CONDUCTING HEALTH-RELATED SOCIAL

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CONDUCTING HEALTH-RELATED SOCIAL SCIENCE RESEARCH IN LOW INCOME SETTINGS: ETHICAL DILEMMAS FACED IN KENYA AND SOUTH AFRICA

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Abstract: The value of the social sciences is increasingly recognised in health services and clinical research, contributing to an increasing number of multi-disciplinary, multi-method studies. Such studies offer numerous advantages, but also pose particular challenges, including different approaches to or foci in research ethics across disciplines. Drawing on two similar studies conducted in coastal Kenya and in rural South Africa, we share the ethical challenges we faced in relation to several key principles, the responses we adopted, and the new dilemmas that resulted from our actions. Given that multi-disciplinary, multi-method studies are often reviewed by committees with greater familiarity with biomedical than social science research, we conclude by drawing on our experiences, and the wider literature and guidelines around conducting social science research, to make suggestions of additional considerations for social science elements of multi-disciplinary research. We also emphasise that in practice it is the social relationships that are established between researchers and field-teams, and between field-teams and community members, that are critical to fulfilling the moral (as opposed to the legal) aspects of ethics guidelines. These essential elements of ethical practice, and of producing quality data, are not easily tested and checked by ethics committees. Rather they are linked to the insight and integrity of the principle investigators and their research teams. Copyright © 2009 John Wiley & Sons, Ltd.

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1 INTRODUCTION

1.1 Multi-Method Health Research in Low Income Settings

There is increasing recognition that social science research can make an enormous contribution to health and development goals (Pope and Mays, 1995; Malterud, 2001; Mays *et al*., 2005). For example an improved understanding of individual and household level health-related behaviours, and the factors influencing people's uptake of and interactions with health services, can lead to more appropriately designed and targeted interventions; or an improved understanding of health systems, including policy making, management and implementation processes, can contribute to strengthened health system functioning. There is also growing recognition that clinical approaches to health and disease need to be complemented by social analyses of the wider causes of susceptibility to ill heath. Thus five out of the six committees who made recommendations for the 2002 Global Forum for health research included in their ideas the need for further research on socio-cultural issues affecting health, and on equity in health (cited in Theobald and Simwaka, 2008). Such research requires stand alone social science studies, but also strong social science elements to be incorporated into multi-disciplinary studies.

Multi-disciplinary or multi-method studies are increasingly recognised as appropriate in studying a health-related research question or problem (Mays *et al*., 2005; Theobald and Simwaka, 2008), often including a variety of field-based methods such as medical examinations, household questionnaires, observations and in depth interviews with participants in the community. Such studies offer potential strengths but also extra challenges, including reconciling the different notions of research ethics in the social sciences and in biomedicine (Hoeyer *et al*., 2005). These differences are particularly strong where social scientists are working from a naturalistic rather than a positivist epistemological base, and where researchers are drawing heavily on qualitative methodologies. Challenges may also be more acute in cross-cultural research, or where research is being carried out in low-income settings by researchers or funding bodies from wealthier countries (Kuritzkes, 2004; Molyneux and Geissler, 2008).

In this paper we present our experiences of conducting two studies of very similar aim and design in two different social contexts: rural and urban coastal Kenya; and rural South Africa. Both were multi-method social science studies that generated quantitative and qualitative data using a cross-sectional household survey, focus group discussions (FGDs) and in-depth interviews, and repeated and intensive visits to a sub-sample of households over 10–12 months (referred to as longitudinal case study households). In presenting and discussing our experiences we

- examine the complex ground realities and ethical challenges of conducting multi-method health-related social science studies in low income settings;
- highlight specific ethical issues arising from multi-method studies in poverty settings in relation to key biomedical ethical principles and guidelines, and;
- share our experiences and practical ideas around how to minimise and cope with these ethical dilemmas.

Following a brief overview of the ethical frameworks guiding biomedical and health related social science research, and the main differences between them, we provide a summary of the Kenyan and South African studies. We then describe some of the challenges we faced in the process of carrying out our research, the response we made, and

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finally return to considering the implications of these experiences and the wider literature on social science ethics for the planning and review of similar studies in such settings in future.

1.2 Comparing Biomedical and Social Science Ethics Guidelines

There is broad general agreement among many biomedics and health-related social scientists on three fundamental ethical values and norms (Murphy and Dingwall, 2001; Emanuel *et al*., 2004; ESRC, 2005; Wassenaar and Corbella, 2008): (a) beneficience and non-maleficence, i.e. that research on human subjects should produce some positive and identifiable benefit, however indirect and long-term, and that researchers should avoid harming participants; (b) respect for persons and, increasingly, communities, i.e. that the values and decisions of research participants and the communities from which they come should be respected, and; (c) justice, i.e. that people should be treated equally. There can be heated debate however about how these values and norms should be applied in practice, particularly for international research where there may be significant differences between researchers/research funders and research participants, in terms of culture and access to information and resources.

A range of ethics regulations and guidelines are aimed at assisting in ethical deliberations and debates for biomedicine, including specific considerations for international research. Emanuel *et al*. (2004) have recently drawn on these to present eight principles and 31 corresponding benchmarks to consider in planning and reviewing clinical research in developing countries. The eight principles are

- collaborative partnership,
- social value,
- scientific validity,
- fair selection of study population,
- favourable risk-benefit ratio,
- independent review,
- informed consent
- and respect for recruited participants and study communities.

