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7 Where next for research ethics?

Introduction

There have been several developments in research methods over the last decade or so which have, arguably, significantly changed the nature of the way in which many social scientists conduct research and consequently the ethical issues with which they engage. In this chapter, trends and developments in qualitative research methods and the ethical issues that they raise are outlined. The chapter concludes by discussing whether these ethical issues demand new approaches to research ethics or involve the re-working of familiar issues in new contexts. It also outlines some ideas about the direction for research ethics in the future.

Developments in research methods

The last decade or so has seen a rapid growth in the development and use of a number of specific methodological approaches in qualitative research. These include: narrative, biographical and performative methods; visual and creative methods; participatory methods; digital and e-research, and data sharing. Some of these developments reflect what has been termed the 'cultural turn' in the social sciences and the interest in identity, while others reflect what has been referred to as the democratisation of research and the moves to the involvement and empowerment of research participants. The rapid growth in digital technology, changes in the ways that people interact online and the scope that online communications provide for understanding aspects of the social world are another factor involved in some of these developments. A further factor is the need to ensure data sharing in the interests of maximising value from research and providing datasets and resources of value to future researchers. It has been observed that the developments outlined here have been driven by a number of factors, such as advances in technology and cross-fertilisation across

disciplines (Xenitidou and Gilbert, 2009). Some of the developments in each of these methods and approaches and the major corresponding ethical issues they raise are explored below. In this brief outline to each of these methodological areas it is possible to identify only very general issues. It is of course the case that the ethical issues that arise within each of these methodological approaches are contextual and will vary according to the nature of the project.

Narrative methods

The use of narrative methods has increased markedly over the last two decades (see Elliott, 2005; Squire, 2008). Narrative methods encompass a wide range of approaches, including event-based narratives, narratives of experience and performative and cultural narratives; the first two of these focus on the content of people's narrative and the latter on the structure and form of narratives. Other forms of narrative approaches include biographical research, life history research and oral history (see Plummer, 2001). The methods employed in qualitative narrative research include the collection of data via interview and observation, generally over prolonged periods, as well as analysis of a range of documentary sources. Key elements of narrative approaches are that they involve researchers enabling research participants to tell stories about their lives, that researchers need to pay close attention to and value respondents' stories, that researchers develop close relationships with their study participants and that they form part of the narratives that are constructed. All these elements highlight the need for reflexivity in narrative research.

Numerous ethical issues have been identified as arising from narrative, life history and biographical approaches. Plummer (2001: 216) identifies seven ethical 'concerns' in life history approaches (see also Elliott, 2005; Squire, 2008). Primary among these are issues of exploitation, risk of harm, anonymity and confidentiality and ownership. Plummer (2001) identifies exploitation as perhaps the most crucial issue in that study participants are encouraged to provide their personal, and perhaps painful, stories but that it is the researcher that benefits, both professionally and materially, from the reporting of these stories in which the subject of the narrative is anonymised and generally receives no credit or reimbursement. The risk of harm is also significant in narrative research. As Elliott (2005: 137) notes, people's narratives are bound up with their sense of identity and

the process of data collection and the interpretation and dissemination of these narratives can, if done insensitively, cause considerable harm to individuals and their relatives, friends and communities. Plummer develops this theme by arguing that (2001: 224):

Telling their stories could literally destroy them – bring them to suicidal edges, murderous thoughts, danger. More modestly, they may be severely traumatised. The telling of a story of life is a deeply problematic and ethical process in which researchers are fully implicated.

Issues of confidentiality and anonymity are also particularly problematic in narrative and biographical research in that these methods often render participants identifiable, or at least potentially so. Often participants are identified in the publication of material, with their consent, but this is not without the sorts of problems discussed in chapter 3. This then raises issues about what can, or should, be confidential in such studies and how such material should be managed.

Narrative approaches appear to raise some specific ethical challenges in relation to the management of relationships with study participants and sensitive handling of their stories. The specific issues raised reflect those in qualitative research more broadly and mirror the traditional areas of concern of research ethics: those of confidentiality, anonymity and risk of harm. Plummer (2001: 228) argues for dealing with them through a post-modern ethics that is grounded in researchers' day-to-day practices but one that is not divorced from broader ethical and moral principles.

Visual and creative methods

There has been a rapid growth in interest in visual research methods over the last decade or so across a range of social science disciplines and research settings. 'Visual methods' comprise a vast array of different types of approaches and data. Visual data include photographs, film, video, drawings, advertisements or media images, sketches, graphical representations and models created by a range of creative media. Prosser and Loxley (2008) identify four different types of visual data: 'found data' (for example family photograph albums); 'researcher created data' (such as images or film taken by researchers); 'respondent created data' (such

as models or drawings created by respondents) and 'representations' (for example graphical representations of data).

