

# On doing qualitative research linked to ethical healthcare



## Volume 1

Priscilla Alderson  
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## Foreword

This report is the outcome of a meeting which arose when Professor Jonathan Glover contacted Dr Priscilla Alderson. Each had been awarded project grant funding by the Wellcome Trust under its newly established Biomedical Ethics Programme. Both research projects involved using qualitative methods to help inform healthcare ethics. Professor Glover, a philosopher, wanted to learn more about qualitative approaches from experienced practitioners. Rather than hold a one-to-one meeting, it was felt that there might be a general interest in this topic and so the idea of the meeting was born.

The report does not seek to present the definitive story on qualitative research. As the following pages make clear, the very idea of a definitive account is problematic, for qualitative research, its benefits and limits and the choice of most appropriate methods, are the subject of lively debate within and outside the social sciences. We hope it will stimulate further development of qualitative approaches and a wider understanding of them.

The report has been subject to the normal process of peer review. The views expressed in this publication are those of the authors and do not represent those of the Wellcome Trust or any of its affiliates. The Wellcome Trust takes no responsibility for any factual errors in this document.

Information about the Wellcome Trust's Biomedical Ethics Programme and about the awards made under this programme can be found on the Wellcome Trust website: [www.wellcome.ac.uk/en/1/mismisethres.html](http://www.wellcome.ac.uk/en/1/mismisethres.html)

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## Introduction

### The conference

#### Qualitative research: a vital resource for ethical healthcare

This report draws on themes discussed at a conference, 'Qualitative research: a vital resource for ethical healthcare', and I am grateful to the speakers Paul Atkinson, Mildred Blaxter and Clare Moynihan, whose lectures I have drawn on in writing the report. The report and the conference were supported by the UK Forum for Health Care, Law and Ethics, which promotes multidisciplinary discussions, and the Wellcome Trust's Biomedical Ethics Programme. The Trust funds research into the social, ethical and public policy implications of scientific and medical advances, and especially multidisciplinary research which crosses traditional boundaries between the natural, medical, and social sciences and the humanities (details of research funding schemes can be found at [www.wellcome.ac.uk](http://www.wellcome.ac.uk)). In such collaborative work, researchers are examining knowledge from other disciplines and, perhaps more importantly, learning about different ways of collecting and understanding that knowledge. This involves working across further boundaries between pure and applied ideas, and between research directed towards abstract theorizing and that directed towards informing policy and practice.

The aim of this volume is to explore how qualitative social research can be useful in these multidisciplinary initiatives intended to inform ethical healthcare. Although this report reviews theories and methods in social research, it is not intended to be a beginner's guide for social researchers. Rather, the intention is to assist people who already know a great deal about research in their own discipline, such as medicine, genetics or philosophy, and who want to expand their skills to include qualitative social research, and to see what qualitative research can offer in terms of opening up new perspectives on their work, besides thinking about the methods and potential problems to avoid. We hope to encourage readers to approach qualitative social scientists and to plan joint work which balances and does justice to each of the disciplines involved, and to feel confident that they know enough about key issues in social research to be able to negotiate and achieve this balance.

We also hope that the report will be of interest to policy makers, medical journal editors and to people who review qualitative protocols and papers which are submitted to funding bodies, research ethics committees and to journals. Some of the criteria for planning and assessing qualitative research differ from those applied to quantitative research, as discussed in this report. The report is also addressed to people working in health and related disciplines who might be more willing to read qualitative reports and use their findings, if they knew a little more about qualitative research.

We know, through the UK Forum for Health Care Law and Ethics, that growing numbers of teachers in law and philosophy are making links with people in social science and doing multidisciplinary research, including that which the Wellcome Trust is sponsoring. Teaching about qualitative methods is increasingly being introduced to medical and nursing students (Blaxter, 2001). On the whole medical students are interested in, and receptive to, qualitative methods which they see as being directly about people, a subject not only of great interest to them in itself but also involving ethical issues which many students are 'hungry' to learn about (Williams, 1996). Experienced medical and other health practitioners are also strongly interested because much of their practice is about talking, listening and understanding, which are also the skills of qualitative research.

Most professionals are happy to say that, although their practice is based on and guided by science, beyond that they are well aware of the importance of differing contexts, of the problems raised by over-rigid definitions, of the need sometimes to respect exceptions to the rule, and of the complications which human behaviour, attitudes and beliefs can raise (Blaxter, 2001). Doctors on qualitative research courses 'are frequently surprised to find how deeply rooted they remain in the biomedical model they encountered in medical school' although 'many have intuitively embraced a more...social approach through their work'. 'They discover with some enthusiasm [the] theoretical foundations [of their social understandings] through...the literature of medical sociology and psychology' (Calvert and Britten, 1999:130) including, we hope, this report.

Qualitative research can help to unpack misleading stereotypes about people. The research aim is to obtain more realistic understanding of the experiences and views of people who provide or use health services.

The Wellcome Trust's Biomedical Ethics Programme emphasizes research for policy making, and this report will consider links between qualitative research and recommendations for policy and practice. Another unusual aspect of this report and of the Wellcome Trust Programme is that they bring together ethics and descriptive research.

Part I will consider how and why qualitative research is a vital resource for ethical healthcare, particularly in the light of new developments in scientific medicine. It compares qualitative and quantitative approaches and ways of combining them. Criteria for assessing qualitative research are reviewed, including: challenging common sense; relevance; validity, reliability or replicability; generalizability or transferability; synthesis; participation by research subjects; and debates about assessing qualitative research. Parts I and II highlight key points raised at the conference by the speakers and the attenders, and add further material. Part II goes into more directly practical details about the stages and methods of doing qualitative research, identifying problems and finding ways of resolving them, and of linking research to ethical healthcare policy and practice. Part III summarizes examples and features of qualitative research which contribute to ethical healthcare policy and practice.

## Part I

### The nature and purposes of qualitative research linked to ethical healthcare

#### Comparing, combining and contrasting qualitative and quantitative research

‘An erudite theologian suspected of being a heretic was asked by a journalist, “Do you believe in God?” The theologian eyed him cautiously, and said, “I can answer you but the answer is complex and I can promise you that you will not understand my answer. Do you want me to go ahead?” “Certainly,” said the journalist. “All right. The answer is yes.”’

(Barraclough, 1999:929)

This encounter illustrates differences between qualitative and quantitative research. The quantitative researcher might breathe a sigh of relief at being able to tick the unambiguous yes box and move quickly through the other pre-planned questions. The qualitative researcher might be pleased at the promise of complexity, mystery, perhaps ambiguity, and the chance to explore them through questions which will be raised spontaneously by both speakers during their interaction.

The two approaches complement one another. Yet there is a broad difference between quantitative research where the questions, the likely answers and their meanings are pre-planned in order to measure incidence, and the more open-ended qualitative approach which continues to search for new questions and meanings through the research process. One researcher might be enquiring, ‘How many theologians believe in God?’ and the other, ‘What do belief and God mean to you in the context of your own life?’ or, for example, in relation to ethical healthcare, ‘What does good quality healthcare mean to you as someone with cancer/arthritis?’ The second kind of question relies on a closer relationship developing between researcher and interviewee if it is to be considered in some depth.

The example of religion might seem to confirm common suspicions which link qualitative research to subjective feelings and unprovable matters, like faith, in contrast to scientific, reliable quantitative research. Yet either research method can deal with all kinds of topics, from religion to reactions to prescribed drugs or surgery. For example, detailed accounts by women about the varied ways in which they recover from breast cancer surgery can be as useful to surgical audits as the vital quantitative data about survival rates. Extensive mastectomies were the routine treatment for breast cancer until surgeons began to realize that many women value quality as well as length of life and prefer to risk less mutilating surgery (Baum, 1988). This knowledge involves the kind of qualitative shift in understanding women’s differing values which open questions in qualitative interviews are likely to begin to reveal.

Qualitative and quantitative research have much in common and overlap (Oakley, 2000), although differences between them have tended to be emphasized. For example, Bryman (1988) identified six characteristic emphases in qualitative research, but these are contested, for example by Silverman (1993):

- commitment to viewing data from the perspective of the people being studied;
- emphasis on describing the setting;
- emphasis on the context and on holism;
- emphasis on process;
- flexible research design;
- reluctance to start out with preset theoretical frameworks.

To some extent, all research asks qualitative questions, from the French meaning ‘of what kind or sort?’ and quantitative ones, meaning ‘how many?’ All research has qualitative stages and issues while researchers think about selecting topics and themes, questions, methods, research sites and samples, and interpretations of the data

(Tesch, 1990). Conversely, quantitative questions, about ‘how exceptional, rare, typical or universal is this example?’, are probably raised by almost all (counting again) readers of qualitative examples. The ‘gold standard’ method is not any one particular method, but the one which is most appropriate and effective in answering the research question, as this report will consider. Both approaches have strengths and limitations and unique ways of answering questions. This report concentrates mainly on the nature and uses of qualitative research, not to imply that this is a superior approach, but because it has been a relatively neglected and under-used approach in healthcare research, and to show how useful qualitative research can be for certain research questions.

### **Why do qualitative healthcare research?**

Qualitative research findings and methods can inform ethical healthcare when this is defined as attending to the ethics of justice, respect and care by listening to patients’ own views and sharing informed decision making with them. Qualitative and quantitative approaches tend to be linked to different implicit concepts of ethical healthcare. Surveys and trials tend to emphasize expert services which protect and support relatively passive patients. Qualitative interviews, by allowing time for patients to give their detailed views, can treat them more fully as knowledgeable partners rather than relatively passive respondents.

Another contrast between qualitative and quantitative research is the way quantitative research tends to be conducted by people who are more confident that they are dealing with facts, a confidence which is an almost essential basis for using binary-based numerical data, whereas qualitative research into the nature and meaning of things tends to be conducted by people who are more openly sceptical about reality and validity, and about the genuine difficulties of validating any research once these crucial questions are raised. The differences should not be overstated and many kinds of researchers grapple with concepts of reality and validity, yet there are generally two main approaches between confidence or tentativeness about facts. Quantitative confidence tends to be favoured over qualitative attention to complex meanings, as a sound basis for planning ethical healthcare. Examples through this volume, however, will illustrate how qualitative research can also provide relevant evidence for policy makers.

When selecting the research method which will best investigate and answer the research questions, qualitative methods are useful for research which aims to do any of the following tasks:

- explore and map out a little known area, such as the ethical dilemmas which perinatal staff think are most important as the new genetics begins to influence perinatal services (Alderson, Farsides and Williams, 2000);
- provide vivid, richly detailed descriptive reports;
- report people’s views and experiences, often in their own words and with an immediacy and flexible variety which standardized quantitative enquiries cannot cater for;
- combine a range of methods, such as interviews, group discussion, research diaries and observations, to gain confirmatory evidence, or to extend the findings, or to reveal complexity and difference, such as when doctors and nurses hold differing views about a best practice;
- add new questions and theories during the project as these emerge through the data collection;
- search for examples which confirm or challenge and test the emerging conclusions;
- repeated interviews which address the new questions, or can be used to discuss and develop emerging conclusions and possibly discuss these with the interviewees;
- include usually silenced and excluded groups, such as very young or mentally impaired people, by combining observations with a range of communication and interpretative methods (Ward, 1997; Alderson and Goodey, 1998) rather than relying solely on the views of parents, teachers and other carers (Rutter 1988);
- thus enable seldom-heard groups to be heard in public debates about matters which affect them;
- record and analyse ambiguity, contradiction and gradual change which are hard to capture in binary and more static quantitative measures;

- examine why people hold their beliefs, reasons and motives and how they try to make sense of the world (this knowledge is essential to health promotion which attempts to alter people's beliefs and behaviours);
- increase understanding of the meanings which give form and content to social processes (Finch, 1986), such as learning to become a doctor, or coming to terms with becoming blind;
- work reflexively, learning from the researchers' own changing views, and how they affect and are affected by the research process (Barry *et al.*, 1999);
- link many intricate details together, such as in a case study of a surgery unit, to see how the parts (staff, patients, resources, routines, policies) relate to and influence and change one another, as in a case study.

An equivalent to qualitative research in medicine is anatomy, which examines in minute detail the form and structure (quality) of, for example, the normal heart, before abnormalities can be identified and their incidence (quantity) can subsequently be measured.

All research, however large-scale, could be criticized for being too context-bound, with samples which are too small to generalize from reliably, when it is impossible to include every relevant example and circumstance. These limitations can be addressed, though never wholly resolved, by the use of statistics and of large representative samples. Smaller qualitative studies can combine qualitative and quantitative methods by relating their examples to relevant published quantitative data from other projects, by using careful sampling methods, and a range of other methods (see Schofield, 1990; Seale, 1999). Only a very few examples, however, are required in order to challenge generalizations. For example, showing how a few two-year-olds have profound understanding of their cancer treatment (Kendrick *et al.*, 1986) alters assumptions that children cannot begin to understand until they are 7, 12 or 14 years, changes clinical practice and increases research interest in this area. Qualitative studies can also draw generalizations from underlying themes and *structures*, which go beyond individual *agents* (Bourdieu, 1977; Giddens, 1991). For example, observations and interviews with only a few well selected GPs and patients can show strong patterns which are likely to be widespread, in the many ways in which doctors and patients misunderstand prescribing decisions (Britten *et al.*, 2000). A study of 44 GPs showed how their generalist concerns conflict with the specialist concerns they are expected by policy makers to develop if they are to implement new genetics into their practice (Kumar and Gantley, 1999). These kinds of patterns are likely to be typical of very many if not most GPs. A study of haematology revealed patterns and structures which apply very broadly to medical practices (Atkinson, 1995). A study of children's ability to consent to major surgery gave detailed exceptions which challenge the general belief that younger children are not competent (Alderson, 1993).