Given the potential inequities between stakeholders involved in international research, special attention is given by Emanuel *et al*. to the principle of ‘collaborative partnership’: equal partnerships between investigators and sponsors in developed countries, and local researchers, policy makers and communities in developing countries. Strong collaborative partnerships can guide research teams in the difficult task of balancing the sometimes conflicting principles or benchmarks in an appropriate way in a given setting. For example community representatives may assist in deciding how to balance achieving a favourable risk-benefit ratio in a particular context against undermining individual informed consent through introducing inducements.

Emanuel *et al*.’s framework is designed to facilitate ‘dialogue and compromise among individuals holding reasonable but differing points of view’. This is useful given the concerns and debates that have been expressed, for example around the independence and capacity of ethics committees in some low-income countries, the extent of community representation on these committees, the post-research responsibilities of research teams, the mounting bureaucracy involved in ethical review, and the prioritisation, appropriate-

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ness and meaningfulness of individual informed consent (Christakis and Fox, 1992; Benatar, 1994, 2002; Alberti, 2000; Bhutta, 2002; Gilman and Garcia, 2004; Hyder *et al*., 2004).

There is a shorter tradition of established research ethics in the social sciences (Wassenaar and Corbella, 2005), but guidelines are increasingly being developed. The Economic and Social Research Council (ESRC) in the UK commissioned the development of an overarching framework specific to the social sciences, which now sets out the ethical requirements for all ESRC funded research (and is available to other funders) (ESRC, 2005). There are some general differences between biomedical and social science guidelines, and particularly anthropological guidelines, summarised by Hoeyer *et al*. (2005) as

- Less codification of ethics in the social sciences compared to biomedicine. Thus, for example, in biomedicine there are usually more elaborate requirements in place around ensuring informed consent, confidentiality, individual benefits for participants and avoidance of harm.
- In the social sciences greater awareness of and attention to conflicting interpersonal relationships and the power imbalances inherent in many research relationships.
- Less concern in the social sciences with respect for the individual and informed consent, and more interest than in biomedicine with the political implications of the research endeavour.

Some social scientists consider Emanuel *et al*. (2004) framework a useful, if not adequate, tool for considering the ethics of health related social science studies, while others are concerned about the relevance of biomedical ethical frameworks and review processes for their studies (see debate outlined in Molyneux and Geissler, 2008). In this paper we focus on health related multi-method studies that include qualitative components, as opposed to purely ethnographic studies. We also focus on research for which the aims, objectives and methods can be fairly well specified at the outset, and where a contribution to health and development—however indirect—is an explicit goal.

1.3 The Multi-Method Case Studies in Kenya and South Africa

The Kenyan and South African case studies aimed to improve understanding of households' access to and use of health services, the social and economic costs of illness, the resources that households mobilise to cope with these costs, and the factors promoting resilience to illness-related risks to livelihoods. The background to all of these studies is that illness remains a major risk to household livelihoods in resource-poor settings, especially with the growing burden of chronic conditions such as HIV and AIDS, and that illness costs are driven, and can be ameliorated by, health system design. Given the relatively small evidence base on these household processes, a better understanding of complex ground realities was required from a range of settings. The findings were to feed into policy debates on how to protect poor households from unaffordable illness cost burdens and impoverishment.

The conceptual framework and design of both studies drew heavily on a previous study carried out in Sri Lanka (Russell and Gilson, 2006), with the household level the focus of research. Methods included formative qualitative research (FGDs, in-depth interviews), cross-sectional surveys, and longitudinal follow up of a relatively small number of case study households (follow up for 8 months to a year). The study in South Africa was carried out in a low-income rural area, and in Kenya in both a rural and urban low-income area. A key policy related difference between the studies was that there were user fees for all levels of care in place at the time in Kenya, but only at hospital level in South Africa. These study area and methodology details are summarised in Table 1.

The Kenyan study was carried out on the Kenyan coast as part of a large set of research activities carried out by the KEMRI-Wellcome Trust Collaborative Research Programme. The South African study was one of numerous household studies carried out in a Demographic and Health Surveillance (DHS) site in Limpopo Province, managed by the Health and Population Unit based at the School of Public Health in the medical faculty at the University of Witwatersrand. Both research teams were therefore part of institutions with a strong biomedical research background, and the ethical reviews of the two studies were conducted by ethics committees who review all biomedical research. In Kenya, the research programme was physically based in the District Hospital compound. Findings from these two studies are in the process of being published (Chuma *et al*., 2006, 2007; Molyneux *et al*., 2007; Goudge *et al*., 2009a,b).

