (e.g. by questioning their choice of colours or shapes) or when discussing in groups (e.g. by contradicting them).
  8. At the end of your visit, explain to the children what will happen next with the information they have produced (i.e. it will be taken back to local HQ, typed up, and then sent to the main HQ in Oxford). Ask them if they have any questions, and allow them time to prepare questions before you leave. If appropriate (i.e. they seem comfortable and forthcoming), ask them how they experienced the activity, and include examples of this in your group report.
  9. Thank the children for their participation. They do not need to thank you, nor should they be expected to. Let the children to say goodbye to you, if they wish to.
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## Finally

10. After fieldwork, you must return all material (written, audio, visual) to the Lead Researcher. Be sensitive to the possibility of inadvertently revealing personal information in the community (e.g. don't recycle paper in the community/locally; after typing your reports, manually shred your notes if necessary). You must respect confidentiality at all times, do not discuss data with people outside the team.

11. Young Lives (country office) and Oxford HQ retain full responsibility for the use of Young Lives material.

(see Morrow 2009: 22-24)

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