# Five

# Money matters: contracts, funding projects and paying participants

Chapters 1–4 have reviewed choices mainly made during the early research design stages before it is possible to apply for funds, although the potential budget might have influenced the study design very much. The early choices were about the aims, questions and methods, although choice-making often continues into later stages. This chapter questions the sources of research funds, problems with budgets and timing, and how contracts can protect ethical standards. It ends with considering the payment of children and young people for their contributions to research.

## Planning, budgeting and research agendas

Much ethics guidance sets high standards, but says little about how the complicated and often messy day-to-day conduct of research can fit these standards. This chapter reviews some of the complicated ethical challenges posed by funding and budgets. Over the past few years money matters have come to have a much stronger hold over research, as is considered in this first section.

Increasingly, commercial and university researchers have to include high overhead costs in their budgets. This can mean that social researchers are less able to apply to the charitable trusts, which do not cover overheads (as of 2009) but which tend to fund the more innovative, exploratory and participative projects. Apart from commercially sponsored market research, which is the largest sector of research with children, most funds are now granted by government departments and agencies, who increasingly support large research studies, evaluations and systematic reviews, mainly about children's and young people's needs and problems, and how services deal with these.

The potential benefits of such research are an improved understanding of children's needs and of effective ways to help them, as well as to check which services are not working well, possibly in order to remove or change substandard services. There are, however, also potential disadvantages in these larger studies. Children's needs, deficits, problems and misdeeds are emphasised in counterproductive ways that can discourage general respect for children and young people and for their competencies and contributions. Longitudinal

research, such as the 1958, 1970, 2000 birth cohorts conducted in the UK, relies on older questions and methods, which may not best suit children in the 2010s. The UK government supports much research about 'What Works?', meaning which services and interventions are most effective? These are tested by comparing two or more groups of people in trials. The aim is to have 'evidence based' planning and policy. This research tends to assume and promote adult control, values and cost-effective recommendations. If costs and cost-effectiveness are the priority, this can mean setting utility before principles and rights (see Boxes 1.7 and 1.8).

Relations between the social scientists, who produce evidence, and the politicians, who select, interpret and use the evidence to support their policies, can be strained. For example, urgent political requirements demand short-term evaluations with expedient, cost-effective and voter-friendly results. Yet on parenting programmes, for example, results may be too premature and 'weak' to provide the necessary evidence that politicians claim to offer. Attention to the majority can overlook the different needs and interests of minorities, for whom services may be working less well. Although the British Sure Start programme, for example, was designed to help disadvantaged young families, it appears to be least helpful to those in greatest need of support, the youngest single mothers (Rutter, 2008), though this is seldom admitted. These are only a few of the ways in which economics can complicate every stage of research, from first plans to final implementation. They are noted here for researchers who are affected by them to consider as part of their review of the ethics of their research.

## Ethics and funding sources

Researchers sometimes have to decide whether or not to accept research funding from sources that may be unethical, such as companies whose products harm children.

## Carbon costs

The UN (2009) reported that an estimated 211 million people were severely harmed by the effects of climate change during 2008. An editorial in the *British Medical Journal* points out that 'most of the health burden of climate change is borne by children in developing countries' from malnutrition, disease and flooding (Roberts and Godlee, 2007: 324–5; IPCC, 2007). The authors estimated that over 10,779 tonnes of carbon were emitted by 15,000 delegates travelling to one American Thoracic Society conference. This approximately equalled the annual carbon emissions or 'footprint' of

around 550 Americans, 11,000 people in India and 110,000 people in Chad. Roberts and Godlee regard this as an ethical matter and conclude that 'doctors must lead by example' and find alternative ways to convene international conferences.

There are online research-related conferences and websites, with lecture and chatrooms, and videos of main lectures and panels discussions. The lecture texts, PowerPoint and oral presentations and the posters can be put online for several months, with space for emailed comments and debates. Virtual conferences can last much longer than real ones. They leave more detailed records to be downloaded, they are open to many more people than those who can afford the time and fares to travel, and can be accessed at any times which suit each 'delegate'.

The Sustainable Trials Study Group (2007) is linked to the worldwide Cochrane Collaboration, which conducts systematic reviews. Their aim is to discover the best evidence from all known relevant research in hundreds of topic areas. The Study Group conducted a carbon audit of a clinical trial held in 49 countries during 1999–2004. They estimated that in one year, 2003–2004, 126 tonnes of greenhouse gases were emitted by the research offices, staff travel and distribution of the trial drugs and materials. The report suggested ways to cut carbon emissions during medical research.