2 PRACTICAL AND ETHICAL DILEMMAS IN THE FIELD: EXPERIENCES FROM KENYA AND SOUTH AFRICA

Both studies were reviewed and passed in advance by ethics and science committees in the funding country (UK) and the countries of study. However, as is often the case in research,

Table 1. Study area and methodology details

	Kenya[1]	South Africa[2]
Study area	Rural and urban comparison on the Kenyan Coast (Ganze and Mtwapa)	Two rural communities in the northeastern part of South Africa, close to the Mozambique border, one with a public health clinic, the other without
Socio-economic information	54% rural and 11% urban adults had no formal education Mean monthly expenditure 13 US$ in rural households, and 55 US$ in urban households Rural livelihoods primarily based on subsistence agriculture with seasonal food insecurity widespread. Urban livelihoods primarily informal income generation activities, often linked to tourism	35% of adults had no formal education Mean household expenditure was 107 US$ a month Unemployment is high at 60% of working age adults Government grant income, as well as remittances from relatives working in urban areas were the main sources of income, supplemented by small income generating activities such as trading or casual labouring
Study methods		
FGDs and key informant interviews	9 FGDs and key informant interviews per setting	5 FGD, and 12 key informant interviews combined
household survey	294 rural and 576 urban HHs	280 households
longitudinal case study follow-ups	initially 30 HHs per site	30 households in both sites

[1] For more information please see Chuma *et al*., 2006, 2007; Molyneux *et al*., 2007.
[2] For more information please see Goudge *et al*., 2007.

many of the ethical dilemmas and challenges were unexpected and faced only once the fieldwork had begun. The challenges we faced reveal significant ethical dilemmas for household studies in poverty settings, and show that 'solutions' often lead to new challenges and complications. The challenges, our responses, and the new issues raised are summarised in Table 2, and discussed in more detail below.

2.1 Scientific Validity and 'Remote-Control' Fieldwork

Good quality research is fundamental to ethical research because it is essential to providing sound knowledge with a potential to impact positively in society in the short or long term. How quality is measured, however, can differ significantly for different types of study, and particularly how reliability and validity are checked. Scientific validity tends to be judged for studies like ours by examining the study aims and appropriateness of the methods to meet those aims. Our proposals, which included these details, were approved in the countries of study. However, often vital for good quality research, but beyond the remit of ethics committees, is consideration of who will do the interviews and observations, their positionality *vis-a-vis* potential participants, and the impact this may have on data quality and achieving the study aims. This is particularly important in qualitative work, and in studies like ours where local fieldworkers rather than the principal investigators (PIs) carry out the interviews, including the repeated and intensive visits to households (the longitudinal case study work).

In both settings we needed fieldworkers who spoke the local languages to operate relatively remotely[1] on behalf of the PIs. It was difficult to recruit people from the local communities who were experienced qualitative researchers. In Kenya, we opted for secondary school leavers familiar with the local institutions, communities and languages, in place of more educated staff from other parts of Kenya who would be considered more as 'outsiders'. For the longitudinal household work, two fieldworkers resided in each study area, supervised by a senior fieldworker and the PIs from Kilifi Town (an hour or so away). Supervision included weekly meetings in town, and regular visits to the fieldworkers in the study area. We believe this arrangement gave us unique access to some information and insights, but for the qualitative research compromised on theoretical understanding and therefore data quality in some elements of the research. In South Africa, more educated staff (graduates) with experience working in the area were employed, with supervision by a researcher living within driving distance, and the PIs 5 h drive away. The PI made regular phone calls to the on-site researcher and field workers, and monthly site visits. A challenge with this arrangement was the difficulty in retaining more highly qualified individuals in rural research for long periods of time[2]. Neither situation was ideal, but in both we felt we gathered adequately detailed and relevant information.

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[1] The term 'remote-control' comes from interviewers joking about field workers sitting under a central tree in a village and asking one person about everybody in a village, rather than visiting each household as is typically required by researchers. The term 'remote-control' might also be used to describe the remoteness between the PI and the research participants, or even the PIs and the field teams.

[2] For example, due to the departure of one fieldworker once the longitudinal work had begun, six of the 36 case study households were dropped rather than trying to find a new fieldworker who might disrupt the close relationships within the field team, and who would be unfamiliar with the conceptual aims of the study.