Visual methods raise a number of ethical issues. Perhaps the primary issue centres around the use of material in which individuals are recognisable, or potentially recognisable, and the challenges this raises in relation to issues of anonymity, confidentiality and consent (see chapter 4). Consent should be obtained for taking and using such images. However, this in itself is not always straightforward in that it may not be possible to obtain consent for all people in images and, even if consent is obtained, respondents may not be able to fully appreciate what the implications of being identified may be. The fact that it is increasingly the preference of both researchers and respondents that study participants are *not* anonymised in visual research findings raises a further set of ethical considerations, not least that this presents a challenge to established ethical practice. Wider ethical issues have also been identified concerning the way that images are constructed by researchers and consumed by those who view them (Rose, 2007: 255). This has drawn attention to the ethical implications, and consequences for individuals and their communities, of the ways in which researchers present images and the interpretations different audiences may make. Many established 'visual' researchers tend to adopt participatory or collaborative relationships with their study participants so that the materials created emerge from collaborations between them and are seen as jointly owned (Banks, 2001; Gold, 1989; Pink, 2007). Nevertheless the potential remains for participants in studies that use visual material (as with all research) to be unhappy about the way they have been portrayed (Pink, 2003; Crow and Wiles, 2008).

Prosser has argued that visual research methods sit uneasily within conventional ethical practice and regulation in social research and that this poses problems in relation to the review of visual research by research ethics committees or boards (Prosser, 2000; Wiles *et al*, 2011). Proponents of visual research have noted the importance of visual researchers developing ethical practice and becoming members of the committees or boards which conduct ethical review to improve the ethical review and decision-making processes in relation to visual research (Pauwels, 2008). The ethical issues raised by visual research are similar to those raised by all research, primarily those of consent, confidentiality and anonymity.

Participatory methods

Interest in participatory research approaches has grown significantly in the last twenty years. This has been fuelled, in part, by pressure from particular groups of 'service users' for involvement in the research that informs their treatment, care and experiences as well as from researchers working in specific fields such as gender studies, childhood studies, ethnic studies and disability studies who have identified the importance of empowering participants. The resulting insistence by some grant-giving bodies for 'user involvement' in research has meant that most researchers working in health and social care in Britain have to have at least some element of involvement from members of the population they are researching in the design and/or conduct of their research. Participatory approaches are most commonly used in research with children and young people (see, for example, Renold *et al*, 2008), research with a range of 'service users', including people with physical and learning disabilities (see, for example, Tarleton *et al*, 2004), and research on community and/or community development (see, for example, Lassiter *et al.*, 2004). There are various participatory research methodologies including participatory action research, participatory rural appraisal, participatory mapping and participatory video but in the main participatory research is distinguished by the level of collaboration between researcher and participants. The levels of involvement that research participants might have with a research project range from consultation, through to collaboration and full control by research participants (Involve 2004; Frankham, 2009). Participatory research is characterised by the involvement of research participants across all stages of a research project.

Researchers using participatory approaches foreground ethical issues as part of their approach. The key ethical issues identified focus primarily around the power differentials between participants and researchers. Frankham (2009) identifies the key ethical issues for researchers attempting to involve service users in research as being tensions around the ownership and authorship of research and the related issues of accountability and remuneration. Similar issues are reflected on by Tarleton *et al* (2004) in relation to research with people with learning disabilities and by Heath *et al* (2009: 73) in relation to research with children and young people. Informed consent has also been identified as a particular challenge in relation to research with children and young people because of the often

longitudinal nature of participatory research and the fluid nature of the interactions between researcher and participant. Renold *et al* (2008), for example, found that in their longitudinal project on children and young people in the care of the local authority they had to devise various strategies to render participation visible throughout the project.

One of the challenges of participatory approaches is that researchers' interactions with their participants are not fixed. This is true for all qualitative research but more markedly so in relation to participatory approaches, when the direction of a study, the specific methods used and the dissemination strategy is always in a state of negotiation. This can create tensions in relation to processes of ethical review which operates on the basis of anticipated ethical issues. As Renold *et al* (2008: 443) note in relation to their research on 'looked-after children', participatory research ethics is not so much about 'multiple negotiated dilemmas'; rather it involves an 'ongoing dialogue in the micro-complexities inherent in everyday fieldwork relations'.

