

Ethical governance as resource and as obstacle: **Findings from a consultation with qualitative researchers**

Iain Lang
Peninsula Medical School
& University of Cambridge
iain.lang@pms.ac.uk

The Qualitative Research Resources project (QRR)

The Qualitative Research Resources project was an ESRC-commissioned study designed to find out what it is that allows researchers to carry out high-quality qualitative research, and in particular how the resourcing of such research could be improved

Primary aims:

- to conduct a broad and in depth consultation with UK social scientists on the nature, existence and use of qualitative research resources
- to identify and propose ways of developing and enhancing these resources

QRR: context and participants

The consultation took place May – September 2003 and involved UK-based researchers from across various social-science disciplines. It was conducted by Karen Henwood and Iain Lang.

30 face-to-face and telephone interviews were conducted, plus **17** group interviews and a participatory workshop

–a total of **135** respondents were involved

Most participants were university researchers, but there were a small number of health service employees (including clinical practitioners), and policy research commissioners and users

QRR: background

The project was developed from a scoping document written by Jennifer Mason, and addressed four main issues:

- What are qualitative research resources? What exists? Where are gaps present?
- How might such resources be used and developed in the medium to long term?
- What skills and methods are necessary, and how can these be developed?
- What costs, risks and benefits are present?

QRR: research process

The research centred on informal, partly researcher and partly participant-led discussions conducted via individual or group interviews (mostly conducted during site visits)

This research design was intended to enable a detailed, qualitative, exploration of the nature of the resources utilised and needed when carrying out qualitative, social-scientific investigations

QRR: guiding principles

The guiding principles of our approach were that:

- researchers' perceptions and understandings of their work environments provide a starting point for examining resourcing issues

- the currency of the term ‘resources’ varies and so understandings of resource issues may differ
- institutional and other contexts vary and differences in perception should be anticipated; awareness and reflexivity about such differences needs to be part of the consultation exercise

QRR: orienting questions

What is the current state of qualitative research in your research area? Have there been recent changes, and how are these regarded by different audiences (policy-makers, practitioners, academic peers, stakeholders and users)?

What research resources are important to you in your research? Are any essential? Which do you wish you had more of? Are there any you don’t have access to, but wish you did?

Can you identify one (or more) particular resource the introduction of which would significantly improve the conduct of qualitative research?

QRR: visual representations

An overview diagram was used as a prompt and to stimulate reflection; this was modified and altered through the course of the research.

- To summarise and suggest connections between key issues raised in the consultation we used a bubble diagram. This was used in the participatory workshop and included in the final report.

There are often inconsistencies and shortcomings in ethics committees’ understandings of qualitative research

- “lay members of committees often tend to take quantitative work on trust, and to tackle anonymization and related issues”
- “I’ve heard of people doing qualitative research being asked about the effects they are measuring, or to supply calculations of effect sizes”
- “most ethics committees are driven by medical research, but that’s irrelevant to anthropology”

Getting ethical clearance is difficult for unstructured forms of research

- “obtaining prior informed consent is impossible when you don’t know in advance what you are doing, but that’s difficult to explain to ethics committees”
- “observational methods are a problem because ethics committees don’t like unstructured approaches”

Are set protocols (“the tick-box approach”) useful in view of the reflexivity and flexibility qualitative researchers see themselves employing?

- “ethics are important, but for passive styles of research with inobtrusive methods I hope that standardized rules aren’t going to appear”
- “ultimately, in this type of research reciprocity of trust is necessary, and that can’t be legislated for”

Inconsistency: between the views of ethics committees, and between ethics committees’ and research funders’ views of proposals

- “we had to deal with 6 different LRECs [Local Research Ethics Committees] and an MREC [Multi-Centre Research Ethics Committee] and they all told us different things and demanded different changes”

Archiving of data: for and against

- “if there was one resource-related issue that could be dealt with, sorting out NHS ethics clearances for qualitative research would be great--for example, in terms of the demands that tapes be destroyed at the end of research.”
- “there is so much pressure to publish, for individual and departmental career reasons... I know someone who wrote their dissertation and then published five articles from it in top-rated journals – would that have been possible if the research had been archived?”

Archiving of data: anonymization

- “new technologies can help deal with ethics problems around archiving, even with visual data... for example, work in Canada on paedophile groups has been able to implement full anonymization”
- “you collect data in a particular context, and it's a problem if someone looks at the data later, out of context... anonymizing data involves a loss of context and of grounding”

Archiving of data: re-use

- “I've done interviews on young gay men's sexuality, and that kind of material could be misused/misrepresented... consent is given with an understanding of how the data will be used, and of the politics of the researcher”
- “there's an issue of informing people about the re-use of their data--this is similar to the issue of giving blood for future studies unrelated to the purpose for which it was originally given”

Is ongoing oversight a useful proposal?

- “you could also have advisory groups on projects... ethical issues come and go through the course of research, they're not just present at the outset. A more dynamic process is involved”
- “it just sounds like another level of bureaucracy for researchers to deal with”

For whose benefit are ethics committees: research participants? universities? researchers? the research community? Should committees be involved in aspects of social research governance beyond the ethical?

- “ethics committees can be a form of quality control”
- “ethics committees tend to comment on methods rather than ethics”
- “ethics committees are concerned with the university's reputation, not with research subjects”

There remain suspicion about ethics committees and doubts over their value

- “there's been a growth in the surveillance of research, and it can be a tremendous barrier... a PhD student of mine had a year-long battle when she wanted to do an observational study in a hospital... the ethics committee wanted to see *every* letter she sent to participants”

- “most anthropologists feel they are professionals and know what they are doing”

In some places qualitative researchers have been able to work positively and constructively with committees—but these remain a minority. Could (or should) there be more specialist qualitative ethics committees?

- “our local ethics committee has two advisors on qualitative researchers, and so there's a much greater understanding and appreciation of qualitative research there than there used to be... colleagues of mine in Oxford have separate qualitative research ethics committees”

How can ethics committees' dealings with qualitative research be improved?

- “ethics committees are key, they can be a catalyst... our school ethics committee is dynamic and changing, they've had extra training and so on... that shows what can be done – but it's not the norm”

Summary

Key issues

- Ethics committees are a growing part of all research, most notably in health-related work
- There are often inconsistencies and shortcomings in ethics committees' understandings of qualitative research
- In some places qualitative researchers have been able to work positively and constructively with committees—but these remain a minority

Questions

- How can ethics committees' dealings with qualitative research be improved? Through training? Through evaluation criteria? Through ongoing oversight?
- Should committees be involved in aspects of social research governance beyond the ethical?
- How can existing good practice in the ethical evaluation of qualitative research be encouraged and developed?