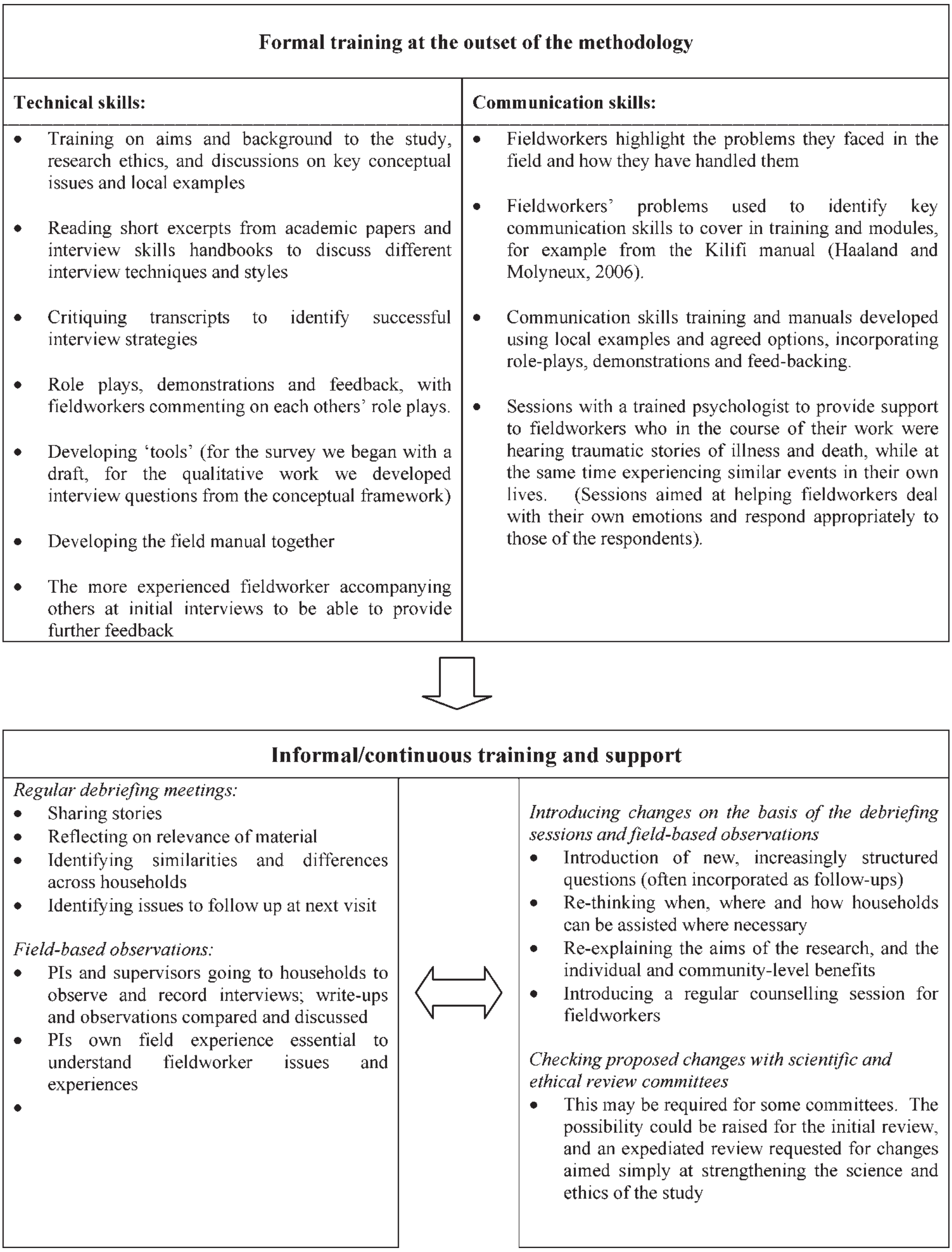
Table 2. Ethical challenges, our responses and new issues raised in relation to several key principles

	Challenges	Responses	New issues raised
Scientific value	PIs with conceptual understanding of the research unable to conduct all interviews Fieldworkers speaking the local languages and with experience in qualitative research not available Fieldworkers having to work relatively remotely from study PIs (1 and 5 h drive away in Kenya and South Africa, respectively)	In Kenya opted for less educated ‘insiders’, and in South Africa for more educated ‘outsiders’. In both, staff resided in villages of study Great emphasis placed on formal and informal training, including in conceptual elements of the study Introduction of taped interviews, more structured tools and regular debriefing sessions	In Kenya, unique access to some information and insights, but less theoretical understanding In South Africa, difficulty in retaining more highly qualified individuals in rural areas for long periods of time In both settings, residing in the villages of study and having access to personal information exposed fieldworkers to some tragic elements of participants’ lives
Informed consent and favourable risk-benefit ratio for individuals	We carefully explained the study, lack of individual benefits and known risks Over the course of the fieldwork, we became increasingly aware of difficulties households were facing financially and in terms of access to health care and other basic services. We were also concerned not to induce participants	In both settings Introduced compensation for time taken for the longitudinal work, but not for the relatively short survey work. Small food gifts were given in Kenya on each regular visit, and in South Africa at key religious festivals. Also gave thank you at end for time and information of photo album. Assistance was offered to households for critical unexpected events	No matter how carefully explained, compensation was (understandably given the context) described by households as a benefit Food gifts introduced new social dynamics and unexpected outcomes within the community. For example sharing food gifts and reportedly some envy by those not selected for longitudinal work
Fair selection of study population and feedback of findings	Complications arise where the above compensation is seen as a benefit, and where selection of those receiving benefits is not random (as with longitudinal households).	Explained to case study households why they were selected Feed back findings (in Kenya to households and in South Africa at community level)	Those who were not selected were not told why they were not. In hindsight information giving should have been to all at the end of the survey interview

We were aware that the PIs' 'remoteness' from the field and fieldworkers had implications for scientific validity, particularly for the qualitative work. Checks and balances possible in quantitative work (for example internal consistency checks and repeating a sub-sample of interviews) are often not appropriate for open-ended methodologies. Team-building activities, support systems, and training activities typical for large quantitative surveys (for example in using the tool and in basic communication skills) may also be inadequate. Interviewers need a clearer grasp of the conceptual issues of a study, in order to know when to probe and explore issues in more depth, to be able to feed back critically to researchers, and to be able to write 'reflective' field notes. In both settings, we therefore placed great emphasis on the training of fieldworkers. Participatory training was designed to bring together the fieldworkers' knowledge of the local community with PIs' understanding of the study aims. As well as a full discussion of the study aims, short readings were used to facilitate a greater level of conceptual engagement by the fieldworkers. For example a transcript of a consultation between patient and doctor was used to prompt a discussion of the types of misunderstandings that can occur. The meaning of the concepts of poverty, well being and livelihood was examined from the point of view of different cultures (ethnic groups, nationality and socio-economic status) represented within the team. Training also covered technical elements of conducting a good qualitative interview, as well as research ethics and communication skills. Fieldworkers contributed heavily to the design of study tools with repeated role plays and translation, allowing extensive discussion of the intention and meaning of individual questions, and re-writing where necessary.