Digital and e-research

Possibly the most significant developments in research methods in the last decade relate to various forms of digital, online and e-research. The majority of the population in the Western World use the internet and increasingly a significant part of social interaction occurs online, particularly for some social groups (Dutton and Blank, 2011). The scope for making use of the internet in research has been widely recognised; Eynon *et al* (2008) note that the internet can be seen as a huge 'social science laboratory'. The ability to collect and combine various types of online and offline digital qualitative and quantitative data is a further development which has generated considerable research activity. Many of the developments in research using digital and online data are quantitative or draw on mixed methods approaches. The development of software tools to analyse activity on the internet, across sites or on specific sites has resulted in a growth in 'webometric' research (see for example Thelwall and Sud, 2012). Research has also been conducted in virtual environments such as 'Second Life' where behavioural experiments have been conducted through the use of avatars (Eynon *et al*, 2009). This type of research has significant ethical implications but, as the methods employed are largely quantitative, they will not be specifically discussed here. Rather the focus is on the

challenges arising from relatively recent developments arising from what has been referred to as 'Web 2.0', primarily focusing on data from social networking sites and other user generated content such as blogs (Snee, 2008). Research on social networking and blogging has used ethnographic methods within sites, often in combination with quantitative methods such as social network analysis (see Eynon *et al*, 2009; Snee, 2008).

The primary ethical issue arising from these developments and online research in general relate to the issues of privacy and consent (see also chapter 3). It was noted in chapter 3 that distinguishing between what is public and private on the web is problematic. Snee (2008) notes the nature of the Web 2.0 environment complicates this further in that social networking sites encourage the sharing of personal and even intimate information. The extent to which such information is viewed by the author as being in the public domain is not necessarily easy to gauge. There are also issues relating to anonymity because, even if people or institutions are anonymised in research reports, information collected from the internet is often easily traceable via a search engine. Identifying when anonymity should be used and when it is appropriate to cite an internet user as an author by name is again not straightforward. It is certainly the case that not all internet users want to remain anonymous; this may apply particularly to authors of blogs, and to anonymise people in such circumstances could be seen as infringing copyright and raise issues of intellectual property. Issues of consent are also potentially problematic, as has been discussed in chapter 3. All these issues are complicated by the fact that in online research geographical boundaries do not exist and thus different legal and ethical regulation applies to the data collected.

In common with the concerns raised by researchers using visual methods, it has been noted that ethical review committees lack knowledge about Web 2.0 and that researchers may need to educate committee members as well as the wider research community. Eynon *et al* (2008: 26) note that despite concerns that online research raises specific ethical challenges, there has more recently been a convergence in the view that research ethics for online research can be drawn from existing frameworks for offline settings. Similarly Snee (2008: 20) found that most internet researchers did not feel that a specific 'Web 2.0' ethics is needed. Nevertheless it is recognised that some special considerations are necessary when researching online and that issues of confidentiality, anonymity,

disclosure, informed consent and privacy are cast in a different light in online research.

Data sharing

In the last decade or so there has been a marked increase in the development of policies to promote or recommend data sharing; this is increasingly a requirement on the part of research funders (Van den Eynden *et al*, 2009). In the UK the qualitative data archive, Qualidata, was established in 1994 (becoming part of the UK Data Archive in 2001) and similar developments have occurred in the US and Europe to enable the sharing and re-use of data from qualitative research (see Corti and Thompson, 2007). In part this development reflects a financial imperative for data sharing in order to achieve better value for money for research funders and avoid duplication of research effort. However, data sharing also provides researchers with opportunities to gain methodological and substantive insights from existing research data. Corti and Thompson (2007) identify six approaches to reusing data: description; comparative research, re-study or follow-up study; re-analysis or secondary analysis; research design or methodological advancement; verification; and, teaching and learning.

It has been noted that archiving for the purposes of data sharing raises significant ethical challenges. Neale and Bishop (2012a) argue that these occur because the priorities and interests of the various parties involved do not necessarily coincide. Balancing the rights and responsibilities of the primary researcher and the research team, secondary researchers who want to make use of the data, the data archivist, research participants, research funders and the general public may present significant challenges. The central issues revolve around informed consent, confidentiality and anonymity.

To ensure that research participants give consent for data archiving and re-use, it is essential that this explicitly forms part of the consent process. Gaining informed consent for data sharing and re-use is particularly problematic in that researchers and their participants do not know what future uses will be made of these data; it is impossible to know what questions researchers will ask of the dataset and how long in the future such secondary analysis may take place. It is possible that secondary research may be conducted in ways that the primary researcher and the research participants are unhappy about. While these concerns may be responded

to by restricting access arrangements for data so that researchers have to register for access to the data and to comply with specific arrangements for viewing the data (such as having to register for its use and to use it only in non-public environments), it is far harder to justify limiting the ways in which secondary researchers analyse these data. Arguably it is not in the interests of the research community, research funders and the general public to limit the uses that can be made of research, especially where it is publicly funded. Neale and Bishop (2012b) argue that researchers have a duty to protect their research participants but they have to balance this with a wider responsibility to the research community and the public and that they need to work closely with their participants to make this explicit in the case of data sharing.

