

# social research Update

## The ethics of the secondary analysis and further use of qualitative data

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- **Codes of ethical conduct suggest that consent obtained from participants at the point of data collection should not be ‘once-and-for-all’ and renewed consent is necessary for secondary analysis**
- **However, the definition of the secondary analysis of qualitative data is ambiguous, thus knowing if renewed consent is needed is not always clear**
- **Further demands are made upon participants in repeated returns for consent and this also presents practical challenges**
- **Lodging qualitative data sets in central archives for continued use by other researchers is at odds with expectations of re-negotiated consent for secondary analysis and raises ethical and practical problems**

The ethics of having consent for the analysis of secondary data arose as an issue during my return to two data sets that I had previously collected and that I now wanted to compare for a journal article. The data had been generated during a long term research project on the life stage impact of cancer in young adults. The first phase had been undertaken with parents of young adults with cancer and the second phase with young people in treatment for cancer (not the sons and daughters of the parents in the first phase). According to the definitions below (Hakim 1982; Heaton 1998), the data were indeed to be subjected to secondary analysis. However, my assumption was that returning to the two sets for this

purpose was a legitimate extension of the original consent. Nevertheless, I was required by the journal editors to account for the consent procedure for the secondary analysis. Turning to the academic literature did not yield any helpful documents and the construction of an argument to support my use of this material led me to question the practical and ethical issues.

Heaton (1998:1) defines secondary analysis as ‘the use of existing data collected for the purposes of a prior study, in order to pursue a research interest which is distinct from that of the original work’, but suggests that it is most commonly associated with the secondary analysis of quantitative data. Hakim’s (1982:1) definition of secondary analysis is ‘any further

analysis of an existing data set which presents interpretations, conclusion of knowledge additional to, or different from, those presented in the first report on the enquiry as a whole and its main results’.

Such definitions may suggest that secondary analysis is undertaken by a researcher using data collected by another. However, it is also the case that the original researcher might use data for secondary analysis by returning to them after the initial analysis has been undertaken. Heaton (1998) offers a number of examples of this.

### Is consent ongoing?

During recruitment for each phase of the research I asked participants for consent to quote from their interviews in any resulting publications. While informed consent is a ‘linchpin of ethical behaviour’ (Bulmer 2008:150), how far the consent for usage extends can be a matter of conjecture. The British Sociological Association’s *Statement of Ethical Practice* (2004) states that researchers must inform participants of the uses to which their data might be put and obtain consent for the future use of the material. The implication is that, once granted, the researcher has consent for the ongoing use of data within the spirit of the original agreement. However, the guidelines also state:

It should also be borne in mind that in some research contexts, especially those involving field research, it may be necessary for the obtaining of consent to be regarded, not as a once-and-for-all prior event, but as a process, subject to renegotiation over time. (BSA 2004: 3)

This process may refer to the re-negotiation that can take place during the fieldwork if an unanticipated research focus emerges. However, my interpretation is that this also applies to a return to the data by the original researcher at a later time. Clearly the ambiguity leaves the researcher some discretion

in judging if further consents are necessary, but there appears to be no guidance about what specific circumstances may require further consents. This raises ethical concerns about returning—or not returning—to participants for future consent. In my own research much of my data has been contributed by participants recalling the most painful experiences of their lives. Continually seeking consent from participants to return to the data for analytical purposes could be interpreted as making further demands on them and raising anxieties about why this is necessary. On the question of whether consent should be ongoing or re-established, Wiles et al (2005) say:

*On the one hand...* [it] ensures people know to what they are consenting as the focus and the direction of a study changes. Addresses participants’ tendency to disregard the information about participation that they are given. *On the other...* One off consent is adequate; seeking ongoing consent irritates participants and encourages them to withdraw from participation. (Wiles, Heath and Crow, 2005, original emphasis: no page number)

The UK Data Archive (UKDA) guide for researchers reiterates many of the points above:

data sharing beyond the research can be a one-off occurrence or an ongoing process. One-off consent is simple, practical, avoids repeated requests to participants, and meets the formal requirements of most Research Ethics Committees. However, it may place too much emphasis on ‘ticking boxes’. If consent is considered throughout the research process, it assures active informed consent from participants. Thus, consent for participation in research, for data use and for data sharing can be considered at different stages of the research, giving participants a clearer view of what participating in the research involves and what the data to be shared consist of. It may, however, be too repetitive and annoying for some participants. Special consent considerations are needed for:

- medical research
- research with children and young

- adults
- research with people with learning difficulties
- research within organisations or the workplace
- research into crime
- internet research (UKDA 2009:19)

Exactly what the ‘special consent considerations’ might be is open to interpretation, and it is possible to argue that the perceived ‘vulnerability’ of some of those on the above list necessitates either obtaining further consent or alternatively avoiding the risk of causing unnecessary anxiety by renegotiating such consent.

There are also practical problems such as the inability to trace participants who may have moved house, changed their telephone number or be untraceable for other reasons. In my own research, it is a possibility that participants will have died from their illness. It could be distressing for the relatives to receive a request for the further use of the data in such circumstances. Indeed, it may be that family members had been unaware of their late relative’s participation in the research. To expose it inadvertently through seeking further consent might, in itself, be considered ethically problematic. While the context of my research is specific, it is possible to envisage other social research scenarios that present similar challenges. Does the lack of ability to contact a participant render their data unusable?

