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- Access to participants in health related research can be difficult to achieve, because consent from ethics committees may not be granted or can take many months.
- As an alternative the Internet may be used as a way of gathering data but may raise unexpected ethical challenges.
- The definition of a 'human participant', issues of privacy, informed consent, and the prevention of harm all present ethical challenges in cyberspace
- The Internet provides a valuable additional source of data but should not be used as an 'easy option'.

The ethics of Internet usage in health and personal narratives research

Anne Grinyer

Researchers are currently beset with ever more barriers to access (Hammersley 2006) and this is felt acutely in health related research where ethical approval procedures are particularly bureaucratic and time consuming (Smith 2004, Brindle 2005, Grinyer 2007). The Internet offers an attractive new source of data, including examples of patient narratives (Lewis 2006). As Cotten (2001) argues, Internet technology has far reaching implications for the way in which medical sociologists gather health related information (Sullivan 2003, Lewis 2006). Suzuki and Beale (2006) suggest that illness narratives gained through more traditional methods such as interviews 'may unduly restrict the revelations of the respondents'. In contrast they claim that:

The Internet age has now provided a different resource which may afford patients greater freedom in how they describe their cancer experience. (Suzuki and Beale 2006:152)

Lewis (2006:4) endorses this positive interpretation and suggests that the online method he used allowed his participants to 'feel at ease in discussing their health disorders in a perceived setting of privacy'. The implication of both Lewis's, and Suzuki and Beale's (2006), argument is that the 'freedom' and 'ease' experienced by online participants who tell a personal illness story provides an approach to data collection that is ethically sounder than requiring participants to recount their narrative in person, a process which may be experienced

as stressful and demanding (Grinyer 2002). However, while using the Internet as a data source may appear to present fewer ethical difficulties than more traditional approaches, there are dimensions of Internet research that may not easily be governed by existing codes of ethical practice. For example, ideas of 'privacy' and 'informed consent' can present the researcher with unexpected dilemmas. The need for caution is captured in the following extract from the British Sociological Association's *Statement of Ethical Practice*.

Members should take special care when carrying out research via the Internet. Ethical standards for Internet research are not well developed as yet. Eliciting informed consent, negotiating access agreements, assessing the boundaries between the public and the private, and ensuring the security of data transmissions are all problematic in Internet research. Members who carry out research online should ensure that they are familiar with ongoing debates on the ethics of Internet research, and might wish to consider erring on the side of caution in making judgements affecting the well-being of online research participants. (BSA 2002:5)

While this extract clearly signals the depth of concern over this new method, the practical guidance it offers is limited. Although dated 2002, it was retrieved from the Internet in 2006, suggesting that the debate has not moved forward.

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Collecting data from young adults with cancer

When I began to seek qualitative data from young adult cancer patients on their illness experience, I applied for National Health Service Multi Site Research Ethics Committee (MREC) approval to conduct face-to-face interviews, a process that took almost 9 months (Grinyer 2007). During this enforced delay I turned to the Internet as an initial source of data (Planet Cancer Forums 2004). As Illingworth (2001) says, the Internet potentially overcomes the barriers encountered when using more conventional methods.

At first sight this approach might appear to be ethically unproblematic; indeed as implied by Lewis (2006) and Suzuki and Beale (2006), it could be interpreted as ethically more sensitive than the planned face-to-face interviews. However, the Association of Internet Researchers (AoIR) (2002) suggests that there are indeed many ethical considerations that may not yet be addressed directly by existing codes of professional conduct.

Stern asks if online research should even qualify as 'human subject' research:

Researchers must determine the extent to which the ethical principles that guide their studies of 'real' people should extend to the manifestations of real people, i.e. their online communication. (2003:256)

Bassett and O'Riordan (2002:233) contest the 'human subjects research model', which they acknowledge may be appropriate in private emails and other electronic communications, but not as a universal approach. They argue that the Internet should be considered as a site for the 'cultural production of texts'. Similarly White (2002) challenges the conception of Internet material as 'people and human subjects'. However, Illingworth (2001:7) argues that while the term 'cyberspace' suggests an independent reality reflecting a view of correspondents with no bodies, faces or histories, there is now an acceptance that the difference in self-presentation online and in 'real life' is not as great as was once assumed. The implication is that those we encounter online should be categorised as human participants. This view is endorsed

by Hudson and Bruckman (2004:136) who claim that access to 'identifiable private information' makes observational research on chatrooms 'human subjects research'.

The Economic and Social Research Council (ESRC) (2005b) has brought in requirements for the institutional consent procedures governing access to human participants that can only be effective if researchers and institutions agree what constitutes a 'human participant'. In the field of health research, there is little doubt that contributors to chatrooms should be defined and treated as human participants because of the way in which they share their illness narratives, disclosing intimate, painful and personal details of their illness experience. To recognise them as human participants is crucial because it governs all subsequent procedures and guidelines relating to permissions and consents.