### **Qualitative research which informs ethical healthcare**

Many health staff respect young patients but are concerned about the risks of litigation if they overrule a competent child or accept the refusal of treatment from a child who may not be competent. Each case is so individual that research about the elusive processes of children's competent decision making is understood more clearly through qualitative case studies rather than through standardized questionnaires. Competence can then be seen as a varying construct rather than a fact, and is heavily influenced by the types of information, support and respect which the adults give to the child. Understandably, busy practitioners prefer definitive, unequivocal research findings. 'So if 16 or 18 is no longer the age of competence, what age shall I look for now?' doctors have frequently asked. There is no simple answer, which is why the research on this topic was reported in a book about the great variety of child patients and their varying circumstances (Alderson, 1993). The examples showed how a child's (in)competence might reside in the eye of the assessor. Part of ethical healthcare is that health professionals work out with each child how able and willing the child is to share in being informed and involved in decision making, instead of making ageist assumptions and predictions.

Qualitative research is less concerned with providing standardized evidence to inform fast, mass healthcare, than with reminding clinicians of the uniqueness of each patient. So for example, the research with children did not offer generalizable, predictable age-based standards. Instead the research suggested: look for emerging competence in every child; work out with each child how much information and shared decision making seems to be in the child's best interests; apply the exploratory methods of qualitative research to clinical practice and respectful



listening can help to avoid doing harm, the first principle in ethical healthcare.

### **Criteria for assessing qualitative research linked to ethical healthcare**

Several authors have proposed guidelines for assessing qualitative research, and have acknowledged that it is easier to agree on assessments of quantitative research (Mays and Pope, 1996/2000; Greenhalgh and Taylor, 1997; and see appendix 1). This section deals briefly with frequently cited criteria for considering whether any kinds of research reports can provide sound evidence to inform healthcare policies and practices. To begin with, here are some priorities for 'ethical healthcare', based on well known principles (Beauchamp and Childress, 1989; Gillon, 1994) which offer criteria for assessing outcomes and methods of related healthcare research.

Ethical healthcare:

- respects the integrity of professionals who provide healthcare services and people who use them;
- respects the importance of uncoerced and informed decision making;
- works for the just, efficient, efficacious use of resources and, where appropriate, the fairer redistribution of resources, guided by the views of healthcare professionals and service users;
- above all strives to avoid doing harm as it is experienced and defined by both professionals and users.

A further aim is to do good, although some ethicists rate this as secondary and already adequately covered by earlier and firmer aims. Evidence-based medicine (EBM), originally influenced by Popper (1972), Cochrane (1972), and Chalmers *et al.*, (1989), also emphasizes avoiding harm more than trying to benefit. This priority of nonmaleficence fits with the integrity of research which, perhaps unfortunately, tends to provide stronger evidence of harm and failings than of definite benefit or satisfaction or grounds for recommending policies which promote hoped for benefits.

Can qualitative research provide a sound basis for ethical policy and practice? It evokes uneasy questions among practitioners, for example: about truth ('How can I tell firstly whether this story about her daily life by someone with Parkinson's reflects reality, and secondly whether the researcher has accurately reported it?'); about justice ('Is it worth spending precious time asking all my patients whether they experience the difficulties this woman describes? How far can I base assessments of patients' average needs on a few accounts, or decide from them how to allocate scarce resources?'); and about respect ('Should I conclude that on average my patients with Parkinson's have more or less problems than this woman and how can I ask them?') Yet all kinds of research, including large surveys and trials, raise such questions about truth and bias and about the just use of resources, as considered later. The questions raised by the principles of respect, justice and avoiding harm, for evaluating research as a sound basis for ethical healthcare policy and practice, will be considered later, in relation to well known and overlapping criteria for assessing research: validity, reliability, representativeness and generalizability.

**Research about making healthcare policy** The methods of data collection and also researchers' broader commitments and intellectual traditions are all significant for social research about healthcare and bioethics. Important areas for research include: understanding the processes of practical decision making and practical reasoning in context; the use of medical technologies in diagnostic inference; lay reasoning and practical action; the division of labour within and between other specialisms; the rhetoric of persuasion and legitimation; the discourse of clinical encounters; the micro-politics of professional work; the social production of expert knowledge and how it is used and understood (Murphy *et al.*, 1998). All these can be investigated through empirical research (Atkinson, 2001) and can illuminate healthcare ethics and policy (Benatar, 1997).

**Challenging common sense** Some criteria for assessing research advise that it should confirm common sense (Greenhalgh and Taylor, 1997). There are problems in over-emphasizing conformity with common sense and with previous knowledge. The most celebrated and valuable research is counterintuitive and controversial, as with Galileo's, Darwin's or Semmelweis's work.

Qualitative interviews and observations can critically address long-held and possibly misleading assumptions: by asking open questions, rephrasing and dwelling on them, and approaching a topic from different angles; by encouraging extended replies during which people may arrive at new insights while they talk; by exploring examples through narrative during which people voluntarily introduce rich examples and incidentally make passing comments that might not occur to them while quickly working through a questionnaire; by examining ambiguities and uncertainties, and reasons for holding stated beliefs; by exploring people's views and experiences through a range of research methods; and by understanding people's responses through the meanings invested in them by the context of their daily lives. Midgley (1996) shows how philosophy, like plumbing, is essential in daily life but tends to be hidden and taken for granted until things obviously go wrong. Through going back to initial questions in research with people with differing perspectives, qualitative studies can help to expose connections and illogical gaps in underlying assumptions on which healthcare policies and practices are based. This challenges common sense by helping to account for the contrasting views based on different perspectives. For example, qualitative research describes and explains a range of reported and perhaps conflicting views, such as when doctors or nurses or researchers disagree (Barry *et al.*, 1999). Qualitative research also deconstructs stereotypes which tend to be taken for granted and then confirmed in quantitative surveys. For example, masculinity overlaps with notions of femininity (Moynihan, 1998, 2001; Charmaz, 1998; Seidler, 1995). Childhood capacities overlap with notions of adulthood (James and Prout, 1990; Alderson, 1993; Mayall, 1994) in very complex ways. Psychometric generalizations about all cancer patients' desire for information at all stages are qualified by small scale in-depth research (Leydon *et al.*, 2000). Disability may be understood, rather than as physical or mental impairments, as disabling experiences which are socially constructed through avoidable barriers and negative attitudes (Oliver, 1996).

**The relevance of qualitative research to investigate beliefs, values, rules and ethics** In his contribution to the conference, Paul Atkinson considered that research methods are empty in and of themselves. Therefore, without productive and appropriate ideas and theoretical perspectives to drive them, no particular research methods alone will support or sustain significant research programmes, nor will they generate systematic, cumulative knowledge about the social world. Collecting and analysing interview data is more complicated than just getting people to talk about their experiences or their beliefs or attitudes. It certainly is not self evident that you can or should treat interview data as unproblematic, as transparent productions of informants' private experiences, or as proxies for what informants and others actually do. Paul Atkinson believes that you can not get direct naïve access to people's inner thoughts in an unmediated way and thus you have to analyse interviews as speech acts, to see how people enact memory and accomplish performance (Atkinson, 2001). While accepting the importance of the interview context, some people at the conference disagreed with this view, as discussed later.

During his lecture, Paul Atkinson explained his concern with examining implicit moral rules. He argued that the moral order is pervasive. Therefore, while we are not mechanistically rule-governed, we orient our actions to shared systems of rules to ensure that everything is done in accordance with rules and conventions. We justify action through appeals to rules. These rules are enforced in many ways, through sanctions, and through the repair of rule breaking. For example, to save face, we are constantly constructing ourselves as moral agents who are more or less competent. We demonstrate how we are in control of our self and our body. An example is a man who suddenly remembers that he has left something at home and turns back to fetch it. To demonstrate that he is rational, and not randomly changing direction, he will go through certain behaviours such as clutching his head to indicate having a new thought or memory. [The point was illustrated dramatically at the conference.]

Qualitative research reveals and explains underlying patterns, including the following:

- selves and identities are socially, collectively, and continually shaped and reshaped. Institutionalized rites of passage shape and mark actors' moral careers;
- social life is a matter of process rather than of fixed determining entities and structures. Meanings and identities are in constant flux, constantly re-defined and re-understood (Atkinson, 2001).

**Assessments of validity** involve asking: How closely does the research report represent the reality that was observed or experienced and recounted? Qualitative research can score highly on validity when 'thick' descriptions (Geertz, 1973/1993) and accounts by the people concerned provide detailed and comprehensive reports of their

daily realities and differing viewpoints. Lengthy observations in everyday settings are likely to yield valid reports, in the sense of being closer to reality, than controlled experiments or standardized questionnaires are likely to. The usually longer format of qualitative research reports includes original data which help readers to make their own assessments, in contrast to the more compressed, coded, aggregated and numerical style of quantitative reports. Further questions about validity include: How carefully and accurately have the data been collected, analysed and reported? How might the research methods influence and alter people's observed behaviour or their accounts? And how are the possible effects explained and accounted for? (Barry *et al.*, 1999).

**Assessments of reliability and replicability** raise, for some reviewers, such questions as: How well do the researchers' analysis and explanations or theories fit their data? How closely would other people's understanding of the data fit the researchers' interpretations? Is there quality control with a team of researchers agreeing the coding? Are the results replicable by other researchers? How reliable are the research conclusions for informing ethical healthcare? How well does it cohere with what we already know? (Mays and Pope, 1996/2000). While these questions are useful in some respects, they imply that maybe anyone could arrive at the same conclusion and, if so, then why not employ just anyone, preferably the lowest paid assistants? The elaborate efforts which funders expend on choosing the best applications indicate a belief that some researchers are better than others, and surely this includes being able to reach unusually probing, complex and innovative analyses. Other people might be thoroughly convinced by the conclusions, but few other people could, perhaps, have originally worked them out.

Replicating any kind of research can be extremely complicated. In physics and chemistry, failure to replicate may be blamed on the laboratory equipment, rather than on the test or hypothesis which was successful for other scientists (Porter, 1995, pp. 15–16). Human responses are still harder to replicate, because people give differing accounts depending on time, place and whom they are talking to. Their knowledge changes and their feelings fluctuate or may be complex and ambiguous. Although types of disease can be classified in standard ways, individuals' experiences of being ill cannot. Reliability in social research about personal experiences of illness, therefore, depends more on giving a faithful report of peoples' changing accounts, than of necessarily tallying with prior or subsequent evidence.

**Evidence, truth and subjectivity** What do we mean by the truth of data and of evidence? The subjectivity of qualitative data gives rise to contradictory responses. Some say there is no proof that research can either discover what people really think and do, or can analyse the data correctly; it is all 'only' subjective. Others believe that there are qualitative methods of analysis which enable us somehow to know what is the 'truth', and that these methods are equivalent to, though different from, those of 'scientific' measures. A further view is that all research can only achieve partial views of complex and changing truths (Alderson, 1998).

Medical students tend to select for their projects the qualitative method they feel most at home with – face-to-face interviews or focus groups – and then run a computer package over the data set, and produce an answer. The whole research process is thus similar to a quantitative survey. Most health practitioners readily accept that health is a subjective state, rather than an observable condition of the body. Yet, when they start to think about research rather than practice, their education in scientific method tends to take over. It is arguable whether health service researchers could, or even should, adopt the same theoretical approaches to qualitative research as, say, sociologists. However, they should at least be taught about these insights, to avoid too simplistic an approach (Blaxter, 2001).

'To treat what people do and say as self evident, without a theoretical framework in which to interpret facts/descriptions, reduces the power of subsequent analysis to little more than accumulated accounts of common sense.'

(Harding and Gantley, 1998:77)

Research then too easily becomes a process of simply adding another brick to the wall of accepted knowledge. But when researchers begin to look beyond people's statements to their underlying beliefs, then the foundations of the wall of knowledge can be examined and questioned. Weaknesses and fallacies in the assumptions on which

strong traditions are founded may be revealed, with the need to begin a new wall on new foundations.

Standards of evidence and truth apply throughout the research process. There are many methods of showing that you are approximating to a truth, but the essential point is that there are various truths. For instance, does a blue acetate or another acetate with the simple wavelength for the colour blue give a truer description of the phenomenon? Both are 'true', and neither is the whole truth. Understanding of reality has to be linked to some kind of theoretical analysis; blue is understood differently by a painter and by a physicist. They draw on different theories, but within each framework of thinking they justify whatever meaning and pattern that are there.

Researchers think about whether they impose or project a pattern, or see one that is already there, when they analyse interviews. By setting research in its context they achieve research which is more than just picking pebbles off the beach. They introduce new meanings and greater understanding of their topics. This includes pointing to negative examples and considering how these might deny the researchers' premises and how each example is influenced by its own context. There are also differences between objective criteria and measures of colour, as people who are colour blind realize, there is no single measure of colour. These questions become still more complex in social and moral research, for example, about whether people with antisocial personality disorder lack moral capacities such as empathy. Researchers may not get even to the level of one of the state of affairs of truth, and may just be imposing their own views, which means that self-aware reflective research becomes even more important (Blaxter, 2001).

