Young Lives Methods Guide

Research Ethics

Research ethics exist to ensure that the principles of justice, respect and avoiding harm are upheld in research processes through the use of agreed standards. While these basic principles are universal, they are open to differing interpretations and understandings which revolve around the central question of balancing the goals of a piece of research with the interests and rights of its subjects. The Young Lives team take a positive view of research ethics as enabling high-quality research while respecting these key principles.

There are particular ethics questions which arise when doing research with children and families and with poor communities in developing countries. There are also ethical challenges involved in research that aims to influence policy. The Young Lives team has had to develop awareness of the ethical dimensions of the study through all its stages, particularly in respect of the power relations between research teams and the children and families who participate in the study.

Background debates in research ethics

In developing an approach to ethical social research, the Young Lives team has drawn on a growing literature on the governance of social research which identifies the key qualities of integrity and transparency, and the basic principles of free and informed consent, confidentiality and anonymity (ESRC 2010). It has also drawn on existing protocols designed to protect children from abuse of their rights through awareness, prevention, reporting and responding (Save the Children 2003).

The approach to research ethics taken in the design stages of Young Lives was strongly grounded in the paradigm of medical and epidemiological research, where there are often direct, visible links between research and its risks for and effects on participants. In this field, the development of committees, standards and ethical protocols are well established. Nonetheless, there may be considerable disjunction between protocol and practice, which depends on how the procedures intended to implement protocols are actually used by fieldworkers, and how research participants interpret them (Fairhead *et al.* 2005). This highlights the importance both of developing clear, transparent structures for research governance and of monitoring and understanding what happens when they are used with research participants. It also points to the potential for misunderstanding between researchers and researched, which is mediated by the power relations between them and frequently shaped by wealth, social class, gender, ethnicity, caste, or age.

In contrast with the field of medicine, where the effects of research on participants are often physical, it is harder to trace the impacts of social research. Possible negative outcomes include damage to people's futures, reputations

and relationships through public reports and influence on policies or practices. There is also the potential to exploit research participants from poor communities by failing to consider how they might benefit from the research.

Social science research uses a range of methods, and there are differences between their ethical implications. Responding to a questionnaire survey, for example, involves a regular encounter between enumerators and respondent within the clearly defined boundary of the questionnaire. In contrast, qualitative research processes may use mixed and multiple methods to work iteratively and reflexively, and often build the trust of the research participant in order to learn about their needs and concerns in depth.

Cutting across these ethics questions is the need to develop clear communication about the study and why it is being done. This crucial issue of translation and understanding has particular importance when research covers multiple countries, cultures and disciplines.

Building an ethical social research programme

The foundations of the approach Young Lives takes to ethics were established before its research activities began. The proposal for the study was checked against the ethics standards of each of its six original partner institutions, and the study was reviewed by the London School of Hygiene and Tropical Medicine ethics committee. A pilot phase which developed and tested the questionnaire in South Africa in 2001–02 was given ethical approval by the Rand Afrikaans University. Save the Children's 2003 Child Protection policy was influential in shaping the ethics approach in the first survey round. The study subsequently received approval from research ethics committees in Vietnam and Peru and from the Social Science Division of Oxford University.

As the programme moved towards the pilot phase of fieldwork, country teams in Peru, India, Ethiopia and Vietnam began to translate ethics from paper into practice during the fieldwork stages of the research. As far as possible, techniques for achieving this were developed collaboratively. Training for qualitative and survey fieldworkers was designed and delivered by the country teams with support and input from the coordination team in the UK, and included sessions discussing ethics. Survey manuals contained detailed ethics guidance, while a set of ethics protocols for the qualitative research was prepared and adapted to be relevant at the local level in each country.

Following piloting of the qualitative research methods in 2007, a Memorandum of Understanding for fieldworkers was developed in collaboration with the qualitative research teams. This document sets out some basic guidance about research procedures and respectful communication with

research participants. It has now been adopted across the study, and is also being used with the survey teams. As far as possible, Young Lives has tried to work with the same field teams in successive rounds of the study, and training for fieldworkers is on-going, with sessions taking place before each new round of survey or qualitative research.

Once data collection was under way, it became important to ensure a consistent focus on ethics throughout the rest of the research process, from data storage and analysis to the use of findings to influence policy. The longitudinal character of Young Lives means that there are many rounds of visits to survey sites. Each visit generates reports and information on ethics. Ethics questions are recorded as they arise, and qualitative data is coded and analysed for participants' views of their involvement with Young Lives. This has generated the collaborative, iterative development of a shared understanding of and collective approach to ethics by researchers in different places whose work focuses on diverse themes and activities. The approach to ethics that has emerged from this iterative process of discussion and practice has several key cornerstones:

- *Informed consent.* Young Lives works on the principle that researchers must obtain informed consent from parents or caregivers and from children themselves, from as early an age as possible. The purpose of the research is clearly explained every time fieldworkers visit a community, emphasising that Young Lives is a study, not a development project. Consent is understood as an on-going process, and is frequently re-checked.

- *Anonymity.* The Young Lives children and their families share a great deal of personal information with us and we have a responsibility to ensure that their confidentiality and identities remain protected. Names of people and places are removed from Young Lives data before archiving, and a set of pseudonyms has been developed for use in publications.

- *Respect and protection for children.* The Memorandum of Understanding covers how to behave respectfully towards children and awareness of child abuse, and establishes a structure for reporting and responding when concerns about this arise. We are also conscious of the need to maintain a gender balance within fieldwork teams, particularly as the children enter adolescence.