British universities are expected to 'take the lead' and to begin now, in line with European and national policies, towards cutting carbon emissions by at least 80 per cent by 2050 (www.hefce.ac.uk/susdevresources/carbon/).

The policy has five aims linked to ethics:

(1) to reduce carbon-related climate change and its effects;
(2) to conserve non-renewable resources for crucial uses, such as oil for plastics;
(3) to prevent the social disorder and conflict that will occur when carbon fuels become too scarce and expensive for most people to use, and societies still mainly depend on them for all aspects of daily life;
(4) to accelerate development of renewable energy resources;
(5) and through renewables and other measures to prepare systems that will support the predicted rise in population from around 6.7 billion now to 9 billion in 2050.

Pearce (2010) predicts that population growth is already levelling off, and will not reach nine billion. He argues that in any case population increase in the most deprived societies is not a threat to climate change or to human survival, when many people live not only at zero carbon levels but minus carbon levels, when their work is mainly, for example, picking rubbish, recycling or forestry. Instead, Pearce thinks, the main threat is from minority world small families who are wealthy high consumers (Gorringe, 1999; Shiva, 2000; Miller, 2002; Plumwood, 2002; Monbiot, 2006; Stephens, 2006; Lynas, 2007; Kempf, 2008; Bell, 2009; Giddens, 2009).

Carbon costs directly relate to the ethics of research with children because:

- those who are being and will be most severely affected by the effects of carbon-related climate change are younger and future generations;
- the present and potential effects on children are under-researched;
- and therefore through their selection of topics as well as their energy-consuming research processes researchers can influence public debates, policies and practices in positive or negative ways.

## Ethics and contracts

The funding contract can have powerful effects on the ethics of each project. Management and budgeting involve the efficient and also ethical treatment of the whole research team with care and respect enabling them all to respect the participants, to develop their own ideas, analyse data in depth, and report the research widely.

If research teams are too hierarchical, it can be harder for junior researchers, who usually work most closely with the young participants, to report any problems they may have, and to get team leaders to attend to these problems. Most unfortunately, some junior researchers report that their concerns about their research project being unethical and exploiting children and young people, are dismissed by senior researchers who say, 'The research ethics committee approved the research and therefore there are no problems' (see Chapter 6).

Contracts with funders for research, consultancies and evaluations may need to allow for:

- reasonable costing and timing, including funds to allow for inclusive methods, such as the extra time and resources that may be needed for children who speak little or no English, and for children with learning difficulties (Braille, signing or IT communication, taxi and escort fares);
- regular discussion times among the research team;
- adequate secretarial, technical and library support, and project accommodation;
- a pilot or flexible initial period to learn from the research participants' responses and then possibly to improve the study design;
- time to collect and analyse the evidence;
- time to report back to the children and young people;
- time to write reports for all who have helped with the research, and for wide dissemination to increase the chance that useful findings might be implemented or might affect policies and attitudes;
- a freedom to publish clause (see below).

Research governance standards are promoting generally higher agreed standards in contracts, which may include funds for a sponsor or advisory

group to oversee the progress of each research project. Contracts could include clauses on:

- the researchers' priorities and values;
- ethical questions raised by the research and the means of addressing these;
- an equal opportunities policy, and how cultural, religious, gender, age, disability or other differences among researchers and participants are respected;
- a disclaimer for funders in reports, saying that sponsorship does not necessarily mean support for the conclusions;
- researchers' intentions to report research problems and actual methods honestly;
- caution about how reliable and generalisable or transferable the data are likely to be;
- avoidance of fabrication and misrepresentation of data;
- final reports to be in sufficient detail to enable other researchers to understand and learn from the study;
- a freedom to publish and copyright clause.

## Freedom to publish

Freedom to publish clauses prevent funders or researchers, research institutions or the agencies that have been researched, from refusing to allow the detailed findings to be published. They help to protect the integrity of the research. The National Children's Bureau Guidelines (1993; slightly less clearly in the newer 2003 version) state that in exceptional cases:

> Where we approach to undertake a study of a confidential or particularly sensitive area [plans for research reports] would need to be agreed between the Bureau and the funding agency at the outset. All reports will be shown to participating organisations and the funding agency in draft form and any comments will be carefully considered. [The Bureau] retains the responsibility for what is finally written [and] copyright, except where agreed otherwise. Evaluative research in particular, by its very nature, will often raise questions concerning certain existing policies or practices. This will always be presented constructively but participating agencies must be prepared for this possibility.