**Bias and accuracy** Selection and therefore some form of bias are inevitable in all research. In qualitative research, instead of 'pushing bias away' by trying to control for it as if it can be entirely deleted, bias is taken account of as part of the methods and the findings. For example, Jocelyn Cornwell (1984) wrote about getting past people's formal 'public' accounts to their intimate private deeper thoughts and about how when she sat and waited for people to speak, this altered their way of talking to her. The way they talk will change over time as people in East London came to talk to her in this more private way. Clare Moynihan acknowledged 'bias' in interviewing men with cancer at home and away from the hospital because they feel more comfortable, and in strongly assuring them that 'whatever you say will not be repeated to the hospital staff, it is between you and me, no one will be able to recognize you in the reports' – all these things affect and 'bias' the interview. Clare conducted a study on knowledge about genetics and cancer, and the men involved who had not had cancer almost all wanted to be interviewed at work, in their offices, where they sat in the largest chair or behind a desk. There was a different balance of power than with the men with cancer, which could be used in drawing out their views (Moynihan, 2001).

Ways of guarding against potentially adverse effects of bias include, for example: asking a balanced range of questions; checking through all the data for how typical or exceptional each kind of response is; examining the important unusual cases as to how and why they might be unusual, and the even more important examples that seem to challenge or disprove a tentative general theory; and trying to be aware of one's own prejudices and how they might be affecting the way the data are collected and interpreted. Selecting a broad sample of different types, such as from among widely varying patients, is also important. For example, children's ability or inability to understand their own illness and treatment can be considered systematically against many aspects of their own characteristics or their circumstances. Every researcher has to worry about fairness and accuracy all the time and in the end all you can do is try to do your best when collecting, collating, analysing and reporting the data.

**Generalization and prediction** Assessments of generalizability link to representativeness, and raise such questions as: How far do the research data and conclusions apply to other groups and contexts? (Greenhalgh and Taylor, 1997; Murphy *et al.*, 1998; Green, 1999). Although numbers can involve vague, misleading and manipulable answers, in an international community of strangers they tend to attract more confidence and less suspicion than words do. Numbers reassure by imposing distance and impersonality on evidence, replacing the forms of personal trust on which people once relied within small communities, such as relationships between a village doctor and the patients, or between a local team of scientists. Quantification is well suited to communication that goes beyond the boundaries of locality and community because it 'helps to produce knowledge independent of the particular people who make it' (Porter, 1995). Mass health services, providing fast, standardized treatment for many strangers rely on an impersonal generalizable research base which transcends

details that are too specific to certain individuals and contexts. Professional expertise is increasingly identified with the objectivity which mathematics and statistics appear to offer, the validity (power) of research results links to statistical 'power' and contributes to professional authority confident of its scientific and fair EBM research base.

Qualitative researchers have conventions and are working towards agreed methods, a whole body of knowledge which is developed and debated. For example, they prefer to talk about transferability rather than the generalizability of qualitative research (Lincoln and Guba, 1985). Generalizability and transferability raise questions such as: How rarely or commonly does this example occur? Is it unique or typical? These questions, raised by all research reports in the reader's mind, are dealt with more directly and systematically in quantitative work. For anyone wanting to apply research findings to healthcare, questions about frequency involve further ones: How transferable or generalizable are the research findings to other similar instances? How valid or strong are the links between the researchers' evidence, the conclusions, and their general applicability? And, therefore, how justifiable or ethical will it be to apply the findings generally?

Answers to these questions include the following. Exact, replicable measurements of people's reported views or activities are often not possible because, as free agents, people change over time and situation. Thus, relative, approximate terms, such as 'more' or 'less', 'most' or 'few', which describe rather than measure precisely, may more realistically report social responses than quoting percentages. Some features will be more broadly generalizable than others. An example is people's general optimism about a form of treatment, though they will report different degrees of hope and individual reasons for being hopeful. The main use of valid generalizations is to be able to identify types of patients and to predict their likely responses. This is vital to scientific medicine when prescribing appropriate medication or surgery, but is not necessarily useful in social aspects of medicine. For example, a paediatrician was frequently told by parents of one-year-old children with a congenital condition that his colleague had given them pessimistic prognoses a year earlier.

'I estimate that half the parents said they didn't really mind and they were relieved that things were not nearly as bad as they expected, and the other half were upset and said they had not enjoyed anything throughout the first year, they were so anxious waiting for awful things to happen. Maybe we need to be able to predict which type the parents are and treat them differently'.

(Personal communication)

There are problems in this solution. It may never be possible to develop rapid and very accurate methods for identifying which of the two types each parent belongs to. Even if it were possible, what should be done when a child's mother and father are in different groups, or when parents' attitudes change? Is it ethical to give one group radically different information about, say, spina bifida from another group, unless they request this? And what would be the policy about answering questions, especially from parents who ask why they were told more or less than another parent? Instead of using quantitative methods to measure reactions in order to classify and predict them, it could be more useful to try qualitative research. There could be observations of the early and follow-up consultations; interviews with the doctors on their views about the information they give and how they audit its accuracy, relevance and effects; and observations and interviews with the families through the first year on how the children progress, on what information they find helpful or unhelpful, and how and why the parents hold their views. This in-depth tracing of the babies' growth and the interactions between the doctors and families could lead to the doctors gaining more realistic knowledge about the range of children's abilities and difficulties and different life styles to share with parents.

The research might follow up suggestions about alternative types of support, and evaluate these with the help of the people concerned. Parents are likely to give a range of mixed responses which do not fit a simple binary format which they can be slotted into quickly. Instead of searching for methods to generalize and predict (and possibly stereotype) types of parents, the doctors could become more aware of the types of prognoses which various parents find realistic and helpful; these may not clearly correlate with the degree of difficulty the child experiences. A child with severe physical impairment may live a much more fulfilling life than one less affected. The doctors could also use clinical approaches similar to qualitative research interview methods which explore

(fairly briefly) with the parents which ‘type’ they belong to and which approach appears to be the best for them as the child grows. Thus, more flexible and helpful information and support might be provided.

Research results showing that 48% of parents in the sample come into one group and 22% into another, linked to a few demographic variables, will not help doctors to classify parents into certain groups, though used as rough guides to ‘more and less likely’ responses, the percentages can help clinicians to know which is the most likely reaction to check for first. One danger of percentages is that, say, 52% may be interpreted as ‘most patients’ and filter into practice as the preferred treatment for all patients. So, in summary, exact quantitative assessments are valuable for the more standardized physiological reactions to a treatment, whereas descriptive qualitative methods are valuable for people’s variable, changeable and often unpredictable psychological and social experiences of health, illness and disability.

**Research about causes or motives** The example of the parents and disabled children illustrates how research about people can be more informative when it investigates motives rather than causes. Young children provide much of their own self healthcare, and the treatment of their illnesses – medication, rest, physiotherapy – usually depends on their active cooperation, not merely their passive compliance. These processes and partnerships of shared care can be accurately researched through qualitative observations, talking, gaining the children’s confidence and sharing in their daily activities. Research which looks for causes and effects assumes a rather passive, reactive, predictable concept of human beings, driven by external circumstances. Even young children, however, have motives, they purposefully influence the people and things around them, make choices, and make sense of experiences by reasoning about them, in many ways as adults do (Dunn, 1993, Alderson, 2000). Qualitative research allows for more detailed study of the subtle, varying and often unpredictable processes through which individuals feel and think about and manage their health and illness.

**Assessments of representativeness** raise questions about: How typical or exceptional is the selected sample? How well is the selection of the samples explained and justified? How do the samples reflect the spectrum and proportion of variety of the total relevant population? Quantitative research is often assumed to deal efficiently with these questions through widely accepted sampling methods, such as randomization, which, with accepted statistical analyses, enable practitioners and policy makers to know how far they can generalize from the research findings. Yet unrepresentativeness is often built in to the most carefully designed randomized controlled trials (RCTs) for reasons of ethics and safety. Clinical trials usually exclude people aged under 18 and over 65, and women of child-bearing years so that in effect they are mainly done with men aged 18–65 years. As a result there is concern that many children are treated with drugs that have not been tested or licensed for them.

Representative is often taken to mean typical of the majority and, in research about patients’ preferences or responses, majority responses may then be cited to support standard treatments for all. Yet when large- or small-scale research reveals variety in patients’ needs and responses, there is greater onus in ethical healthcare to provide flexible services which are sensitive to patients’ diverse needs. The aim in ethical healthcare and research is to discover how to predict different patients’ likely responses, by classifying them into identified response groups, as described in the previous section, and this supports standardized, and therefore just, services.

Representativeness is vital in research intended to respect justice and accuracy. Yet people’s beliefs and behaviours, such as their responses to living with a genetic or neurological condition, are too complex and fluctuating to be pinned down easily into static categories. Reports about exploratory, open-ended qualitative interview *methods*, as well as the diverse *findings*, can be useful to practitioners who identify ethical healthcare with balancing sensitivity to individual need with fair and high standards for all (Barbour *et al.*, 2000, a, b).

When there is a range of preferences, statistical representativeness is less important than collecting evidence about as wide a range of responses as possible. For this, qualitative sampling methods which are purposive and theoretical are useful as Silverman (1989), Hammersley (1985), Hammersley and Atkinson (1995), for example, discuss. *Purposive or judgement sampling*, for example in a study about nursing, would select nurses of different ages and educational background, grades and experience to cover as wide a range as possible. *Theoretical sampling* may be used later, either to fill in gaps discovered in earlier stages, such as lack of agency nurses, or else to expand the range of nurses linked to a topic which came to be seen as important, such as how they believe

their ethnicity affects their work. The later samples can illustrate and test emerging theories, such as that nurses from different ethnic backgrounds do, or do not, seem to have different nursing styles. Another important part of sampling concerns *exceptions or 'deviant' cases*, examples of people who do not seem to fit an emerging theory, which become useful for testing how valid the theory is. *Opportunistic or convenience sampling*, picking the first people to be found, or those who live nearby, or the few who are willing to help with research, may be justified if, for example, they belong to very rare groups, or are very hard to gain access to, and when the research is beginning to explore new topics and questions, possibly to prepare for future more systematic projects. Snowball sampling, a version of convenience sampling, gathers contacts through people already involved in the research.

Any research report should explain and justify the sampling methods used, and acknowledge the risks of misleadingly over- or under-emphasizing certain concerns, in incidence or intensity, even in very large samples. It should explain how the research analysis takes account of these risks. Representativeness relates to comprehensiveness, which can be approached through showing a spectrum of wide-ranging examples. Alternately a deliberately narrow sample, such as Punjabi-speaking patients in a neurological unit, can be shown to share or not share characteristics of larger groups found in relevant quantitative studies. More structured studies can indicate representativeness of replies within the sample by giving tables of the number of each type of reply next to the quoted examples.

As mentioned earlier, in research about issues such as children's competence, representativeness need not be very important, because the question for ethical healthcare is not, 'How *many* children of a certain age are competent to give consent to surgery?' but, 'Are *any* children, perhaps exceptional ones, competent at this age?' Only a few children can give valid reliable evidence to support a recommendation that clinicians should check this possibility with each young patient. Qualitative research on children's competence (Alderson, 1993) emphasized that although some of the views and experiences of the 120 children could be presented in graphs, the sample should not be taken as representative, or as giving a 'mean age' of consent. The children were atypical in being unusually experienced and knowledgeable about their elective orthopaedic surgery, on average having already had four or five operations. They were deliberately chosen to see how well they would be able to understand, their potential capacity, given the best possible information and support and circumstances. In some ways they were typical, in their wide range of ability which included pupils at special schools for learning difficulties. Yet in important ways they were very unusual, not in their inner characteristics, but in their exceptional experiences, of serious illness or disability and treatment.

These experiences, though very unfortunate, gave many of the children the opportunity to demonstrate and become aware of their great capacities, such as their understanding and moral courage. Typical children probably have these strengths which often go unrecognized because (fortunately) most children do not have the adverse experiences which reveal these capacities. They live such safe, protected lives that their potential and capacities tend to be under-estimated. Young patients being treated for acute conditions, or in emergencies, would probably give very different replies. The danger with an emergency group would be of mistaking children's lack of opportunity to learn and understand with an inability to do so, and of concluding that all children or average children are equally ignorant and frightened as people in an emergency tend to be. Qualitative research is more likely to uncover exceptional competencies than standardized surveys of representative (mainly healthy) children are. It is vital in all research to be cautious about over-generalizing from any group.

**Passive and active patients** One criterion for assessing qualitative research is how directly and convincingly interviewees, such as patients, speak in research reports. The words passive and patient share the same root, and there is a tradition in medical research of transferring the doctor-patient relationship into the researcher-subject relationship, so that research, in quantitative/scientific mode, is defined as something which is done by the expert to a passive, objectified subject. It requires a shift of perspective to acknowledge that the people being studied, the authors of documents being analysed, and those whose attitudes or experiences are being described, may be experts in the data, experts in their own knowledge, who take a more active part in the research (Blaxter, 2001). Qualitative research can contribute to evidence-based medicine by showing that what people know, think, or experience is also very important evidence. Qualitative research is a different way of getting at different truths,

and if it were more often combined with quantitative research, that might increase wider interest in, and use of, both kinds of research evidence.