Once the fieldwork was underway, continuous informal training and support was organised through regular debriefing sessions and supervision in the field by the seniors and PIs. For the longitudinal work, debriefings included discussions on the relevance of information gathered, and the appropriateness of the types of assistance offered by the research team to households and fieldworkers. These discussions recognised the work was being conducted in conditions where poverty, hunger and unmet medical needs are common. In South Africa, formal counselling sessions were arranged for the fieldworkers in response to circumstances and stories of death and grief they were being exposed to, and in some cases were experiencing in their own families. Examples of the approaches adopted to strengthen the scientific validity of the research, and to support fieldworkers, are summarised in Figure 1.

Despite training and regular debriefing sessions, challenges to scientific validity arose. In both settings it was difficult for fieldworkers to work with open-ended interview schedules and be sure what information was important to record. We therefore moved especially in Kenya towards increasingly detailed question guidelines, and supplementing information documented in fieldworker notes with information emerging from detailed debriefings. Two examples (Box 1) illustrate that we would have otherwise lost valuable information. In South Africa (and for some elements of the Kenyan study), there was an increasing move towards tape-recording interviews, and later summarising the information on pre-prepared documents with simple headings covering areas of interest. Fieldworkers were encouraged to put all information on the form, even if it was unclear under which heading it should be placed. This approach allowed the interview to remain relatively unstructured and to capture important information that might not seem relevant. In South Africa fieldworkers attended a 4 week computing course to support this approach; a skill and certificate they appreciated for their own future.



Formal training at the outset of the methodology

Technical skills:	**Communication skills:**
• Training on aims and background to the study, research ethics, and discussions on key conceptual issues and local examples • Reading short excerpts from academic papers and interview skills handbooks to discuss different interview techniques and styles • Critiquing transcripts to identify successful interview strategies • Role plays, demonstrations and feedback, with fieldworkers commenting on each others' role plays. • Developing 'tools' (for the survey we began with a draft, for the qualitative work we developed interview questions from the conceptual framework) • Developing the field manual together • The more experienced fieldworker accompanying others at initial interviews to be able to provide further feedback	• Fieldworkers highlight the problems they faced in the field and how they have handled them • Fieldworkers' problems used to identify key communication skills to cover in training and modules, for example from the Kilifi manual (Haaland and Molyneux, 2006). • Communication skills training and manuals developed using local examples and agreed options, incorporating role-plays, demonstrations and feed-backing. • Sessions with a trained psychologist to provide support to fieldworkers who in the course of their work were hearing traumatic stories of illness and death, while at the same time experiencing similar events in their own lives. (Sessions aimed at helping fieldworkers deal with their own emotions and respond appropriately to those of the respondents).

Informal/continuous training and support

Regular debriefing meetings:

- Sharing stories
- Reflecting on relevance of material
- Identifying similarities and differences across households
- Identifying issues to follow up at next visit

Field-based observations:

- PIs and supervisors going to households to observe and record interviews; write-ups and observations compared and discussed
- PIs own field experience essential to understand fieldworker issues and experiences
-

Introducing changes on the basis of the debriefing sessions and field-based observations

- Introduction of new, increasingly structured questions (often incorporated as follow-ups)
- Re-thinking when, where and how households can be assisted where necessary
- Re-explaining the aims of the research, and the individual and community-level benefits
- Introducing a regular counselling session for fieldworkers

Checking proposed changes with scientific and ethical review committees

- This may be required for some committees. The possibility could be raised for the initial review, and an expediated review requested for changes aimed simply at strengthening the science and ethics of the study

Figure 1. Examples of approaches adopted to strengthen scientific validity of the research

Box 1: Kenyan examples of information that would have been lost in the absence of regular debriefing sessions

- One fieldworker reported that a wife and mother in a household said she regularly slept with another male in the community for money in order to afford basic food and health care for her children. The fieldworker had not noted this because it was 'gossip' rather than information. We resolved in future to include any such information in order to assist us in understanding the strategies used by vulnerable people in these communities to cope with illness or hunger, and for the PIs to consider its' relevance. However this fieldworker was clearly and understandably also feeling concerned about documenting information given in confidence about a highly taboo activity. While consent had been sought for the work, there is clearly a feeling—supported in social science ethics guidelines—that researchers do not simply have a licence to study everything. But where is the line drawn in open-ended methods?
- A fieldworker mentioned that a participant on TB treatment had been imprisoned. The fieldworker had found out from other family members that the TB patient had run out of TB drugs the day he was imprisoned but would not dare tell the prison warden. The fieldworker happened to know the prison warden, phoned him, and organised for the patient to be seen by a doctor and to receive his next batch of drugs. The fieldworker had not documented this, because it was not data collection but 'just assisting this person in his personal capacity'. These processes were related to costs and coping with illness (the study aim), but of course we did not have any specific questions around imprisonment in our interview guides and had not considered it in training.