- *Working with local researchers.* This helps minimise the risk of inadvertently causing damage to participants through misunderstanding local contexts.

- *Flexibility about rewards and compensation.* The research teams in our study countries each take a culturally appropriate approach towards compensating research participants, ranging from paying them for their time to giving small gifts to thank them.

- *Reporting back to communities.* With each study round we are developing new ways to provide information about Young Lives research findings to respondents, enabling the respectful implementation of the study. Findings are presented at meetings in a range of locally relevant ways that are intended to be accessible to all members of the communities, and that highlight the usefulness of the data they are providing.

Practical challenges and lessons learned

Many of the challenges encountered in implementing this approach to ethics concern misunderstandings between researchers and participants, in particular about the nature and purpose of the research. In Ethiopia and Peru for example this has meant researchers having to assuage the fears of parents that Young Lives will take their children away.

In all four countries, the presence of researchers has raised the expectations of people who live in poor communities that they will benefit directly from their participation. Despite consistent efforts at clear communication, researchers have encountered widely differing understandings of the research among participants. In particular, they have found that the use of the word 'project' is loaded with expectations of financial and material benefits. In Ethiopia and Vietnam, where government departments are involved in data collection, and sites where Save the Children is a research partner, association between Young Lives, government and NGOs has sometimes further contributed to misunderstandings about the purpose and outcomes of the research. One consequence of this in some places has been difficulty in renewing informed consent as participants have come to fully understand that the research is not going to directly improve their lives.

High expectations about possible benefits of the research are closely related to the question of compensating participants for their time. Here the challenge has been to balance different understandings of the value of people's time, their willingness to undertake research activities for the common good, and the reality of their having to take time away from work to talk to researchers. Over the course of the study, the question of payment has become more important as economies have become increasingly monetised, and people have become more aware of the financial value of their time.

While explaining that the research will not bring direct benefits in the form of 'projects' or 'programmes', teams do explain to participants that the information they provide will be used to try to improve the situation of children more broadly. This raises the questions of reciprocity in research and of how best to learn about what people think would be useful to them without this being seen as a promise or an aid intervention. It also demands that research teams explain to participants and their communities how messages from the research are being taken to governments and used to advocate for change.

The key strategy for meeting the challenges outlined above has been a reflexive approach to ethics which will continue to develop. In many cases, this has meant making relatively small changes in response to particular challenges – for example, endeavouring to talk about the 'study' rather than the 'project', or ensuring that research teams do not travel to sites in vehicles with NGO logos. It has also meant investing a great deal of researchers' time in patient explanation of the research and reassurance about its motives. An example from India which records a researcher explaining the sampling process to parents illustrates how this has been undertaken in locally relevant terms:

"Now, let me explain why we have selected [your child] for the research. While cooking rice, you will take some grains and test whether it's cooked or not. You will not check the whole rice. In the same way, we select some children to know how they are and to know about their lives, and to know how the lives of children are in [this community]. That's why [your child] has been chosen."

Equally important is working in a way that allows people to express their concerns and worries, as illustrated in this extract from group discussions with local authority workers in Peru, one of whom has said that there are rumours in the community that Young Lives is going to take children away:

Fieldworker: "It is good that you're mentioning this because, as the authorities, it is good that you're informed […] No one is going to take any of the children, no way are we taking them away from their homes. In fact, what we want is to see how they grow up in their homes, how some improve and others do not, and the reasons why some make progress and others do not […] You can tell us any fears or worries that you have. In each visit we hand out a leaflet, a letter for the families with telephone numbers and address, and you can call and ask any time. We've also handed out a letter in the municipality, where you'll find our phone numbers and addresses […]"

Professional: "Are you all Peruvians?"

Fieldworker: "Everyone; we are all as Peruvian as *yucca* [cassava] and potatoes!"

While broad shared ethics practices are crucial, these need to be applied with some flexibility according to each situation that arises. The importance of understanding dynamic local contexts cannot be overemphasised. When research teams visit sites, they are not going into neutral situations. Circumstances can change very rapidly, and these changes themselves need careful documentation.

Understanding local contexts is equally crucial to explanations of how research participants respond to being involved in a longitudinal data-gathering exercise. An integral part of an ethical approach to this kind of study is to follow the effects of participation on children and their families over time, partly to try to ensure that they are not negative.

Maintaining an iterative approach means continuing to adapt the existing Memorandum of Understanding with research teams and fieldworkers, through learning from participants and adapting methods and standards to fit their views more closely. Similarly, questions on informed consent and managing raised expectations need constant reflection. For Young Lives perhaps the most challenging part of maintaining a responsive approach to ethics is following through on policy work in ways that can demonstrate potential change in children's lives, thereby meeting its fundamental ethical responsibilities to children, families and communities.

Further Reading

Alderson, P. and V. Morrow (2011) *The Ethics of Research with Children and Young People: A Practical Handbook*, London: Sage

Economic and Social Research Council (2010) *Framework for Research Ethics*, Swindon: ESRC, http://www.esrc.ac.uk/about-esrc/information/research-ethics.aspx

Fairhead, J., M. Leach and M. Small (2005) 'Public Engagement with Science? Local Understandings of a Vaccine Trial in the Gambia', *Journal of Biosocial Science* 38: 103-16

Morrow, V. (2009) *The Ethics of Social Research with Children and Families in Young Lives: Practical Experiences*, http://www.younglives.org.uk/files/working-papers/wp53-the-ethics-of-social-research-with-children-and-families-in-young-lives-practical-experiences

Save the Children (2003) *Child Protection Policy*, London: Save the Children Alliance.