**Synthesis** Of the criteria reviewed so far, qualitative research projects can be strong on validity and, with careful selection of a wide-ranging sample, reasonably reliable. Another relevant though seldom mentioned criterion, for judging the quality of any written or spoken accounts, could be described as synthesis. How deeply do the authors appear to have reflected critically on all the main relevant material, revised their thinking if challenged by new insights, used precise, accurate language and the most apposite, relevant illustrative examples, and avoided the odd phrase which reveals ignorance or superficial knowledge? Have they digested all the information and ideas into a complex, comprehensive, convincing coherence, a distilled essence of the most relevant information? Time-consuming reading and re-reading of the research data and related literature, while familiar texts are re-read in the light of new data and insights, and writing and re-writing of research reports, are essential for synthesis. Small details in wording can reveal levels of synthesis and understanding. For example, many papers about consent use phrases such as ‘the patient must consent before research can be carried out’. Yet valid consent is a voluntary choice, so that ‘must consent’ is a contradiction in terms. It is more accurate to say, ‘researchers cannot proceed unless the patient has consented’.

**Reflexive research** Qualitative research involves being reflexive, which means examining not only what people say and do, but why they might be saying these words and how the interview setting, the questions and themes, and the relationship between interviewee and interviewer might influence how each person reacts, as together they construct and re-construct their conversation, as shown in the following examples. Qualitative researchers speak of themselves as human beings being ‘the research instrument’ and of being ‘immersed’ in the data in order to understand it. Researchers try to be in tune with their own thoughts, feelings and sensations which may alert them to new insights, sometimes with a eureka effect. Archimedes in his bath suddenly realized that his own body was giving him the answer on how to measure body mass.

So, for example, at the conference Clare Moynihan described how the young men she interviewed talked very openly to her about their cancer. The reflexive questions this observation might raise include: Were the young men with cancer so forthcoming during their interviews because they were at home but talking with a relative stranger, because of the care and respect shown concerning their consent and confidentiality, and because Clare Moynihan was not a clinician or another man, but a woman and old enough to be their mother? Was her response to them affected by her son being about their age, and was she able to establish closer less formal contact because through her son she knew the language which young people are comfortable with? All these aspects possibly played into the conversations, but rather than push this bias away as if it didn’t exist, it was used as a subject of enquiry in its own right (Moynihan, 2001).

Reflexive research can inform health professionals about similar underlying, deeply entrenched aspects of their own relationships with patients. Raising standards of ethical healthcare is not simply about applying research knowledge but also about becoming more aware of oneself and of hidden strengths and weaknesses in relationships with patients. For example, men as doctors and patients both appear to need silence and avoidance as ways of maintaining their masculine identity. This may partly explain doctors’ reticence in the past to discuss cancer with patients. The patients Clare Moynihan interviewed often described how male clinicians spoke in detached terms of ‘firing blanks’ when referring to possible or real infertility; and how the loss of a testicle and the fear of potential sexual problems were referred to as ‘a plane flying on one engine and landing safely,’ or that ‘one cylinder is as good as two.’ This language reinforces men’s tendency to think about their bodies as machines, controllable and controlled, and separate from the self. During the video which was shown during the conference, when Sean said the doctors ‘treated him like a robot,’ he sounded angry at this, even 18 years later. He is able to express his feelings now, but at the time, the doctors’ seemingly insensitive approach may have blocked him from moving forward, as it did many men in the study. On the other hand that way of curtailing a patient’s possible need to explore further may also have served to reinforce an armour that many men need to weave around themselves, as was so obvious during the interviews (Moynihan, 2001).



**Accepting the validity of differing viewpoints** Numerous influences are transforming how we think about research. Oriental concepts challenge accepted views in Western science (Said, 1978) and, like feminist scholarship (Stanley and Wise, 1983), they raise questions about relationships between ‘expert’, authoritative researchers and the people they research. Each side may speak with unique knowledge and authority. Today, research methods and analyses, the social world, and the construction of research texts are all seen as more complex, and are subjected to more critical scrutiny and moral reflection than we realized decades ago. There is no single field of culture, but different voices and perspectives, with researchers conducting a tentative series of dialogues with others and negotiating between the different perspectives of, say, doctors, nurses and patients to produce many-layered texts (Atkinson, 2001). The complexity of qualitative research is increased in interdisciplinary research, such as projects conducted by sociologists with philosophers. How can they understand representations, interpretations and constructions as they differ between disciplines? One approach is to examine how each discipline holds a different perspective and how people talk and persuade each other about what is proper and reasonable. A radically different vocabulary or morality is not necessarily a barrier, as long as people take the differences as a topic to research (Atkinson, 2001). For example, replicability is assumed to be a sign of scientific rigour, but it can become a research question. Replication of certain experiments is subject to arguments about how genuine the replication is. The research community tried to test Webber’s claim to have detected gravity waves. They didn’t believe in gravity waves and interpreted their failure to detect them as undermining Webber’s claim. Webber claimed that their experiments and equipment were inadequate. Nowadays, people do expect to detect gravity waves and are genuinely trying to develop equipment so that they can replicate the original experiment. They show how the logic of scientific discovery depends on scientists’ expectations, trust and plausibility. Replication means ‘when enough serious people agree that it has been done’ and not that the same results are obtained every time. This is like any other human activity and can be observed as a process of belief and disbelief and persuasion, out of which comes useful knowledge. In this light, social, scientific and medical knowledge can be researched on similar levels (Atkinson 1990, 1992; Alderson, 2001).

**Trust and belief** Methods of respecting informed and willing consent to opt-in research also help to establish vitally important mutual trust, conducive to more open exchange within interviews. This is indicated by the men’s comment to Clare Moynihan during her research when she had asked them when they spoke by telephone not to read up about cancer and genetics before they met. They would say they were ‘clueless’ about the research questions, and made sure she knew that they had not ‘gened up on genetics’ as more than one man put it. Clare added:

‘And I believed them. I think you can know that you know what people with cancer are saying to you, when they say the same things to me over the 15 years I have been working at the Marsden Hospital. They say these things in different ways, but they are saying the same thing. I think they believed me when I assured them of confidentiality, and a chance to see their transcripts and a final report, so that they too could have a say as to how I had interpreted their talk using the respondents’ validation Mildred Blaxter mentioned. When negotiating access for these very sensitive interviews, I warn people about what the sessions might be like so that they can make an informed decision about whether to talk to me. I send the questionnaire to the men before I ask for their consent, for them to read before they decide. I think this is one way of getting over the huge problems which this kind of qualitative and quantitative work presents. We offer back-up to everyone, a geneticist is on hand and we also always offer follow-up counselling’.

(Moynihan, 2001)

Having discussed why qualitative healthcare research is useful research and considered criteria for assessing qualitative research linked to ethical healthcare in Part I, Part II of this report will turn to focus on some of the stages and challenges of doing qualitative research.

## Part II

### A brief introduction to doing qualitative research linked to ethical healthcare

#### Selecting themes and approaches

Quantitative researchers tend to select and exclude issues and possibilities near the start of each project, and confine the design to specific hypotheses and questions. Qualitative researchers usually begin with a few general questions and add new questions as these arise through the project, while collecting huge amounts of data. Gradually data collection becomes more selective about which themes and evidence to concentrate on and which to set aside. A famous example is a study of levels of awareness of dying, the researchers gradually identified four levels, tested these against new examples and decided to end their collecting of new cases when they were certain that their four types covered every likely case (Glaser and Strauss, 1967). As already mentioned, in all kinds of research, selection is inevitably biased in stressing certain issues and excluding others. Yet whereas rigid selection is taken for granted and usually hidden before the main work is done in quantitative research, selection is much more transparent towards the end of qualitative projects and is therefore usually more open to criticism and debate.

The people attending the conference discussed whether researchers select or design a project because of their own opinions, or bring open questions and a genuine wish to investigate. Should they come from complete ignorance or with a desire to prove something? Being in 'complete ignorance' is not necessarily helpful, or a sign of open-mindedness or lack of bias. Before beginning the research you have to review the literature, find out what is already known and where the gaps are, and possibly why there are these particular gaps.

**A wide range of methods** was discussed at the conference which will not be covered here, but included the following.

*Conversation and discourse analysis* This detailed concentration on language in, say, a hospital, requires several weeks of watching and listening to tape or video recordings of social interventions in team meetings, case conferences, ward rounds, counselling, and clinical sessions. And the search for these cannot be approached naïvely, although it often is. Understanding the context and organization of, for example, the clinical encounter is important, through systematic knowledge about language which has its own intrinsic forms and organizational features (Atkinson, 2001).

An example from meticulous conversation analysis illustrates how therapists and patients may be talking at cross purposes when what makes sense to one person makes non-sense to the other (Gardner 1998). The details about the conversation rules which each person applies illuminate how patients interpret information and how healthcarers can give it more clearly if they treat patients as more equal partners.

*Combining observation and interviews: theory and method* Very detailed observations or recordings can usually only be collected through relatively few examples, although Dunn (1993), for example, has combined qualitative work with involving many children in quantitative analysis. Yet the scale, standardized methods and necessary speed of much quantitative research tend to limit people's responses, partly by fitting brief replies into pre-ordained categories, rather than considering each person's distinctive perceptions at some length. In-depth interviews also include observations, especially with people who do not speak and who communicate with signing and other body language (Alderson and Goodey, 1998).

Interviews may spill over into everyday life, as when Tina aged 12 said she wanted to be involved in decisions about surgery: 'Most of the doctors I go to talk over my shoulder to my Mum and I don't like that. I'd rather they talk to me, 'cos I think, "Cor, well, I'm having the operation, why are you talking to Mummy?"' During her interview, Tina had a heated argument with her mother and aunt about an experimental growth treatment she wanted to refuse. She ran through her arguments fluently, showing her clear understanding of the harms and

benefits of research, potential conflicts between her present and future interests, how new social arrangements and aids at home had made her restricted mobility much easier to cope with, and her determination to be accepted for herself, 'I'd rather stay like me.' During the argument, Tina spontaneously made comments which showed her ability to weigh decisions and accept the risk that, 'If I make the wrong decision, it's my own fault, not my Mum's' (Alderson, 1993, pp. 37–9). Her comments, through being volunteered, could be seen as having greater validity and being closer to her actual feelings than if she had been replying to sets of specific questions.

Qualitative research linked to ethical healthcare involves methods intended to be as inclusive as possible, such as by using plain language, and making time for people to talk about their own concerns in open-ended interviews and through shared activities. Interviews with children, or with adults who have learning difficulty, about their understanding of consent to health treatment and their competence to make decisions, go beyond being simply research accounts. They are similar to clinical interviews between patients and practitioners who are trying to assess competence. The research method and 'raw data' are like the clinical method and data. Clinicians who check whether the child can 'really' understand rely on flexible interviews when through the conversation they discover whether children are simply repeating phrases, or are speaking with understanding and intention (Alderson, 2001). Senior and junior people, expert and 'lay' people's views should be treated with equal respect (Becker, 1967). 'Muted', seldom-heard groups, as women were until a few decades ago, are valuable sources for research which can transform the understanding of people in these groups (Ardener and Ardener, 1972; Atkinson, 2001).

**Informed consent** Most professionals, especially in the health field, have the interests of their patients or clients at heart and feel responsible for them. Yet this admirable attitude may present problems when healthcare practitioners and students begin to do qualitative research projects, in respecting and obtaining patients' truly informed consent. The rules on consent to a drug randomized control trial are clearly agreed. However, qualitative research may seem like 'only' talking to people, or observing them, or using written material they have provided. Surely this can do no harm, and have no side-effects, and is part of everyday routine consulting practice? Some doctors feel that, in a sense, they 'own' their patients, they already know many confidential things about them and feel that no-one will be forced to talk unless they positively wish to by research nurses or other workers employed under their direction. 'Only' talking, however, may have strong and possibly distressing effects. The ethics of consent do not simply relate to the legal dangers of being sued for physical harm; people have rights over their own lives and beliefs and actions, and the use that is made of information about them. Nevertheless, the idea that formal informed consent is required from their 'own' patients for a qualitative research study is very foreign to many professionals. The real position, however, is that anything which is done for research purposes rather than in an explicitly therapeutic relationship between individual professional and client requires informed consent, involving the giving of clear information about what the research is for and how it will be used, and respecting each person's decision (Blaxter, 2001).

A similar problem, which applies to much student project work even if it is not conducted in their own practices, relates to their customary practice of exchanging information among their own professional group. They may see no ethical or confidentiality relevance in obtaining clinical records before there has even been a chance to seek consent, or in discussing their research subjects and findings with other health practitioners, or in seeing the names, diagnoses and other details on lists of patients. Is it over-scrupulous to say that records of women, for example, who have had a termination of pregnancy or who have multiple sclerosis, should not be given out for research purposes without consent, whether or not the researcher is medically qualified? Students should be introduced to the standard methods of asking consent first, and of considering exactly what rights to information without consent a professional qualification bestows on them. Wider use of ethical guidelines for qualitative research would increase its legitimacy and acceptability (Alderson, 1995, Appendix 1; Blaxter, 2001).

Is covert research ever ethical, if it adds to knowledge and does no harm? People should have the chance to agree or to refuse to take part and it is useful to have a third party to request the consent or to act as witness. In research with 'incompetent' patients, if they have intelligible views, then presumably they can have some understanding about the consent, including young children. As far as is humanly possible, people should be asked for their consent. Even if things of great value might on occasions be found without full consent, researchers must assure

full confidentiality, and think very carefully about drawing a boundary and balancing the interests of the subjects and of the research. One way is to discuss with the subjects the use to be made of the research. Occasionally, people may veto research reports, such as those about a hospital or clinic, and the decision must be respected, although re-negotiation could be tried. Frequently, senior staff give permission for the research, and maybe tell the junior staff, and maybe inform them but not ask for their consent. So the researchers should try to get consent from everyone, all the way down the hierarchy, and at every meeting or observation. This may be impossible which is troubling. Probably everyone knows at one level that you are researchers, but are they aware of what you are researching and about your aims and intentions? There are so many partly conflicting pressures in research (Blaxter, 2001).