In both settings the approaches adopted were based on the skills and training of the fieldworkers, and it was the repeated discussions with PIs (rather than simply changes to data collection instruments) that the PIs felt enabled fieldworkers to assess more critically which information would be useful and which would not, and so led to improvements in data quality.

2.2 Informed Consent and a Favourable Risk-Benefit Ratio

Risk-benefit ratios can be harder to judge in social science research than in biomedicine. The prime concern in clinical research is typically risks associated with physically invasive procedures. In social science research, risks are more likely to be psychological and social. The benefits that accrue from social science research can also be difficult to predict at the outset.

Our studies involved interviews and observations only. Risks we were aware of included the potential sensitivity of questions about illness, income, expenditure and wealth, the time taken to answer our questions, and the potential to develop unrealistic expectations regarding the rewards of being involved. These risks were potentially highest for the longitudinal case study household participants, which in rural Kenya were being conducted at a time of drought and crop failures for many households. At an individual level, no tangible benefits were built into the original proposals for neither Kenya nor South Africa[3]. As policy-orientated research, the aim is for data collected in both countries to feed into on-going decision-making around health sector reforms to ensure greater availability and access for all, particularly the poor. However we recognise that the research-policy-practice interface is far from straight forward, and significant time and proactive effort is needed to bring research findings into the world of policy making (Gilson and McIntyre, 2008).

Discussions with fieldworkers suggested that the biggest risk for households would be the amount of time taken, which would prevent them from performing daily activities or earning an income, and the importance of keeping individual and household information confidential. We were also aware that in Kenya the link of the research team with KEMRI—well known locally for offering excellent paediatric services—had to be taken into account in all of our interactions. All of these issues were therefore covered in fieldworker training, and careful introductions to all activities with households in both studies. Nevertheless, during initial explanations to community level gatekeepers and representatives, we were often asked what tangible benefits participants and the wider community would get from the work. Also, over the course of the household survey work we became increasingly aware of the economic difficulties households were facing, and that for the longitudinal case study work it would not be socially or ethically acceptable to carry out this work without some form of compensation for the time given by households. In both study settings, on the basis of discussions with fieldworkers, we built in the following individual and community level benefits to the research.

2.2.1 Benefits at individual level

First, for the longitudinal study we offered compensation for time taken with household members, but not for the cross-sectional survey households. Regarding the latter, the interviews were relatively short (approximately 1 h), we were concerned not to induce households to participate, and we did not want to jeopardise other future research including routine government surveys. These issues differed for the longitudinal case study households: much more household time was required, and relationships developed with households over time. In Kenya, time was compensated for by a gift of food per regular visit which would cover the basic food needed for 1 day for all household members. In South Africa, food parcels were provided at key religious festivals to all longitudinal case study households, at the end of the study, and periodically to those households in desperate need. As such the gifts did introduce new social dynamics and unexpected outcomes within the community. Some households for example shared the food gifts with neighbours and friends, and in some cases those not in the study were reportedly envious of those who were.

Second, we presented an additional gift to longitudinal case study household members at the end of the research as a thank you for their time and information. In both countries we offered a photo album with photos taken during each visit to the household. Where households changed their minds about participation, the album was offered at the time of withdrawal.

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[3] Although we were aware that some people may be relieved by or enjoy sharing their experiences, find participating in unusual exercises such as social network maps entertaining, and appreciate developing friendships with fieldworkers.

Third, we offered assistance during critical events such as a serious illness when fieldworkers felt intervention was essential. In Kenya fieldworkers were given enough money to assist a household in an obvious crisis, for example taking a fitting child to the nearest public health care facility. Fieldworkers were also encouraged to present other situations to the PIs for consideration that they perceived were unethical to ignore, for example one family was transported to the district hospital for tests and ultimately treatment for bilharzia. In South Africa, in discussions prior to the fieldwork, the field team were encouraged to make their own judgements as to when it would be culturally unacceptable to ignore a critical illness, and the field vehicle was available for transport in such circumstances. This led to a critical case of TB being taken to the nearest public facility, and the transport of a mentally ill patient and his mother to the nearest hospital to register for a disability grant. The possibility of assistance was not discussed at the outset with households to prevent them delaying treatment (as they wait for a fieldworker), and to avoid inaccurate accounts aimed at receiving assistance; both scenarios which would undermine the science and wider social value of the study.

The food gifts and photo albums were much appreciated in both settings and considered a real benefit of participating in the study. However, they did not appear to affect data quality or prevent households from withdrawing from the study (several did withdraw). In Kenya, we had included information on these ‘gifts’ at the outset of the longitudinal work, because we felt that a frank discussion of the known benefits and risks was essential in that context. We believe we avoided dependence on the food by having visits only every 6–8 weeks, and by not informing households about specific dates until close to the interview. In South Africa giving food parcels at key religious festivals also limited dependence, and meant that gifts were given at a time of more general gift giving.

Nevertheless, situations did emerge in the field that illustrated the difficulty of retaining a clear and consistent line in the types of benefits offered. It was difficult for fieldworkers to refrain from becoming embroiled in the lives of families for example, and ultimately becoming a social network member. An example from Kenya of this situation is one urban case study participant with whom it had been difficult for the fieldworker to meet regularly, due to his busy DVD business. The fieldworker had been slowly trying to establish a relationship with the participant when he was asked whether he would invest in the participant’s business. In a de-briefing session the fieldworker reported feeling torn: on the one hand he knew he could not do this, but on the other he felt if he refused he would undermine the progress he had made in developing the relationship.