Once 'in the field' there are new ethical challenges that generate practical problems. The easy availability of and access to electronic data presents the researcher with ethical questions concerning the privacy of the site's users. As Hakken (1999: 210) suggests, 'it may be more difficult for everyone to act ethically in cyberspace'. Does the mere accessibility of information automatically make it publicly available? 'Lurking', when researchers covertly collect data without participating or stating their aims, has been criticised as encroaching upon the unwitting participants' privacy and placing too much power in the hands of the researcher (Heath et al, 1999). Conversely, Herring (1996) argues that the very accessibility of, for example, mailing lists, chatrooms and newsgroups make them part of the public arena by default since private, enclosed forms of these communication channels are available. The fact that the user chose the public forum makes all communication therein public and available for research purposes.

Hudson and Bruckman (2005:298) use the concept of 'reasonable expectations of privacy' and claim that research has repeatedly shown that 'people in public, online environments often act as if these environments were private'. In their study of Internet users, they conclude that

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participants in public chatrooms acted as if they had been violated when they were told that they had been studied, thus suggesting an expectation of privacy whether 'reasonable' or not. However, treating Internet users as 'human participants' with a reasonable expectation of privacy raises the challenging issue of informed consent. The AoIR (2002) guidelines suggest that it is necessary to gain informed consent and to make clear to subjects how their material will be used.

Hudson and Bruckman (2005:299) offer a deontological perspective, that a violation of the rights of research participants 'whether or not the subject is aware of the violation, constitutes harm'. However, these authors go on to say that when they did attempt to gain consent they annoyed approximately two-thirds of potential participants and were removed from the chatroom. They ask what constitutes the greater harm: annoying participants or not seeking consent. It seems that if we hold to the concept of human participants, a right to a reasonable expectation of privacy and the right to give informed consent, the greater harm lies in not seeking consent even if participants would be unaware of a violation.

Nevertheless, an insurmountable problem arises with material from a chatroom that cannot be traced back to its (anonymous) contributor because no explicit consent for its use can be gained. Here lies a crucial difference between engaging in dialogue with Internet users while declaring the research purpose and the use of pre-existing material. Lewis (2006) makes it clear that he developed a relationship of trust with his participants as a fellow user of the site. He was not just a researcher, but also a member of a cohesive online community. It was only after five months of membership of this community that he invited other members to participate in his research and, in contrast to Hudson and Bruckman (2005), they willingly agreed. But Lewis (2005) was an authentic member of an online support group for people living with Irritable Bowel Syndrome (IBS) while Hudson and Bruckman's declared purpose was to study the language used

in online communication, suggesting that genuine membership affects the likelihood of consent.

In my research, not only was I not a member of the online community of young adults with cancer, the material I accessed was historic, posted by young people who had adopted pseudonyms and who were therefore untraceable and from whom it was impossible to gain informed consent. As a result I reluctantly concluded that the material is ethically inadmissible despite its potential to illuminate issues of importance and I did not include it as research data. One can speculate on the feelings of violation and exploitation readers might feel should they recognise their own words taken from the chatroom and quoted in a published text without consent. Thus such material must remain contextual and inform our understanding without becoming primary data.

An additional problem relates to the ethical obligation to protect participants (and others) from harm (BSA 2002). What should I have done if I had encountered material that suggested intent to self-harm or to incite such behaviour in others? Stern (2003) asks what a researcher should do when encountering 'distressing' disclosures online. Does the researcher have a moral obligation to intervene? Stern concludes that online researchers must decide on a case-by-case basis whether the distressing information demands a response, if a response or intervention is indeed a possibility. Stern suggests that it is more likely that disclosures might be made online as the medium allows for anonymity. But paradoxically, the very anonymity of the contributions coupled with their possibly historical nature means that we have no means of intervening. If an intervention were possible in a live chatroom, the same ethical codes should govern our intervention as would be the case with a face-to-face method.

Conclusion

Without doubt the relative ease of access to electronic data sources has opened up a valuable new world of research opportunities. As Illingworth (2001)

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says, the world-wide, low cost, almost instantaneous access to material that circumvents many conventional barriers to research must be welcomed, although she warns against its use as an 'easy option' and argues for a more developed focus on the justification for its use as a method. As we have seen, it comes not only with many of the same ethical concerns as traditional methods but adds some new ones. Indeed, there may be greater concerns because under some circumstances electronic methods may bypass the scrutiny of an ethics committee, leaving the researcher without guidance or the protection of institutional approval. Issues of privacy and informed consent are complex and controversial and still the subject of debate. It may be that a categorisation of the type of material accessed is necessary in order to govern the ethical principles of its usage. Perhaps contributors to the sites, or the site managers, should indicate whether the material may be used for research purposes and the procedure for gaining consent.

The evolution of technology suggests that its fast changing character necessitates ongoing vigilance to ensure that ethical practice keeps pace with technological innovation. The rapid development of new and as yet possibly unimagined sources for research data demands a continuing debate that informs and shapes codes of ethical conduct across disciplines that will in time generate their own disciplinary norms.

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