Paul Atkinson, as an anthropologist, described his difficulties.

'I have done ethnographic research, which in retrospect seems deeply unethical. Sometimes I could obtain informed consent from clinicians and medical students but not from patients. If you're walking along with students and a surgeon, and you all go into the ward, the surgeon says, "Good morning", and pulls back the bed clothes, adding, "What is your opinion of this scar?" you can either stay, or leave and not do the research data collection. You cannot say, "Wait a minute I've just got to ask for this patient's informed consent to my presence here." Relations with people when you have the time and opportunity to inform them are less problematic'.

(Atkinson, 2001)

Further questions about consent are raised by the Economic and Social Research Council's (ESRC) qualidata archive. People are asked not only to agree to take part in the research, but also for their (anonymized) verbatim histories and responses to be archived for other researchers to use in future. There are three levels of consent here: to take part in the research; for the data they give to be published; and consent to secondary analysis. This is very different from the archiving of statistical data as qualitative data are much more personal, context specific and likely to be identifiable (Blaxter, 2001).

**Confidentiality and reporting** Other practical problems relate to issues of confidentiality and the writing-up of research. There is a tradition in clinical work and research either of very detailed case reports or else of quantitative or experimental research which offers to patients complete confidentiality: data will be used only in aggregate form, and no individuals will be identified. These two rather contradictory practices lead students to tend to be either careless or else over-anxious about confidentiality. For example, with a small sample, they may list all the relevant social and medical characteristics of each subject, which even if no names are given make them identifiable to their doctor or other staff involved with them. Alternatively, students may worry that qualitative research is impossible because of confidentiality problems. Absolute confidentiality, that no-one would ever be written about in a way recognizable to their family, colleagues, doctor – or to themselves – is rarely possible. Verbatim passages are often being used, and of course people can recognize their own words. One solution – if the example matters enough to be reported – is to alter unimportant details of research subjects, as long as this is not relevant to the results. Even so, some medical students believe that this is unscientific. The ethics of using potentially harmful or distressing data is tricky, but you would have to have very strong reasons indeed for using any data that you would not want the subjects to see.

**Respondent validation** The approved way of dealing with confidentiality questions and with offering evidence of the validity of the analysis is respondent validation, which is to send copies of transcripts or draft reports about them to the people quoted or described. They can then correct the researcher's mistakes or misinterpretations. If you have seen a verbatim transcript of your own words in an interview or discussion you will know that it is possible to say things you do not mean or, unintentionally, to give a false impression. Some students see this correcting of data as unethical and unscientific. Trying to represent truly what the subjects of research want to say is also an ethical question. Of course, subject validation is not always possible, and it depends on the type of research. In conversational analysis, which involves looking at every word of taped interactions, the words are the objective data and cannot be changed. And other types of research are concerned with precisely what was at the front of people's minds, and what their instinctive expressions and situated

opinions were, rather than their considered thoughts. However, some sort of subject validation of the actual analysis is usually still profitable (Blaxter, 2001).

When reliability is checked with research subjects such as patients and doctors, the research reports are likely to increase in credibility and potential usefulness to healthcare (Daly *et al.*, 1992). Action research can involve the people being researched with (rather than on), and draw on their expertise, at all stages (Meyer, 2000).

**Professional responsibility** The professional ethos may lead to extra problems for practitioners and students who do research. What should they do if their subjects are distressed, at risk of danger, need immediate professional help, or ask for professional advice? Much qualitative research is about people who are ill, in crisis, or in distress, and with people in sensitive or stigmatized groups such as the terminally ill, with whom it is difficult to do quantitative, large-sample research. What should researchers do if they observe dangerous or negligent or unethical healthcare? Qualitative research implies empathy, which means it is difficult at the same time to stand back with scientific detachment. All researchers share these problems where, as human beings, we could not offer to help to refer someone for professional action, and we did not write about them because of confidentiality. We are all asked for advice by interviewees, when giving of advice might jeopardize the research design. In emergencies no research project is worth more than risk to one subject's life or wellbeing and it may be necessary to take action and to withdraw that person from the research, or in lesser cases to find some compromise. The intervention may be built in to the research, such as to contact everyone with problems, except in an emergency, after six months and offer to be an adviser and referral agent. Nevertheless, practitioners and students can have extra ethical difficulties in stepping out of their professional role and not advising and interfering. There are, again, routine answers for controlled trials about withdrawing patients or ending a trial prematurely. Qualitative research raises less risk of actually causing harm, yet reveals more clearly when individuals are experiencing neglect, distress or deprivation. When searching for solutions, it may be helpful for researchers to discuss their ethical problems and the cases (anonymously) with colleagues (Blaxter, 2001). Qualitative research is not a set of off-the-peg methods (Atkinson, 2001), and the research problems and ways of working towards solutions can become part of the research data and findings, as well as illuminating them further.

**Literature review** The wide ranging nature of qualitative research processes which may leave possibilities open until the later stages of the project means that the relevant literature can cover many topics and disciplines. The literature review stage is valuable in searching for relevant themes and theories and for examining how previous researchers have addressed the themes, besides showing insights and limitations and omissions from their work. One way to conduct the review is to make evaluative searches which apply sociological attention to underlying theories, in order to classify and manage the vast amounts of literature now available, as described by Hart (1998).

**Jigsaw or grid** Within a single qualitative project, a theme may be discussed at length during one interview and hardly touched on in another, depending on the relevance to each interviewee. Doing qualitative research is like making up a large jigsaw, with every interviewee adding colourful new pieces which expand understanding of the research topics and possibly add new topics. Gradually, the jigsaw's irregular outline becomes clearer and gaps are filled in. In contrast, traditional survey or experimental research is more like a pre-drawn grid, with the columns coloured in through a predictable order as data are analysed. Here, researchers aim to control the data collection and collation firmly. Qualitative researchers expect to feel less certain and confident about the nature and organization of the data at first, and this can be worrying, although worry may be a source of insight when it alerts researchers to new uncertainties or contradictions in their work which need to be unravelled. It is ultimately rewarding when the data, theories and methods influence one another interactively.

**Observation: discovering as you go along** Ethnography especially uses observation to study social groups and to describe and understand the members' activities. The researcher takes a more or less obvious and active part in the group being observed; the advantages have been described in this way:

‘Participant observation enables one to go behind the public front of a conspicuous service bureaucracy to witness “back stage” behaviour when the actors are off stage, not performing to the public, and not peddling stereotyped scripts for the benefit of bystanders. In essence, field work is concerned with real people...in all their baffling complexity [and] is a fruitful antidote to a positivist methodology and a natural science model for the social sciences.’

(Punch, 1993, p.185)

Observations constantly raise new questions about why people, nurses in a ward for example, do certain things, and these questions relate back to professional standards, traditions, economics, and formal or informal policies. Small details such as the ways the people observed speak and dress, and how the researcher also dresses can all increase understanding of unspoken rules, values and relationships besides determining who will speak freely to the researcher or be more cautious (Atkinson, 2001).

Detailed research notes kept throughout the project help researchers to see how their views and emphases change. The notes remind them of things they thought strange and important at first and later came to take for granted though these issues may still be important. Perhaps this change of view came through ‘going native’ – becoming too much of an accustomed insider instead of a questioning ‘stranger’. The researcher has to try to keep a naïve, questioning viewpoint which does not take well-known routines for granted. Conversely, details that were scarcely noticed at first may gradually acquire significance during a project with a range of meanings that turn them into key concepts. For example, the seeming reluctance of breast cancer staff to enrol patients into trials gradually assumed more importance during research which began as an enquiry about patients’ reluctance to join trials. Vignettes were introduced into interviews with staff and patient about the kinds of trials they would agree to be randomized into. Many staff then spoke about their personal dislike of the thought of their own treatment being randomly allocated (Alderson *et al.*, 1994).

Researchers can maintain some distance by writing and reflecting about experiences ‘in the field’ between visits. Useful questions arise, which might at first seem obvious or silly, about: what are the rules; who makes them; how do various people interpret them differently; how do new staff and patients learn them; when are rules resisted or negotiated; how are they justified and by whom to whom; and how do the rules vary in importance? (Hammersley and Atkinson, 1995, p. 35). Why do inefficient, uncomfortable, even unethical practices persist, despite great efforts to change them? A study of an orthopaedic hospital mixed ethnographic observations with psycho-analytic analyses to show how the nurses each tended to mistrust the more junior nurses and feel angry at being mistrusted by the more senior nurses, whatever their position in the hierarchy. This qualitative research powerfully revealed the social dynamics of many kinds of institutions where change is blocked because of anxiety about taking risks and trusting colleagues (Menzies Lyth, 1988).

Qualitative research originated partly from anthropological studies about exotic societies where detailed descriptions of the intricate daily life were valued findings in their own right. Descriptions of features of our own society and sequences of events and patterns of interacting can also be valuable. Groups which are seldom seen or heard can be heard through research, such as children on long-term ventilation (Noyes, 1999). National policies and funding are shown in a new light when seen from the children’s perspectives as they wait months or years in hospital before support at home can be arranged for them. Interactions which are assumed to be well understood can also be seen in new ways. An example is the study of misunderstandings in the reassurance which doctors attempt but fail to give to patients with arthritis (Donovan and Blake, 2000).

Observing can be so interesting that it is tempting simply to continue to collect data about everything. To avoid aimless data collection, researchers should decide on their main themes as soon as possible, though not prematurely, and check for when the data collection seems to be ‘saturated’ with examples, and new examples appear to yield no fresh evidence or ideas. Later on, when writing reports, researchers face the challenge of providing enough evidence to support and explain their theories, but not so much that readers feel bogged down in details and miss the main theoretical conclusions. There is always a tension between detailed descriptions

which open up many theoretical possibilities, and theory development which ‘involves a narrowing of focus and a process of abstraction’ (Hammersley and Atkinson, 1995, p. 177).

**Interviews** Qualitative interviews may be semi-structured with open-ended questions or in-depth when a few themes are covered in great detail. Open general questions often encourage interviewees to give long, rich accounts with little further questioning apart from prompts about details along the way. Interviewees may themselves raise most of the themes which researchers intended to cover, in response to such opening questions as: ‘How did you find out that you had multiple sclerosis?’ or, ‘What happened when you had your accident?’ In one study the question ‘How do you cope with diabetes?’ elicited detailed reports from mothers and affected teenagers on how they manage the daily care at home (Williams, 2000) which are valuable to health staff who work with them. The researcher’s tasks are then mainly to attend intently to the account; to prompt for details along the way if necessary; to introduce further themes as neatly into the narrative as possible without interrupting the flow; to guide gently and; towards the end of the interview, to check that the main themes have all been addressed. Skilful researchers try to avoid imposing their own structures and assumptions upon interviewees’ view of the world (Britten, 1996).

Health practitioners’ clinical interviews which they routinely conduct with patients differ from research interviews (Britten, 1996). The latter are more open and conversational. They require the skilful use of prompts, offer the interviewee a greater share in guiding the discussion and involve asking ‘damn-fool’ questions in the research effort to take nothing for granted. They also involve ‘generating data’ (Mason, 1996) rather than discovering facts. The data are acknowledged to be ‘produced’, as they also are in trials and surveys, rather than being discovered by research. Generating data is not simply a technique but refers to a wide range of ‘intellectual, analytical and interpretive’ activities, often shared by the speakers during interviews or groups (Barbour *et al.*, 2000, a:79). Even in modern physics and chemistry, research data can be said to be generated rather than discovered in two ways. One way is through the researcher’s perceptions, and the other is because of the elaborate instruments and processes now necessary in ‘techno-science’ which is remote from simple observation of nature (Latour, 1987).

Interviews within one project may vary widely, depending on each person’s views and experiences and their interactions with the researcher. When possible, asking people to give specific examples to illustrate their general and abstract points elicits more informative data. A research design which allows for follow-up interviews can provide time to listen to individuals’ different interests at some length, as well as the chance to cover with everyone, if necessary, topics which emerge at later stages of the first series of interviews.

Interviews, focus group discussions in which data are generated by interactions between group members, observed talk, documents and all other data need to be placed in context, which includes examining the motives and purposes of the speakers or writers. For example, medical records are misread if they are taken as comprehensive accounts of what it is like, say, to live with thalassaemia, because their purpose is to note the problems, treatment and outcomes, not to record details of daily life. Placing interviews in the context of the research subjects’ life can show them in a new light. During interviews about women’s experience of breast cancer, the illness appeared to be described as the worst episode in their life, until the researchers began asking, ‘What is the worst thing that has happened in your life?’ The women then described other adverse events, particularly ones that affected people they loved, and not breast cancer (Alderson *et al.*, 1994), whereas many cancer research reports inadvertently imply that cancer is the worst experience the subjects have ever had.

Reflexive research also considers how interviewee and interviewer regard one another and interact in producing interview data. For example, bereaved people may treat an interview about the recent death of a relative partly as a kind of mourning ritual, to show how they tried to act for the best, and to repeat reassurance they have received that, in their absence, the person died peacefully (Seale, 1998). A strength of reflexive research is the cautious attention paid to how research methods and context may shape the data and conclusions. Some researchers advise treating interview data as displays of respondents’ perspectives, and not as potentially accurate reports of external realities (Silverman, 1993; Dingwall, 1997). Yet this can be as potentially misleading as disregarding how data may be contingent to the interview.