The above discussion shows how social science research requiring the development of relationships involves social encounters with risks and benefits for respondent and fieldworkers. They also illustrate the range and complexity of the ethical issues presented to field staff, and the challenges they face in having to deal with these in a locally appropriate, sensitive way that does not undermine established relationships and the potential scientific and social value of the work.

2.2.2 Benefits at community level

Beyond the individual level we wanted to contribute to some tangible benefit to the local community through summaries of the information gathered being fed back to the local community, and to governmental and non-government organisations. These groups could then use the information in developing proposals or in identifying interventions. In both settings these summaries have been warmly received, but we are not sure if and how they have been used.

In Kenya we had also considered offering a local training course for representatives of community-based organisations (CBOs) on issues that emerged as important over the course of the research. Examples considered were Voluntary Counselling and Testing (VCT) initiatives in the study areas, or proposal writing to access development money. However, selection from among the many CBOs would have been difficult, it was not clear that the intervention would be beneficial beyond the workshop participants; and we did not ourselves have the appropriate skills to run the training. Other activities in Kenya included contributing to the story line of a soap opera that is very popular in East Africa (over 4 million viewers). Our key messages in the soap opera are aimed at ensuring communities are aware that they have a right to hold health facilities to account through their facility committees, and that they should consult with committee members for information on charges and information on quality of care. It is beyond our ability to monitor the impact of this activity.

In both South Africa and Kenya there were benefits to the local community associated with the long term presence of the research institution. In South Africa, a community office was set up by the DHS site office to provide a link between the research institute and all residents of the DHS site, establishing contact between those in need and social workers, and assisting households with necessary paperwork to apply for social grants. It enabled donations by researchers, such as second hand clothes, to be distributed to the community without establishing a link between a gift and participation in a research project. In Kenya, KEMRI assists the Ministry of Health with the running of the district hospital paediatric wards, and several dispensaries in the district.

2.3 Fair Selection of Study Participants and Feeding Back Study Results to Individuals

Fair selection of the study population is clearly a key ethical principle, and it becomes crucial in circumstances where there are perceived or real benefits for individuals associated with participation in a study. Community perceptions of fairness become particularly complicated where not everyone can receive the benefits, and where random selection is not the appropriate approach for selecting households, as was the case for our longitudinal case study households. We believed that clarity and transparency were critical in explaining how case study households were selected, and therefore incorporated this into informed consent processes for joining the longitudinal research. In Kenya this was explained to all survey households. Later, however, many survey households complained that they had not been selected for the longitudinal work and wanted to know why they had been ‘left out’. In hind-sight a more appropriate approach might have been to try to explain selection to each household on completion of the survey. In South Africa, a meeting was held in each community at the beginning of the research to explain how households were selected, particularly that a few households experiencing illness would be selected for the longitudinal phase. Despite this, some households still expressed dissatisfaction that they were not included.

In Kenya, following discussions with fieldworkers, we gave feedback of key findings to longitudinal case study households. This was an overview of what was learned from both the rural and urban households, as opposed to an analysis of the household itself over the follow-up period. We felt it would be an important sign of respect and gratitude for their assistance, clarify again what our work was about, and symbolise the end of the research relationship with the households we had come to know so well. This activity, using a simple one page summary discussed in person with the fieldworker, was highly appreciated. Aside from the majority of households being delighted to see the fieldworkers, they appeared to be appreciative that they had been remembered, that they had clearly contributed to a body of knowledge, and that their realities had been documented on paper and were being forwarded to administrators and policy makers. They were also pleased that the fieldworkers had clearly been considered to have done a ‘good job’ by their employers. In South Africa, regular community feedback sessions were organised by the DHS site office, providing information on a range of studies, and the information from this study was fed into this process. Again, these institution wide initiatives appeared to be much appreciated by local communities.

3 CONCLUSIONS

Our experiences suggest that the ethical framework developed by Emanuel *et al*. (2004) for clinical research in developing countries can inform consideration of ethical questions for multi-method social science studies, including those with substantial qualitative components. However, based on our experiences and other reviews we suggest an additional set of factors for social science researchers to consider that are rarely emphasised in biomedical guidelines but that can have an important bearing on ethical practice for all research.

3.1 Scientific Validity and Collaborative Partnerships

- Scientific validity (or ‘trustworthiness’ of findings) often depends heavily on fieldworkers’ ability to establish rapport with research participants and to use research instruments effectively. Differences between the fieldworker and interviewees (and their families) in terms of for example race, class, nationality, gender or education, together with the attitudes and communication skills of interviewers, can influence openness and honesty in participant responses, and ultimately data quality. This is particularly true where sensitive information is required, where research involves fieldworkers from an institution or community with better access to information, formal education and other resources than is the case for interviewees (as is often the case in international health research and where researchers are linked to health institutions offering much needed treatment), and in qualitative interviews (where interviewers are expected to understand concepts and follow new lines of enquiry).
- The types of training and background required for staff involved with different aspects of multi-method research needs careful consideration from the outset. Data collection tools, and approaches to handling difficult, often profoundly ethical, situations in the field, may need revision and adaptation during the initial phases of fieldwork in response to fieldworker skills and abilities, and the situations they encounter.
- Fieldworkers are essential members of a research team. They can act as cultural brokers between researchers and community members or participants, and can have a key role in shaping the nature and quality of data, particularly for qualitative research. We suggest that these staff are considered as key collaborators or partners in a research team, rather

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than simply as data collectors. In Figure 1 we have suggested some approaches for doing this at different stages of a study. Carefully considering with fieldworkers their own career needs, for example through relevant training and certification for training activities conducted, may also build motivation and collaborative relationships within the team.