It can also be important to participants that their data are used to the full. It may be that it is the volume of output and continued use of their data that makes the demands of participation worthwhile. As Helen V, one of my participants in the first phase of the research, said: “If the stories had only been used for one or two articles in academic journals, the effort would not have felt so worthwhile.” (Grinyer 2004: 1331). This suggests that the more use made of the data in publications,

the more satisfied participants are with the process. Participants' hopes for the maximum use of the data both imply and confer continuing consent for further analysis and publication.

So is the solution to these challenges to seek specific consent that would cover all eventualities at the time of data collection? To be able to achieve this appears unlikely as it is not always clear in what direction the research will develop. As Merrell and Williams (1994) argue, the unexpected ideas that arise through the reflexive nature of qualitative research mean that informing participants of the exact path that their data will take is not possible.

In research where the output has been disseminated in the public domain, any reader could undertake a secondary analysis without obtaining any consents. Darlington and Scott (2002:30) argue that researchers have little control over how published data are re-analysed and the selective use of quotes may prove problematic and at odds with the original purpose.

### Data archives

Access to archived material is governed by rigorous codes of practice (Parry and Mauthner 2009:140) and, as can be seen from the earlier UKDA quote, issues of consent are recognised as a matter of concern. Nevertheless archives do offer access to future researchers that raises ethical issues.

Parry and Mauthner (2004:141) claim that social scientists are increasingly encouraged to locate, access and analyse data via such archives. They argue that the previous acceptance that this was unproblematic for the storage of quantitative data has been extended to a similar assumption about qualitative data. Carusi and Jirotko (2009) concur, arguing that there is a lack of policy and guidelines on how to deal with digital archive data, which is

particularly susceptible to being copied, manipulated and de-contextualised.

According to Parry and Mauthner (2004), issues of copyright and confidentiality raise significant concerns as 'the reality is that respondents, researchers and grant holders relinquish control over deposited data' (2004:142). While it is unlikely that a secondary researcher would abuse the ability to access data archives, particularly given the protection mechanisms in place (UKDA 2009), there are nevertheless issues of concern relating to consent. Even if consent to archiving was freely given on the basis of a desire for the data to be used to maximum effect, there are potential hazards:

For a research participant to see their words used or, as they might perceive it, misused, in the public domain can be a deeply violating experience even if their identity is not revealed (Darlington and Scott 2002:30). However, Darlington and Scott also point out that allowing other researchers access to data for the purpose of secondary analysis can be an important safeguard against fraudulent research. A balance therefore needs to be struck between the research community's wider need for confidence in the legitimacy of research data and participants' confidence that researchers will protect their interests.

Corti et al (2000) report that Qualidata, the specialist service of the Economic and Social Data Service (ESDS) led by the UK Data Archive (UKDA), has undertaken consultation to ensure the data are protected. For example, Corti, Foster and Thompson (1995), all key staff at Qualidata, suggest that requests for access could be vetted by the depositor and the UKDA guidance contains the following:

Best practice for qualitative data is to:

- plan anonymisation at the time of transcription or initial write up

- use pseudonyms or replacements
- retain unedited versions of data for use within the research team and for preservation
- create an anonymisation log of all replacements, aggregations or removals made; care should be taken to store such a log separately from the anonymised data files
- identify replacements in a meaningful way, e.g. with [brackets] (UKDA 2009:21)

While such guidelines are helpful, there is still no suggestion that renewed consent is viable but in part this seems to be addressed by the suggestion the raw data are preserved and an edited version is archived. Carusi and Jirotko (2009) go further and argue that an overarching principle should be putting the research subjects at the forefront and giving them control of their data by registering them as participants on archiving sites if this is their wish.

### The implications for research practice

This discussion has drawn out a number of contradictory positions in the debate about the secondary analysis of data. For example:

- the expectation of renewed agreement for data usage *versus* the possible annoyance caused by repeated returns for consent
- ambivalence about the placing of data in accessible archives *versus* the desire to disseminate as widely as possible on behalf of participants
- the apparent discrepancy between the requirement that the original researcher gains renewed consent *versus* a secondary researcher's ability to access data from archived material.

The key to such dichotomies is the issue of most fundamental importance, that is, to understand how participants wish their data to be used and what they want their input to result in. If researchers engage fully in a dialogue about such issues at the point of data collection, some of the dilemmas discussed above might be avoided.

While much is made of informed consent as a basic principle of ethical research, too often this may be a one way transfer of information from the researcher to the participant. Having discharged their responsibility, researchers may then move on to data collection without any real grasp of what would be a satisfactory long term outcome for the participant. However, the 'right' course of action may vary from project to project and from person to person and as a result remains difficult to legislate for in codes of practice.

As Hallowell et al (2005:147) argue, the assumption that the ethical issues arising during the course of research can be predetermined is rarely the case. Thus, while codes of ethical conduct are an important framework for the guidance of ethically sound research, they cannot anticipate every eventuality. This means that a central component of the education and training of researchers should be that they are aware of the codes but understand that they rarely anticipate the situational ethics of the field (Punch 1986). As Fisher et al (2002) state, the situational advice that is necessary is:

not intended to serve as regulation, policy, or absolute prescriptions for research ethics practices. Rather, the goal is to assist investigators... in identifying key ethical crossroads and in developing culturally sensitive decision-making strategies that reflect the values and merit...trust. (2002: 1024)

Thus, when ethical judgments have to be exercised in secondary analysis, it is of fundamental importance to be 'ethically aware' and make decisions that are located in the context of the research and the wishes of our participants.

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