As already mentioned, researchers debate whether interviews can produce valid evidence of people's 'real' thoughts and actions. Some believe that interviews with people who use health services should not be taken at face value but should be treated as self-justifying accounts or as unique encounters which cannot be generalized from (Mischler, 1979; Silverman, 1993, p.95; Dingwall, 1997; Murphy *et al.*, 1998:120–2). Other researchers describe breaking through formalities into 'private', frank and mutually absorbing discussions (Oakley, 1981; Cornwell, 1984; Finch, 1984; West, 1990; Pill, 1995) and into unanticipated areas (Britten, 1996), when patients and carers openly discuss their views, such as their reasons for not complying with prescribed healthcare (Morgan and Watkins, 1988). Some researchers regard these interviews as among the richest resources which qualitative research can offer to ethical healthcare, although they sometimes worry that this shared intimacy risks opening up people, exposing and potentially exploiting them beyond what they would wish (Finch, 1984). Young children and people with Down's syndrome provide interesting challenges to this denial about the possibility of talking about deep and original thoughts. In some interviews, they express profound ideas too clearly to be imitating or parroting other people's speech, and also in too unusual and idiosyncratic a way. Qualitative interviews can reach a level of truth when children's talk about their understanding of the nature, purpose and effects of their treatment demonstrate a competence which cannot be expressed unless it is actually possessed (Alderson, 2001).

**Researchers and gender** Gender differences between the former group of sceptics who tend to be men, and the latter group who find qualitative interviews substantively convincing and who tend to be women suggest psychological as well as methodological origins for their different views. Gilligan's research, for example, of men's and women's stories about pictures of pairs of people close together or at some distance showed how women tend to see intimacy as safe and distance as dangerous whereas men tended to assume the opposite view (Gilligan, 1982). Tannen (1991) demonstrated, using years of conversation analysis research how women tended to use communication to make connections and men tended to use it to take control, one to become engaged the other to remain detached.

Women do most of the data collecting, partly because social research is likely to be directed by men and conducted by women. Some men carry out very sensitive and insightful research, although women may have some advantages when researching families and children, as 'parents' in research are usually mothers. It may be easier for women to slip into homes, to talk with families perhaps less obtrusively, and to be trusted to interview children on their own. Clare Moynihan's interviews with men about their cancer, mentioned in Part I, may not have been different or any better if the interviewer had been a man, although the men in that research said they felt threatened by other men, by the way some of the doctors talked and, in a sense, by their masculinity (Moynihan, 2001).

**Data analysis** Diary notes of observations (made as fully and as near the time as possible), transcripts of tape or video recordings, relevant documents, press cuttings and journal articles, electronic lists of references and abstracts, and researchers' notes about their own theories, their analytical ideas and interpretations can easily accumulate into thousands of pages and become overwhelming. So recording, organizing and analysing the data are crucial stages of research, as many texts on qualitative research make clear. Although the research stages overlap partly with analysis and report writing starting well before the end of data collection, adequate time must be allowed after the main 'field work' is completed to analyse, reflect and write reports. This may be half the total project time. When reading notes and transcripts, and writing reports, researchers often find that many new ideas develop.

Analysis during a research project develops through several processes which may include:

- systematic sorting of transcripts, line by line, to sift, chart, and sort material into key issues and themes (Richie and Spencer, 1994);
- intensely scrutinizing notes and transcripts for the many possible themes;
- checking and re-checking through the accumulating data regularly, to see that selected ideas actually are central and are supported by the data;
- 'constant comparative method' (Glaser and Strauss, 1967) which compares each segment in turn to see its



relevance to one or more of the selected categories;

- using comparisons to map the range and variation of each category or typology;
- using software packages such as NUD\*IST or Ethnograph or word processing search and cascade facilities to code and retrieve related data systematically;
- counting, for example, all references to certain issues or use of certain words;
- indexing and categorizing recurrent themes, clarifying the categories and reducing them to the least possible number that will cover all the related examples;
- reflexively examining how the researcher is affected by and could be affecting the observations, interactions with people interviewed and observed, and the data collection and, when working in teams, separately coding the data;
- noting, during longer studies, how the researchers and the people observed might change over time as they construct and reconstruct their understanding and move between categories;
- writing regular analyses, reformulating the precise problems, theories and research plans, and then identifying which theories and topics should guide data collection with theoretical sensitivity and insight (Glaser and Strauss, 1967);
- weaving reflections on these processes into the analysis;
- deciding when to discard secondary themes and their related data (often reluctantly, perhaps they can be used in the future);
- checking for examples and comparing cases which support and expand the tentative theoretical conclusions;
- sorting all the cases into types, such as the example given earlier of terminally ill people's varying levels of awareness that they are dying ('grounded theory' when theories grow out of the research data) (Glaser and Strauss, 1967);
- comparing how different sources and research methods, including other researchers' theories, might throw new light on to a single topic, and how data from different sources confirm or conflict with one another (triangulation) (Denzin, 1978);
- possibly involving research subjects, such as by discussing earlier interviews and tentative theories in follow-up interviews with them;
- revising plans for the later stages of research in order to clarify and test the main theories;
- examining, especially examples which might limit or contradict these theories;
- deciding how to explain these contradictions and whether or how to revise and refine theories in response to them;
- reviewing how reliable or at least transferable to other settings the evidence and conclusions are likely to be (Lincoln and Guba, 1985);
- developing the analytical potential of the theories, by showing how they deepen understanding of society, and by suggesting how they could be applied more broadly to other contexts or events (Roth, 1963; Douglas, 1966; Menzies Lyth, 1988).

The stages of qualitative analysis have also been described in a very helpful handbook as: familiarization with the data; identifying a thematic framework; indexing; charting; mapping and interpreting (Mays and Pope, 2000; see also Pope, Ziebland and Mays, 2000). Researchers stress that qualitative data analysis is very time consuming and requires skilled, experienced researchers if it is to avoid being 'anecdotal, unreflective' and lacking focus and coherent enquiry (Fielding, 1993). A practical account of a workshop on analysing data gives many helpful ideas and warns against over-mystifying this process (Barbour *et al.*, 2000, a, b).

Various approaches with texts that explain them have been offered. Yet this array may make the moment of

beginning analysis, which experienced researchers find daunting, even worse. How can all the masses of data be controlled, organized and remembered as a whole? Start on a small level. Read one transcript or notes of one case. Look for a main theme or question of your research, marking the page each time it seems to appear. Alternatively you may be looking for stages in a sequence of events. After a while subdivisions will start to form. For example, when people are talking about considering consent to brain surgery they may talk about feelings – hope, fear, disgust, dread. Each feeling can be marked with a different colour. Fear may begin to subdivide into what people fear, how afraid they say they are, and how despairing dread may gradually change towards anxious hope. After checking through one transcript several times, move on to the next. Does it fit the tentative subheadings-colours you have begun to use? Do you need to subdivide them further, or can you combine some? What about mixed feelings, such as squeamishness and humour? The data begin to seem to form into groups as the analysis grows organically and the researcher can gain confidence that the analysis and theory generating are well grounded in the evidence – rather as the patients gradually gain confidence in the planned treatment.

Many texts on qualitative analysis seem to be influenced by quantitative traditions and a model of large teams of people, few of whom have designed the research or collected the data, with plenty of time, using every single collected item, and suddenly being magically surprised as computers begin to show the results in the percentage rates of the responses. In contrast, qualitative researchers often work alone or in small teams, with little time and funding. They have designed their work and through observing and interviewing will already know much about the findings, the main themes and theories. Although intensely checking the data will bring surprises, it is not a matter of waiting for some theory to emerge from it like a genie from a bottle. Start by searching for one of the main themes you originally planned to examine, and see what happens. There will not be time to write up everything, although it can all be used to support or challenge the sections which are used intensively. Qualitative research is less about seeing how often how many people refer to a theme than to discover and report new insights from a carefully selected range of examples.

**Writing up** The main ethical problems in social research may arise less during the data collection stages than when writing, publishing and disseminating reports. Qualitative reports may distress people who took part in the research by identifying them more readily than numerical quantitative reports are likely to do. Both kinds of research can also affect ethical healthcare by the general impact the reports may have on all people in the categories covered by the research (Alderson, 1995), such as all mentally ill people, if the reports cast them in a negative light or are widely quoted as seeming to do so. Reports may also be used by policy makers to alter services in negative ways. Researchers cannot prevent this from happening, but can address such possibilities in their reports.

To overlap the research stages of data collection, analysis and writing helps to deepen and organize work on all these stages. Beginning to write journal papers about themes in the research quite early during the data collection stage helps to clarify insights gained and gaps in evidence to be filled, and also shows how all the possible background literature might be used selectively for each theme. Writing up becomes part of the data analysis when ideas unfold and coalesce through the task of writing. Writing research reports can feel like having a conversation with the data. Qualitative research is also called interpretive research because of the attention paid to ways in which people perceive, interpret and make sense of their experiences. These emphases continue through the report writing, as the researcher continues to make sense of the data and scrutinize the language through which they are expressed. Reflexive researchers accept that there is no neutral language or neutral means of selecting and presenting their material; research accounts are constructed as any other accounts are (Hammersley and Atkinson, 1995, p. 207), and words are loaded. For example, ‘baby’ and ‘fetus’ each express types of prenatal moral status and there is no neutral alternative word. So reports cannot simply reflect the world, more like a lamp than a mirror they illuminate certain features of it (Gouldner, 1977).

Texts on doing research say little about the report writing stage, perhaps because the writing and data analysis stages so closely overlap, and writing is largely a matter of recording the earlier stages. Writing qualitative research reports is individual and the best instruction is probably gained from reading other research reports. When organizing material into texts it can be helpful to distance yourself from the place where data were collected and also from the data, treating these as strange, no longer familiar. This helps the writer to concentrate on

selecting and presenting the data in order to explain and support a coherent thematic or analytic framework to the unknowing reader. Published books and papers illustrate how texts can be organized by topics or themes, chronological order, or into a series of individual or composite examples. Recounting, describing and quoting from observations, interviews and other sources are vital parts of the reports. There should be sufficient detail to convey something of the original realities and experiences to the readers, and to enable them to form their own views about the data without having to rely wholly on the researchers' conclusions. This facility is a strength of qualitative research. Yet the theoretical purpose of selecting each example should be made clear, and examples should be as brief, well edited and well selected as possible. Vivid and evocative examples may need to be mixed with more mundane ones to illustrate the general tenor of the material gathered.

The usual format of quantitative reports, with separate sections for methods, results and discussion/conclusion, does not fit qualitative research so well, partly because all these aspects overlap, and repetitive and even longer reports may result. However, many qualitative reports do fit this format. Qualitative research reports draw on a range of techniques, including 'generic conceptual framework, novel, elaborated, eventful and abundantly documented with data or interpenetrated with empirical materials' (Lofland, 1974, quoted in Hammersley and Atkinson, 1995, p. 214) or also 'natural history; chronology; narrowing and expanding the focus; separating narration and analysis; and thematic organizations' (Hammersley and Atkinson, 1995, pp. 214–227). One way to organize and select the material and to clarify the purpose of each paper or chapter being written is to keep a reader in mind, such as a policy maker, practitioner or patient, and to write as if talking to that person. A second way, which also saves time and effort, is to decide before beginning to write which journal or publisher the piece is intended for. With journal articles, use the format and type of content required by the intended journal as guides and aids to writing. Asking colleagues, and possibly former interviewees or future intended readers, to comment critically on drafts can help to clarify reports.

**Getting published** Publication in a leading peer-reviewed practitioners' journal, with inclusion on electronic lists, increases the chance that the report will be read and referred to and thus might influence healthcare policy and practice. Qualitative researchers face particular problems when submitting their work to health service journals. It can be easier to write a book than an article, to do justice to the lengthy, diverse, detailed material, and to have space to explain and justify the qualitative methods, theories and potential application. Academic sociological journals allow more generous space, but reports published in them tend to be read by academics and students, so make little contribution to healthcare services, and may be appreciated only by a rather insular community of qualitative researchers.

The *British Medical Journal (BMJ)* requires articles to be 800 or 2500 words to suit busy practitioners, although a system of putting whole longer versions of printed papers on to the *BMJ* webpage has begun. Low word totals suit quantitative reports which can compress so much into tables, and also explain their widely accepted methods, such as randomization, briefly. However, qualitative researchers may be required to explain and justify purposive sampling, and also explain why they did not use quantitative methods. Their problems are increased when medical journal editors send the papers to be reviewed by academic sociologists who want much more to be added on theory and reflexivity and many more references to be given. This uses up even more of the permitted word total. Medical reviewers, on the other hand, want more on results, reliability and practical recommendations, and less on sociological analysis, and many papers fail between the conflicting demands. Problems arise in the minds of critical readers when social researchers not only deal with less tangible data such as behaviour and beliefs, but also discuss the equivocal nature of these data, and indeed of all data. Qualitative researchers' published and responsible scruples about the truth of evidence can inadvertently increase the imbalance that favours quantitative research. Until recently, the lack of published qualitative research, and the lack of well known links between qualitative research and raising standards of ethical healthcare policy and practice, discouraged funders from understanding or supporting qualitative work, leading to a further dearth of projects and reports. Fortunately this is now beginning to change, as demonstrated by recent reports referenced in this report.