3.2 Social Value and Risk-Benefit Ratios

- Health-related social science aims primarily to contribute to benefits to society in future, however indirectly, through improved knowledge. Individual risks and benefits are not as obviously and automatically incorporated into studies in the way they often are for epidemiological or clinical studies. For example, if a blood sample is required from a febrile person to test for malaria, a positive slide will usually lead to free treatment. The risks and benefits to participating individuals, communities and countries, and how these will be explained, need particularly careful consideration from the outset for social science research. The benefits ideally should not induce people to participate in the study, and should not lead to expectations and dependence on further gifts. Together, it has been argued that the balance of risks and benefits should ensure that the opportunities for others to do research in the area in the future are preserved (Murphy and Dingwall, 2001).
- At an individual level, careful discussion with participants about the benefits being offered can be based on an understanding of risks such as time taken, sensitivity of questions, contextual expectations, and potential for inducement. This can help ensure meaningful informed consent, minimise unrealistic expectations, contribute to forming clear and transparent relationships, and ultimately improve data quality.
- At the community level, benefits can include direct interventions by the research team, members of the research team negotiating links or referrals to other relevant institutions at the outset of the study or over time as priority issues emerge, or feeding into wider institutional level initiatives. Again, which of these options is most appropriate can be considered and discussed with individuals with significant local expertise.
- All research interactions and activities will have an impact on individuals, households and communities, often in unpredictable ways. In addition to carefully thinking through the possibilities at the outset with a range of stakeholders, including fieldworkers, reactions and implications might require monitoring throughout the research to identify and minimise unintended negative consequences.

3.3 Informed Consent and Respect for Recruited Participants and Communities

- Informed consent is sometimes given less weight in social science research than in biomedicine, at least in terms of a standard set of messages to give formally to all potential participants at the outset of the study followed by a signature: risks and benefits, and even the final outputs of the work, are often not as clear and predictable at the outset. For anthropological elements of studies it can be difficult to know from whom consent is needed (multiple participants can be involved in fleeting ways, and possibly not even recognised as participants until the analysis stage of work); and requirements particularly for signed consent can be considered to impact negatively on developing a

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comfortable and open relationship with participants; a relationship which can be essential to gathering honest information.

- Although we faced significant challenges in explaining our work, we believe that ensuring that all members of the team were clear on the key study messages, and how to handle expected questions in the specific context that they were working, was essential in minimising unrealistically high expectations. We also felt it was critical to have a series of mechanisms in place to assist field staff in handling unexpected yet pressing issues—often ethical—that were encountered in the field.
- Feeding back findings to research participants at the end of a study—at an individual level and/or a community level, and to an individuals and members of local organisations—can be an important way of showing respect and gratitude for the assistance received over the course of the work, clarify again the aims and objectives of the work, symbolise the end of what will inevitably have become a relationship between members of a community and research group, and potentially contribute to making a difference locally.

3.4 Independent Review

- Many health-related multi-disciplinary studies that include qualitative research will be reviewed by committees who are also charged with reviewing a range of biomedical studies. In our case we did not face any challenges in this respect. Nevertheless, concerns about biomedical committees' ability to assess qualitative elements of studies have led to calls for strengthened capacity in this area all over the world. A particular challenge in many sub-Saharan African settings is the significant capacity constraints in the social sciences (Wright, 2008). Given the importance of committees as gatekeepers of research, and the challenges faced in terms of the resources available and the range and number of studies they have to review, several authors have advocated for strengthened support to these committees in their review of social science studies, and particularly qualitative research (Molyneux and Geissler, 2008; Theobald and Simwaka, 2008; Wassenaar and Corbella, 2005).
- In reviewing social science elements of multi-method studies, committees could consider the above suggestions, and pay special attention to the process of research and the nature of interaction between the different actors involved (in addition to the more typical focus on study design and tools). This not only requires strong social science capacity, but is also difficult to do at the outset of a study and away from the research context. But discussion as part of the ethical review of potential ethical dilemmas and how the research team would respond would help to those involved to think advance of how they might deal with the challenges ahead.

The above considerations can be valuable in thinking about how to conduct multi-disciplinary research 'ethically', but the social relationships established between researchers and field-teams, and between field-teams and community members, are critical to fulfilling the moral (as opposed to legal) aspects of ethics guidelines. These essential elements of ethical practice, and of producing quality data, are not easily tested and checked by ethics committees. Rather they are linked to the insight and integrity of the principle investigators and their research teams. We emphasise that our experiences shared here raise a series of issues and challenges rather than any concrete solutions of best practice.

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