Researchers may produce important but disturbing findings that their own employers do not wish to publish, for fear of alienating patrons or funders. Contracts guard against this when they mention researchers' (and not only their agencies' or employers') rights to publish. However, another barrier to this freedom is having to satisfy editors, and in academic journals the peer reviewers, before publishing reports in the press. Many unexpected problems may arise during research. Foresight, well-thought-out contracts, and attention to ethical questions can all partly help to prevent or reduce these problems. This chapter concludes by considering payments for young people.

## Paying young researchers and participants

Payments may be made for several reasons:

- to reimburse expenses, including escorts' fares;
- to compensate for time, inconvenience and possible discomfort;
- to show a token appreciation for participants' help;
- to pay for young people's help just as adults are paid;
- to recompense people who would have been earning by working or begging if they had not been helping with the research.

These payments can be ethical 'fair returns' for young participants' and young researchers' contributions to the research. Some guidelines advise that payments may be made to encourage participants to take part 'as an incentive'. However, they contravene the *Nuremberg* standards that no persuasion or pressure of any kind should be put on participants. Yet any payments, however fair, may still bribe or even coerce people into taking part. A payment that may be small to some people can be high for others, including disadvantaged people and many children. They may then feel pressured into accepting payment and feeling that they have to divulge more than they would choose to say, or say more strongly what they think researchers want to hear.

Should people be paid at the start and assured that, whatever they say or do, such as leave the study, the payment stands? Or should payment only be given 'as a surprise' afterwards, when there would be no risk of bribing people? Some funders do not allow payments to be made. However, on the importance of respecting and rewarding young people, see Box 7.5.

The advantages and disadvantages of paying young people are debated in a review of ethics guidelines (Wendler et al., 2002) that usefully separates the four types of payment – reimbursement, compensation, appreciation and incentive. The review concludes with 11 safeguards, given here for readers to debate. The safeguards aim to reduce the chance that parents' and children's decisions, about whether to join a study, will be distorted by promise of a payment.

(1) Develop guidelines for all four types of payment.
(2) Adopt an explicit policy on advertising payment to children.
(3) Require explicit justification for all incentives.
(4) Allow that children are paid less than adults in identical studies.
(5) Ensure payment to subjects who withdraw.
(6) Consider carefully any cases when there is concern that people are consenting because of payment and not because they wish to take part.
(7) Develop a general policy on describing payments in consent and assent forms.
(8) Make direct payments to the proper party.
(9) Avoid lump sum payments.

(10) Consider deferred payments.
(11) Consider non-cash payments.

Children in Scotland (2001: section 4) give another example of guidance on payment.

> Children in Scotland will refund all reasonable travel and subsistence expenses incurred by informants in the course of participating in the research, on production of receipts.
>
> Children in Scotland may also pay research contacts [participants] in addition to expenses as inducement to participate, as recompense for time, or as appreciation of the contribution. It may be made in the form of cash, vouchers, or in the form of a donation or gift to a group, school or other organisation. In survey research a prize draw may be used as an inducement to return the form.

Readers may wish to discuss the mention of 'inducement' and also the 'prize draw'. Although almost everyone supports lotteries, some people do not, and does this complicate the aims that the research be inclusive? One safeguard is when researchers alone do not have to make all the ethics decisions, but can share them with an ethics review committee, as considered in Chapter 6.

## Payments in context

Research with children (and adults) in very poor or precarious situations, or where people mainly give or exchange practical help and things, rather than money, raises difficult questions about how to compensate people for their time. Payment can lead to misunderstandings and embarrassment between researchers and participants and others who help with the research. The question of payment needs to be understood in context. Sime (2008) discusses using gift vouchers as tokens of thanks in research with disadvantaged children in the UK. Vakaoti (2009) paid street children in Suva, Fiji, and gave them cinema vouchers.

Payment may be made in kind instead of in cash, such as giving school children pencils, pens and notebooks. One PhD student, Natalia Streuli, based in London and carrying out research in the Peruvian highlands, noticed how when she gave the children refreshments during the research activities, they carefully wrapped any leftovers to take home to their families. The next day, they came with plastic boxes so that could take any more leftovers, reflecting not only local norms that children contribute to the family economy, but also that reciprocity seemed to be very valuable to these families (Streuli, 2010).

## Box 5.1 Young Lives

http://www.younglives.org.uk

Based in Oxford UK, Young Lives is doing government sponsored research on child poverty with 12,000 children over 15 years in Ethiopia, India, Peru and Vietnam. Each country research team deals with payment in ways that reflect cultural contexts about the value of people's time, their willingness to help with research 'for the common good', their poverty and not having to miss a day's wages to spend time talking to researchers. Norms of reciprocity and community, and/or obeying the government affect people's participation. However, paying respondents may lead to confusion.