The leading clinical journals have agreed the ethical standards of the Vancouver guidelines (1991) for acceptable papers, such as that research with patients has gained the prior approval of a research ethics committee and the informed consent of the research subjects. Although reports now tend to call them 'research participants', this can

be a misnomer when people are not fully aware that they are being researched on. Some ethics guidelines speak of 'participants' on one page and on permitting covert research on the next (BPS, 1991). Sociology journals do not have agreed formal guidelines which could raise ethical standards in these journals. The standards could help to ensure, for example, that authors who use other researchers' material credit the original researchers appropriately, treat the interviewees' responses respectfully and possibly give them some right of reply if transcripts are used in ways which the interviewees might not have consented to (see, for example, Murphy, 1999). Some sociologists argue that review by ethics committee and respect for informed consent do not fit well with open-ended qualitative research (Murphy *et al.*, 1998). These academics repeat doctors' former arguments against ethics committees in debates before the 1990s when doctors came generally to accept the committees. Yet unless they have some prior and agreed aim and purpose, it is questionable why interviews and observations should take up the time and attention of either researchers or research subjects. Informed consent can be requested to broad and open-ended themes and not only to very precise ones (see Appendix 2). It is unfortunate when valuable qualitative research reports are rejected by medical journals for lack of prior ethics committee approval, and are thus less likely to influence healthcare services. It is also paradoxical if research intended to support ethical healthcare does not observe generally agreed ethical standards.

## Part III

### Linking research to ethical healthcare

This title theme has already been discussed, and is reviewed here in relation to the practical research process. Increasingly, funders such as the Research Councils and large Trusts prefer research that will be useful to users of research: practitioners, policy makers, voluntary organizations and health service users. Publications of theoretical work and of examples which link qualitative evidence to generalizable theories and practical recommendations are increasing, as shown by examples in this report. There are risks in any research of being over-intrusive, and of supplying misleading evidence which might encourage policies which, for example, lead to patients either being under-informed or else over-informed and feeling loaded with responsibility, guilt and anxiety which they would prefer health professionals to bear for them. These serious dangers require careful discussion and reporting throughout the research process and, as far as possible, when the research is disseminated, interpreted and applied. This final part of the report summarizes examples and features of qualitative research which contribute to ethical healthcare policy and practice.

**What works well?** Contributions from qualitative research help to increase knowledge about how to reduce morbidity and mortality. Research in which patients play an active part reveals their crucial part in managing their self healthcare, their informed cooperation which goes far beyond the passive ‘compliance’ that usually features in research reports. An example is a qualitative project funded by the Wellcome Trust among East Londoners originally from Bangladesh who have type 2 diabetes (Greenhalgh, 1999). Many of the participants speak a dialect which has no written form. Researchers found that the people had gained most of their knowledge about good management from their friends, not from health professionals, and through telling stories, an activity they valued highly. Much useful knowledge was gained from the research about the problems people experienced, and the story medium through which they enjoyed communicating. A two-year development project currently involves introducing story telling as an integral part of ‘empowering’ healthcare, and is training advocates in story telling skills to work with individuals and groups to increase ways they can help one another. The research illustrates how the ethos and methods, as well as the findings, of qualitative research can inform healthcare practices. Patients’ systematically collected views vitally inform medical and surgical audit of the process and outcomes of treatment. Patients’ priorities may differ from the ones which clinicians assume for them. One example is a boy with bent legs who enjoyed playing football. The orthopaedic surgeon regarded surgery which straightened the legs as a success. To the boy, this was a failure, as he could no longer run and play with his friends.

**Working out shared priorities** Effective local or global health policies partly depend on knowing what the intended beneficiaries themselves think that they need and taking their viewpoints seriously. This is best achieved through detailed qualitative studies (Johnson *et al.*, 1995; Ennew and Connolly, 1996). Eleven Bangladeshi street children aged 10–15 years interviewed 51 other street children aged 7–15 years in Dhaka. The research team held 16 meetings to choose the topics and questions, the methods and the interviewees. They discussed every interview and argued about which were the main difficulties the respondents said they experienced to list in their reports. Most of these difficulties concerned disrespect, abuse and cheating from adults. The children wanted more justice and respect (Khan, 1997). Their conclusions challenge international aid policies which emphasize medical and education programmes provided by Western agencies and commercial companies. The children drew attention to broader concepts of health which addressed their most severe problems.

**‘Non-compliance’** Instead of asking why patients do not comply, and seeing them as ignorant or irrational, researchers can take patients seriously and ask: Why do they do what they do? What is their reasoning? Doctors may have a legitimate desire to change people’s behaviour, but people use their information, beliefs and feelings in different ways. For example, Evelyn Parsons found that women’s understanding of genetics risks translate percentages into categorical and not ordinal data. The women were given interval data to translate into non-directional ordinal – high and low – risks. They turned these into directional categorical ones, such as, ‘I can’t have children’ or ‘I can’t have boys’. Another example is the way that ordinal percentages of genetic risk, perceived as non-directional by health staff, are seen by pregnant women as categorical or directional percentages

(Parsons and Atkinson, 1992). Detailed conversation analysis reveals hidden pressures in counselling which is intended and assumed by the staff to be free of any pressure. This kind of qualitative research unravels how misunderstandings arise when doctors and patients each assume that the other shares their own understanding (Parsons and Atkinson, 1992; Atkinson, 2001). By approaching the research question through qualitative methods which uncover meanings, contradictions and ambiguous feelings, we can begin to suggest practical changes in doctor patient interactions, and illuminate problems in medical research and practice that need further investigation. The men with cancer showed how any intervention, whether an in-depth interview or a questionnaire, may be damaging. This raises ethical questions that need to be thought through across the spectrum of research with people (Moynihan, 2001).

**Links to policy** Attenders at the conference questioned whether qualitative research can succeed in influencing policy in local hospitals and also nationally – how can we ‘sell’ this research? The children’s consent to surgery work (Alderson, 1993) does seem to have contributed to a national change. Nurses have done follow-up studies, and at medical and nursing conferences now, not only parents’ consent but also informing children, listening to them, and involving them in decisions about treatment, are taken seriously by many people. Practitioners are extremely concerned about current uncertainties in English law about children’s consent and refusal. In July 1999, three High Court cases over-ruled children’s views, to the extent of authorizing that a heart transplant might be enforced on a 15-year-old girl. A report by a sociologist and a lawyer (Alderson and Montgomery, 1996) based on qualitative research recommended that the law was too blunt an instrument to promote clinical standards of good practice, a Code of Practice would be more effective. The British Medical Association (2001) is publishing an agreed Code intended to help practitioners to have more confidence in respecting children’s views. It is a very slow process, but fortunately very many people are engaged in it\*.

\*The report is now published: Romano-Critchely, G and Sommerville, A *Consent, rights and choices in healthcare for children and young people* (BMA, 2001).

## Summary of further ways in which qualitative research can inform ethical healthcare

This section summarizes points made earlier through the report.

- Surveys and trials tend to emphasize expert services which protect and support relatively passive patients. Qualitative interviews, by allowing time for patients to give their detailed views, can treat them more fully as knowledgeable partners rather than relatively passive respondents. The methods and findings contribute to more sensitive and imaginative healthcare (for example, Greenhalgh, 1999).
- Interviews with seldom heard groups, such as children on long-term ventilation (Noyes, 1999), can inform healthcare policies through direct reports of the people’s own words. Young children and people with severe learning difficulties can be found through qualitative interviews to have far higher competence than is usually assumed.
- Lengthy observations enable researchers to report ‘what is really going on’ in the health services, thus presenting detailed evidence on which to base informed policy.
- The variety of views, experiences and competencies within each group of patients can be appreciated, as well as the ways their views may change over time. A mixture of interviews and observations can show how patients’ competence alters depending on the information and support which staff give to each patient and according to varying perceptions and contexts. This detailed attention to interactions between health practitioners and patients can illustrate the importance of training and support to enable practitioners to respond sensitively to human variety, and to avoid giving overly impersonal standard care.
- Underlying structures can be revealed through a few examples, such as the generalist views of GPs which fit uneasily with efforts to get them to inform their practice by the more individualist concepts in genetics (Kumar and Gantley, 1999). Low response rates are often seen as failures of the research, but qualitative analysis may find important information concealed within them. Men’s low responses to cancer research about affected relatives showed how seldom men speak about illness to close male relatives, and this knowledge can inform familial and genetic research methods and practices which are based on assumptions

that relatives do talk together (Moynihan, 2001). Like the evidence that routine counselling distresses men with cancer, the research shows how different approaches need to be found in the relevant research and services.

- Empirical qualitative evidence shows the processes of forming and implementing policies, the division of labour within and between specialisms, the micro-politics of professional work, and the rhetoric of persuasion and legitimation required if policies are to be adopted and really implemented, instead of being rejected or misapplied.
- Purposive sampling of as varied a range of relevant examples as possible within small scale qualitative research helps to inform health services of the range and variety of needs within a single patient group, and of possible ways of meeting these clinical, social and psychological needs.
- Epidemiological research about links between inequalities in health, disadvantaged childhood and later adult ill health, do not explain why and how habits are acquired in childhood which undermine health in later life. Many social surveys are profoundly non-social by ignoring complex interactions between personal experiences, beliefs and activities and large-scale social policies and pressures (Popay *et al.*, 1998). One way to begin to examine these is to conduct detailed research with small samples using a range of methods (for example, Morrow, 2000).
- Published discussion by researchers about the extra ethical problems of consent and respect for confidentiality posed by qualitative research, as well as researchers' cautious attention to their own prejudices, subjectivity, motives and their relationships with interviewees, can inform health practitioners' similar concerns.
- Qualitative research appears to have had far more impact in creating modern medicine than quantitative work has, such as through knowledge of anatomy, physiology, genetics, antisepsis, anaesthesia and surgical methods, among countless examples. Qualitative understanding of the greater mysteries of the human psyche, relationships and institutions is at least as relevant and revealing an approach as counting frequencies.

### **And finally**

Each stage of qualitative research cannot be fully explained or standardized or set out in models to be copied, and can only be explained partly, leaving newer researchers to develop their own skills. Inevitably there are many omissions in this short report. All research raises ultimately irresolvable questions: What do we know? How do we know that we know it? And how do we convince others about what we know? This report has not attempted to cover the extensive debates about how these questions, which particularly worry qualitative researchers, might be answered through theories about realism, idealism, 'subtle realism' ('all science is limited in plausibility and credibility') (Hammersley, 1992), or 'critical realism' (Bhaskar, 1986). There are also omissions about types of qualitative research methods. Social researchers often stress the complex skills required to do qualitative research which are learned through practice rather than through summarized guides and checklists. This report simply attempts to offer a brief practical introduction with suggestions for further reading, in response to questions from people who attended the conference on qualitative research and ethical healthcare in 1999. Many points are posed as questions for researchers to contend with, rather than as solutions.

## Afterword

### Jonathan Glover

The English are reputed to have a genius for compromise, and perhaps one example of this is to arrange a one-day conference on so complex a topic as qualitative research. During the day, we considered the relevance of qualitative research to policy, and to matters which we hope to have some influence in changing. As a philosopher, I am researching with a psychiatrist in a special psychiatric hospital and asking, how do I begin to do qualitative research? We held this conference in the belief that replies to this question would interest many people working in health research or planning to do so.

Our first speaker, Professor Blaxter, spoke about how policy in the broader sense needs to be informed by qualitative research which should have a wider audience. Yet the average academic paper is read by only three people. I welcome the idea of expanding the audience for qualitative research, for extending its links with evidence-based medicine, and with ethics and multidisciplinary research. I would add a plea for moral reflection itself during the research process. It is a pity that no philosopher was involved with drawing up the ethics guidance on qualitative research. I will briefly review some of the main themes of the day.

**Ethics** Qualitative and quantitative research raise many ethical issues and deep methodological problems throughout their processes. It is wrong to suppose that talking cannot have any benign or adverse effect on people. Just as much a matter of potential concern are questionnaires. There is also no absolute guarantee of confidentiality, and we ought to think pretty hard about what standards of confidentiality we are going to agree on. The ethical problems raised by research have been made clear, and I don't have obvious answers to them.

**Methods** Professor Atkinson pointed out, regarding methods, that qualitative research is not a discipline in itself. Researchers working in specific disciplines need to bring their discipline to it, with sharply focused questions from our own discipline and our human experience. We have to ask, why have this pattern and method and not others? How can we avoid bias in selection? These are very real problems, but almost any human study is going to have this problem.

**History** Because qualitative research is a fairly recent phenomenon, people tend to think these points are new. But would we say that history should not be done because it is inevitably selective? If you ask what are the dates for the second world war, you would get very different replies from the UK, the USA, Japan and Russia, because they joined at different times. Yet that doesn't discredit the whole subject of history.

**Principles and communication** Paul Atkinson talked about principles, and he thought we would accept his analysis of the social shaping of identities and the pervasiveness of the moral order which constructs our identities. I thoroughly enjoyed his splendid take-off of a person walking along and changing direction. It seems to have ring of truth, but you don't need to be a social scientist to know this. Novelists can write about it too, as Alan Bennet has done when describing being in a doctor's waiting room. When his suit against the sofa made a fart-like noise, he moved about a lot on the sofa, to make clear to everyone else there that the noise was not what they thought it was.