Researchers themselves are also vulnerable to criticism from other researchers as a result of archiving their research data. Neale and Bishop (2012b) note that researchers undertaking secondary analysis may criticise a primary researcher's ways of working or not take account of the different cultural and intellectual environments in which these data were produced. They argue that both secondary and primary researchers have ethical responsibilities to adopt an ethics of care approach in their dealings with each other so that the primary researcher acknowledges the rights of the secondary researcher to analyse their data as they see fit but that this should occur in ways that respect the integrity of the primary researcher's original work.

Issues of anonymity and confidentiality are also prominent in relation to archiving and data sharing. Ensuring confidentiality through processes of anonymisation is important but at the same time the integrity of the data needs to be protected to ensure its utility. The usefulness of data can be undermined if relational information, geographical references or alterations to aural or visual data are made such that its value to secondary researchers is minimal. Neale and Bishop (2012b) note that while researchers have a duty to protect participants they also have a responsibility to get their accounts heard as widely as possible. Managing this issue involves balancing these competing responsibilities.

Where next for research ethics?

Researchers working in each of the methodological approaches outlined above have identified the specific ethical challenges raised. The topics

relate, broadly, to the general issues identified in traditional qualitative approaches and discussed in the various ethical and moral research ethics frameworks presented in chapter 2; those of anonymity and confidentiality, informed consent, and risk of harm. This is perhaps not surprising given that this is the framework by which ethical questions in social research are addressed. Nevertheless, some of the specific issues identified within these broad ethical topics imply, to a greater or lesser extent, a re-framing of traditional approaches to ethics. This is perhaps particularly pertinent in relation to the issue of anonymity. In all five approaches discussed above some challenges to the need for anonymity are raised. This is a view supported by many researchers, particularly visual and participatory researchers, who argue that research participants often want to be identified and should have the right to be, providing this does not pose risks to their or other participants' well-being (Grinyer, 2002; Wiles *et al*, 2011). Tilley and Woodthorpe (2011) argue that the concept of anonymity may be inappropriate in the context of twenty-first century qualitative research activity. They note that anonymity can conflict with demands to disseminate widely, particularly on the internet which poses various threats to anonymity. They also note that anonymity can conflict with the wishes of funding bodies and with knowledge transfer to policy-makers and practitioners. It seems likely that it is in the area of anonymity that the greatest challenge to traditional research ethics will occur in the future.

A further important issue raised by the review of the above approaches is that research ethics committees and regulation more broadly are viewed by many people as curtailing or limiting research using these approaches. It is argued that members of ethics committees lack understanding of non-traditional methods and that researchers using, for example, visual and online approaches, need to educate them to ensure that this does not pose a challenge to such research being conducted. These criticisms form part of a wider critique of the ethical governance and regulation of the social sciences in the UK and elsewhere (Atkinson, 2009; Hammersley, 2009). Criticisms of the regulation of research in the UK have thus far had limited impact on what has been referred to as 'ethics creep'. It seems probable that debates about the merits of regulation, and perhaps also resistance to it, will remain a feature of social science research into the foreseeable future (see Stanley and Wise, 2010).

One of the key issues that researchers using the approaches outlined above identify is the need for situational relativist approaches to be

adopted in managing the ethical issues that emerge in research rather than adherence to a set of principles or rules. Adherence to principle and rule-based ethical frameworks appears to be identified as particularly challenging in relation to these developing and emerging research approaches. This is a key debate in the research ethics literature and one which, arguably, lies at the heart of concerns about regulation. Plummer (2001: 226) regards the distinction between ethical absolutists (who view ethical principles as important in driving ethical decision-making) and situational relativists (who view ethical decision-making as emerging from an individual researcher's moral framework) as an unhelpful dichotomy. His argument, consistent with the one which I have put forward in this book (see chapter 2), is that ethical decision-making needs to be guided by an ethical framework. Such frameworks do not *determine* decision-making but rather provide researchers with a means of thinking systematically about moral behaviour in research.

Summary

The last decade or so has seen a rapid growth in the development and use of a number of specific methodological approaches in qualitative research. These include: narrative, biographical and performative methods; visual and creative methods; participatory methods; digital and e-research, and data sharing. Some of the ethical issues raised by these approaches imply a re-framing of traditional approaches to ethics. This is perhaps particularly pertinent in relation to the issue of anonymity. Research ethics committees and regulation more broadly are viewed as curtailing or limiting research using these approaches. It seems likely that debates about the merits and form of regulation will remain a feature of social science research in the foreseeable future.

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