In Ethiopia, children were encouraged to use the money to buy school materials. Families living in extreme poverty at first perceived Young Lives as an aid agency giving out practical help and money. Later, researchers were careful to explain that the research 'project' does not provide any aid to communities or individuals (Tafere et al., 2009).

In Peru, researchers gave small gifts as a 'thank you', as well as some supplies to local schools. In India, research teams also provided some resources to schools, as requested by local community leaders, to benefit all the local children and, up to 2009, they did not directly pay the participants. However, some participants thought it was unfair, that their time was not paid when it was given to benefit everyone in the community.

Cultures are not fixed and, by 2010, the question of remuneration to Young Lives research respondents became increasingly important as economies become more market oriented. For example, in Andhra Pradesh India, the National Rural Employment Guarantee Scheme, which pays workers at least Rs.60/- (the equivalent of 75 pence or about US$1) for a morning's work, has recently been implemented. Whereas in the past, the opportunity cost of spending time talking to a researcher may have been zero, or respondents could carry out domestic chores or work on the farm while talking with researchers, they are now becoming more aware of the financial value of their time, and are more likely to expect payment. Thus, Young Lives has decided to pay participants for their time in subsequent research rounds in India and might do so in the other countries. Otherwise, people might refuse to participate in future, especially in urban areas where it is already difficult to keep people involved.

Poverty might induce children and adults to feel under great pressure to consent, and to continue in research unwillingly, in order to receive payment. Care has to be exercised. Some people suggest that children should not be paid to help in research, because of this potential pressure, and because it puts

them in a contractual relationship and diminishes their freedom to withdraw. Poor people also usually have low status, which can further reduce their power to refuse or to withdraw. (We will discuss consent in Chapter 8.)

Meanwhile, poverty and associated low status raise questions to consider. What kind of relationship do you want to have with the people who help with your research and supply information? Is it simply a contractual relationship? Do you hope to have a relationship of trust and shared interest in the information supplied? How might these relationships affect and shape the information supplied? Perhaps the possibility of mixed motives could be raised. Here we are talking about the pragmatics of collecting good quality data as well as ethics. It could be argued that relationships of trust can only be mutual, and sustained within some reciprocity (see Chapter 9) and some equality of power. This is hard to sustain when researchers can be so much more powerful than participants, although that is why respect and consent are so vital (Chapter 8).

Researchers may have mixed motives when their 'principled' refusal to pay participants keeps down research budgets, reduces administration, and avoids potential disputes and bargaining about pay rates. An example from Zimbabwe questions whether people are more willing to be honest if they are paid, or if they feel that they should produce or invent extra responses to deserve the fee. Groceries were presented at the end of each interview, when one man became embarrassed. He said he had thought this was some kind of government survey, not the long-term study with which he was well acquainted. He told the interviewer to throw away his notes and start the interview again – this time he would tell the truth! (Michael Bourdillion, pers. comm., March 2010). The example points to the vital need to establish the right kinds of relationships, those which produce reliable information.

## Box 5.2 Fieldwork in Ethiopia

Tatek Abebe (2009: 461) describes how:

> Conducting fieldwork among economically disadvantaged children as a privileged, educated, car-driving man raised complex personal questions relating to material inequalities. As most of the participants were from low-income groups and many of them, including child beggars, move in different places to earn their daily income, I believed … that giving them some money was adequate reward for their time and labour, and hopefully a way of encouraging their participation. In schools, I gave or paid for children's stationery materials. On streets, I gave money to children, and paid for the meals we frequently shared.
>
> However, my relationships with many of the children were deep and mutual. The children bought me gifts on different occasions, invited me to their houses,

*(Continued)*

*(Continued)*

shared their food with me ... Looking at the contexts of deep-seated poverty and harsh material deprivation, I became compelled not to detach myself from their circumstances. Although I never made any promises for the future, (temporary) reciprocal relationships have nurtured the research space in many fruitful ways ... reciprocity ... reflects how ethical spatiality is the product of interrelationships ... and that dominant ethical principles are actually lived in, reproduced and experienced by research participants through interactions.

## Summary of questions

- Should the research funds be raised only from agencies that avoid activities that can harm children?
- Does the funding allow for time and resources to enable researchers to liaise adequately with the children, and to collect, collate and analyse the data efficiently and accurately?
- Are the children's and parent's or carers' expenses repaid?
- Should children be paid or given some reward after helping with research?