But I wondered about these principles of moral display, as if we have to see people's beliefs and categories in a slightly detached way, as a product of their circumstances. Do we really see other people's principles in this way and, if so, what do we make of Paul Atkinson's own principles and account? Nietzsche said that there are no truths, only perspectives. Yet is this point also only a perspective and, if so, how can it ultimately deny truth? Nietzsche's point applies to some of these highly debatable points in social science. We were presented with very different ethical and methodological issues, which made me wonder if I'd made a wrong move into qualitative research, it seems so enormously difficult. In later sessions, there were quite a few impressive grounds for hope, especially in cases of a degree of intuitive interpretation that doesn't exactly look like science.



**Intuition** Do we too often dismiss human intuitive knowledge of each other as not rigorously scientific enough? Science must be as rigorous as possible, but Aristotle advises us to have the right degree of position that is appropriate to the subject matter. Human beings are pretty well equipped to understand each other's behaviour intuitively. This shows in novels. We understand each other very well, although we are open to different interpretations. For example, in *Anna Karenina* two people were widely expected to get married. They both thought they would, and all their friends thought so too. They went to look for mushrooms in the birch woods and each thought this was the right moment. He was a bit nervous and he walked off to prepare what to say to Varenka. When he returned and began to speak to her, she blurted out a question about mushrooms. He was thrown, and they both felt the momentum dying away, and they didn't get married after all. Intuitively, we understand that kind of story very well. We all have failed to say things because of social awkwardness, and so on.

As far as possible, we must subject our interpretations to rigorous scrutiny in social science research. Yet because there are very many things that could be said about Sean's account, we don't need to say that Clare's interpretation is implausible. Nick Humphrey's psychological work suggests that on evolutionary grounds, we would expect humans to understand each other fairly clearly, unless someone has a psychological disorder. And when this happens, one way we identify and define certain types of psychological disorder is to say that the complex sophisticated mutual understanding we expect is not happening. But we see this as 'disorder', not as a usual state of affairs. Part of the human brain is devoted to the interpretation of faces. We are highly programmed, it seems, to interpret other people's beliefs and attitudes.

Paul and Priscilla spoke about getting through to other people's deep beliefs. We can get people to talk about deep beliefs, and there is respectable evidence that people will do this, though I agree with being alert to stereotypes when interviewing – our own and other people's. I am concerned about this in my future interviews with people with neuro and psychiatric conditions, and I do not want to say, 'don't let's worry about the science, let's just get as close as we can.' I do also want to explore intuition, how we gauge and relate to one another. I was in the hospital sitting room when a woman with a trolley came up and shouted at me, 'Would you like a milky drink?' I said, 'No, thanks.' On hearing my voice, she said, 'I'm terribly sorry I thought you were a patient.' We have heard about qualitative papers being turned down by the *British Medical Journal* because they were 'too soft'. Should we question the categories of hard and soft? Otherwise an enormous amount of human material of vital importance will simply slip through the net of published research that might influence policy.

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## APPENDIX 1

### Criteria for the evaluation of qualitative research papers

Adopted by the Medical Sociology Group of the British Sociological Association, 1996

#### **1 Are the methods of the research appropriate to the nature of the question being asked?**

- Does the research seek to understand processes or structures, or illuminate subjective experiences or meanings?
- Are the categories or groups being examined of a type which cannot be preselected, or the possible outcomes cannot be specified in advance?
- Could a quantitative approach have addressed the issue better?

#### **2 Is the connection to an existing body of knowledge or theory clear?**

- Is there adequate reference to the literature?
- Does the work cohere with, or critically address, existing theory?

#### **Methods**

#### **3 Are there clear accounts of the criteria used for the selection of subjects for study, and of the data collection and analysis?**

#### **4 Is the selection of cases or participants theoretically justified?**

- The unit of research may be people, or events, institutions, samples of natural behaviour, conversations, written material, etc. In any case, while random sampling may not be appropriate, is it nevertheless clear what population the sample refers to?
- Is consideration given to whether the units chosen were unusual in some important way?

#### **5 Does the sensitivity of the methods match the needs of the research questions?**

- Does the method accept the implications of an approach which respects the perceptions of those being studied?
- To what extent are any definitions or agendas taken for granted, rather than being critically examined or left open?
- Are the limitations of any structured interview method considered?

#### **6 Has the relationship between field workers and subjects been considered, and is there evidence about how the research was presented and explained to its subjects?**

- If more than one worker was involved, has comparability been considered?
- Is there evidence about how the subjects perceived the research?
- Is there evidence about how any group processes were conducted?

## **7 Was the data collection and record keeping systematic?**

- Were careful records kept?
- Is the evidence available for independent examination?
- Were full records or transcripts of conversations used if appropriate?

### **Analysis**

## **8 Is reference made to accepted procedures for analysis?**

- Is it clear how the analysis is done? (Detailed repetition of how to perform standard procedures ought not to be expected).
- Has its reliability been considered, ideally by independent repetition?

## **9 How systematic is the analysis?**

- What steps were taken to guard against selectivity in the use of data?
- In research with individuals, is it clear that there has not been selection of some cases and ignoring of less-interesting ones? In group research, are all categories of opinion taken into account?

## **10 Is there adequate discussion of how themes, concepts and categories were derived from the data?**

- It is sometimes inevitable that externally-given or predetermined descriptive categories are used, but have they been examined for their real meaning or any possible ambiguities?

## **11 Is there adequate discussion of the evidence both for and against the researcher's arguments?**

- Are negative data given? Has there been any search for cases which might refute the conclusions?

## **12 Have measures been taken to test the validity of the findings?**

- For instance, have methods such as feeding findings back to the respondents, triangulation, or procedures such as grounded theory been used?

## **13 Have any steps been taken to see whether the analysis would be comprehensible to the participants, if this is possible and relevant?**

- Has the meaning of their accounts been explored with respondents? Have apparent anomalies and contradictions been discussed with them, rather than assumptions being made?

### **Presentation**

## **14 Is the research clearly contextualized?**

- Is all the relevant information about the setting and subjects supplied?
- Are the cases or variables which are being studied integrated in their social context, rather than being abstracted and decontextualized?

## **15 Are the data presented systematically?**

- Are quotations, field notes, etc. identified in a way which enables the reader to judge the range of evidence being used?



### **16 Is a clear distinction made between the data and its interpretation?**

- Do the conclusions follow from the data? (It should be noted that the phases of research – data collection, analysis, discussion – are not usually separate and papers do not necessarily follow the quantitative pattern of methods, results, discussion.)

### **17 Is sufficient of the original evidence presented to satisfy the reader of the relationship between the evidence and the conclusions?**

- Though the presentation of discursive data is always going to require more space than numerical data, is the paper as concise as possible?

### **18 Is the author's own position clearly stated?**

- Is the researcher's perspective described?
- Has the researcher examined their own role, possible bias, and influence on the research?

### **19 Are the results credible and appropriate?**

- Do they address the research question(s)?
- Are they plausible and coherent?
- Are they important, either theoretically or practically, or trivial?

## **Ethics**

### **20 Have ethical issues been adequately considered?**

- Has the issue of confidentiality (often particularly difficult in qualitative work) been adequately dealt with?
- Have the consequences of the research – including establishing relationships with the subjects, raising expectations, changing behaviour, etc. – been considered?

## APPENDIX 2

### **Examples of information leaflets for qualitative research that have been approved by a research ethics committee**

#### **Living with cystic fibrosis**

#### **The views of young people aged 16 to 25**

#### **Would you be interested in helping with this research?**

This leaflet gives an outline idea of the project.

Please contact me if you would like to have more details.

#### **What is the research about?**

The project is about your views about your daily life, your family and friends, your school or college, your work – or being out of work. I would like to know about your aims and hopes, the things you enjoy doing, and parts of your life you might like to change.

The research also asks what you think about the new genetics, gene tests and antenatal screening. If you don't know much about genetics and screening, I still hope that you will talk to me. I am not looking for expert answers, it is your own views that would help this project.

I am talking with 50 young people during this project who have different genetic conditions, including ten who have cystic fibrosis.

I am working with researchers in England, Finland, Holland and Greece. We are asking groups of people for their views about genetics, antenatal screening and living with a condition that can be tested. The groups include nurses and doctors, pregnant women, the general public and the people most directly concerned – those who live with a condition that can be tested. Researchers hardly ever involve this most important group, and little is known about their views. This is why we hope that you will take part in the project.

#### **What is the research for?**

- 1 To report a wide range of views from around Europe.
- 2 To increase informed public debate about screening.
- 3 To make sure that the views of people who are most directly concerned are more widely known.
- 4 To inform those who plan and provide health services around Europe about the kinds of services people want to have.

#### **What does helping with the project involve?**

I am inviting you to take part in an interview. We would meet for about an hour, at your home or somewhere else that suits you. If you agree, we would tape-record the session. I will 'phone each person one week after their interview, to see if there is anything more they wish to talk about. I will send a short report about the research later this year to everyone who helps me.

## Research and your rights

- It is for you to decide if you want to talk to me.
- You do not have to say 'yes'.
- If you do say 'yes', you do not have to do the whole interview.
- We could stop when you want to, or have a break.
- If you do not want to answer some of the questions, you can just say 'pass'.
- Before you decide whether to help me, you might like to talk about this project with your parents or with a friend.
- I keep tapes and notes of the interviews in a safe, lockable place.
- When I talk about the research and write reports, I always change people's names, to keep their views anonymous.
- I would not talk to anyone you know about what you have said, unless you talk about the risk of someone being harmed. If so, we would talk with you first about what could be done to help.

## Sponsor

The European Commission, 1996–1999

## Contact

Priscilla Alderson, Social Science Research Unit, Institute of Education, University of London,  
18 Woburn Square, London WC1H 0NS, 020 7612 6396 p.alderson@ioe.ac.uk

Priscilla Alderson has researched with young people in schools and in hospitals, about their views of their daily life and of their healthcare and education. Her books have helped to change services for them.

## Lots of research is done with people with cystic fibrosis.

### What is new about this project?

- 1 Most research about people with cystic fibrosis sees them as patients and is about their health treatment. This project is about you as a person and about your own views on your life.
- 2 I am planning and doing this research with people with cystic fibrosis and aim to work with them as partners.
- 3 A great deal is known about doctors' and nurses' views about screening and life with a disability. Little research has been done about the views of people whose lives they affect.
- 4 If they are to plan useful health and screening services, the planners need to know more about the views of the people they want to help.

## **Example 2 (Set out in A5 folded leaflet)**

### **Cross currents in genetics**

A study of how staff working in perinatal services in two London Hospitals address questions about genetics and ethics which affect their work

April 1999–September 2001

### **Please would you help us with our research?**

We are asking 32 members of staff at your hospital

- to take part, over 14 months, in two interviews;
- to take part in one two-hour small group discussion, about ethical and legal issues raised by advances in genetic knowledge;
- to allow us to observe them working with their colleagues;
- and, if appropriate to observe them working with patients at times to be agreed with them.

**We hope that people who take part in this project will find it personally useful to them.**

### **Researchers:**

Priscilla Alderson PhD Reader  
020 7612 6396  
p.alderson@ioe.ac.uk

Bobbie Farsides PhD  
Senior Lecturer in Medical Ethics, Centre for Medical Law and Ethics  
020 7848 2382  
bobbie.farsides@kcl.ac.uk

Clare Williams PhD RGN HVResearch Officer  
020 8898 6728

### **The research questions**

- How does new genetic knowledge affect policy and practice in perinatal healthcare services?
- What challenges and opportunities does the knowledge present?
- How do healthcare staff address these in their daily work, individually and together?
- What aims and values guide them, and how can insights from ethics and social science help?
- How can such insights be shared in more useful ways with busy practitioners?
- How can small multidisciplinary group meetings help staff to discuss and resolve dilemmas?

### **Research aim**

To work with perinatal staff to develop ways to address ethical and legal issues, raised by genetic advances, which help staff who inform and support patients affected by these advances.

### **Research methods**

- Talking with and observing the work of 32 staff from 16 disciplines: medicine, nursing, midwifery, counselling, technicians, clergy, research, administration and management.

- Eight 2-hour multidisciplinary taped discussion groups, each for 4–6 staff, led by a philosopher, about ethical and legal issues raised by advances in genetic knowledge.
- Over 14 months, 2 audio-taped interviews with the 32 staff, lasting 1 to 2 hours.
- Qualitative and quantitative analysis of data, to report in journals for practitioners, policy makers, and medical law and ethics teachers.

### **Risks, discomfort**

Some staff might feel anxious about some of the topics we will discuss with them, but our aim is to help them to find supportive ways of tackling dilemmas.

This project mainly concerns the health staff, but some patients will be indirectly involved when we observe the staff during their daily work. If our observations appear to distress patients or staff, or to interfere with professional care, we will withdraw.

### **Rights of all staff and patients affected by the research**

We respect your rights:

- to take time to decide whether to agree to help us;
- to refuse to take part or to be observed, without this affecting your work or care;
- to sign a consent form if you agree to help us;
- to refuse to answer certain questions;
- to withdraw from this project at any time;
- to have notes and tapes about you kept in a safe lockable place and registered under the 1998 Data Protection Act;
- to be kept informed about the research and reports if you wish;
- to have your privacy respected, by making sure you cannot be identified, if we repeat your comments to other people, and when we publish reports about the research.

### **The project has the approval of:**

Hospital Research Ethics Committee 99/119 and of  
Professor ---- Consultant Obstetrician.

### **Funder**

The Wellcome Trust

### **Heads of Department**

Professor Ann Oakley  
Social Science Research Unit  
Institute of Education  
University of London

Professor Jonathan Glover  
Centre for Medical Law and Ethics  
King's College  
University of London

May 1999