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## Ethical Issues in Using the Internet in Research: Commentary

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*Research Ethics* 2008 4: 117

DOI: 10.1177/174701610800400307

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Case study 11

# Ethical issues in using the internet in research: commentary

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*This study appeared in full in the last issue of Research Ethics Review (2008; 4 (2): 68). MJ's research focuses on those patients with brain damage following trauma such as a road traffic accident. She wants to find out about their experiences of daily life once they have been discharged from hospital. She plans to use a phenomenological approach in which each participant will be asked to take part in a series of in-depth interviews, via email, over a period of about two years. These interviews will allow her to compare participants' experiences in different parts of the UK. MJ has a research partner in Auckland; the two of them are planning a similar series of interviews in New Zealand to allow for comparison between participants' experiences in the two countries.*

## Questions for discussion

### What ethical issues might arise in the conduct of this research?

MJ's research reflects a growing trend in the use of electronic means to gather and record data. This is particularly the case where studies focus on the needs and experiences of people who find other research methods too demanding. Some previous studies on adults who have survived traumatic brain injuries illustrate this point. Egan et al. [1], for example, conducted email interviews in Australia with adults who had survived traumatic brain injuries. When asked their opinion of this method of data collection, participants 'overwhelmingly reported that they preferred email interviewing to a face-to-face encounter'. Reasons for this preference included difficulties in coping with the multiple stimuli generated in face-to-face meetings in which verbal and non-verbal signals have to be de-coded alongside whatever is being said, the need for frequent breaks because of pain or other physical problems, and limited energy levels. Using email to collect data allowed participants to take part in their own time, as and when they felt able, and take breaks whenever they liked.

Thus, participation can be combined with other activities such as watching television or minding children [2]. Participants may be widely dispersed over large geographical areas and still be able to take part; the researcher will not have to make appointments or bear the costs of travel [1,3,4]. The lack of face-to-face communication can have a disinhibiting effect, enabling participants to talk frankly about issues that they might otherwise feel too embarrassed or unable to discuss [2]. Thus participants who have survived traumatic brain injury, may feel able to talk freely, in emails, about those aspects of their lives which those

immediately involved in caring for them do not wish or know how to address.

However, using email can also create a number of challenges for MJ. First is the issue of access and skills. Whilst email and the internet have the potential to enable the recruitment of participants from many different social and geographical settings they also may exclude the poor, elderly and, unemployed [3]. MJ ought to consider whether the people she plans to study have access to email and the skills required to take part in the study. Egan et al. [5,6] developed a training programme for survivors of traumatic brain injury. All those involved had cognitive-linguistic impairments but proved able to learn. If they are to take part in research, participants need to be literate in the language used in the project, able to switch on a computer, and know how to use email. Training may help to make the project more attractive to potential recruits and be seen, by them, as one of the benefits of taking part. Thus MJ could say, in her information for participants, that training in basic computer skills and in using email will be given as part of the project. However, training is only useful if it is backed up by good support so that participants know whom to turn to if difficulties arise. Researchers should be computer literate and familiar with the procedures they are asking participants to use. They should either be able to cope with electronic problems themselves or have good technical support in place.

Second, MJ will need to consider the ethical principle of respect for autonomy [7]. Potential participants should be regarded in the same light as anyone else invited to take part in research. Participant information is just as important, although MJ can explore the possibility of different modes of presentation such as podcasts, rather than text, providing that these

meet research governance standards. Consent could also be recorded verbally and stored in a sound file unless a written signature is deemed essential and can be obtained [8]. What matters is that potential participants receive appropriate information and are able to make informed decisions about whether they wish to take part. However, extra care may be needed in obtaining consent from those who have survived brain injuries. Egan et al. [1] asked each potential participant to nominate a support person who could go through the information with them and verify their understanding. The involvement of the support person continued throughout the project providing help if the participant became distressed and acting as a point of contact for the researcher if she became worried about an individual. Consent was also obtained from legal guardians, where these had been appointed. On paper, this approach seemed very reasonable but nine people, that is to say half, of the participants deeply resented it. They argued that they were highly dependent on others for every aspect of their lives and their involvement in the project provided a space in which they could deal with something by themselves; the project offered one small step towards independence. Clearly the views of these participants did not match those of researchers and REC members who tend to regard those with brain injuries as ‘vulnerable’. Egan et al’s research [1] demonstrates that ideas about vulnerability may be experienced as patronising and perhaps unhelpful by those they are intended to protect. One solution to this issue may be found in consulting directly with people who have survived brain injury and trying to elicit their views on the best approaches to use.

Third, and allied to respect for autonomy, is the ethical principle of non-maleficence, the avoidance of harm [7]. Data collection is likely to remind participants of very painful experiences: the events surrounding their trauma, being in hospital, fear of death, changes in family relationships and coping with, what for some, may be a profound disability and loss of independence. Such recollections can be difficult for both the participant and the researcher. The researcher has a responsibility to ensure that all reasonable steps are taken to help participants cope with the aftermath of the interview. Providing appropriate help requires careful thought, the ability to anticipate some of the problems that may arise and a willingness to try different approaches. For example, a debriefing programme might be developed in the form of a podcast that could be sent either when the interview is complete or at any point at which the researcher becomes concerned about a participant’s well being [8]. Alternatively, it may be appropriate to identify and recruit help from local sources of support. Egan et al. [1] were correct in principle to appoint local support people but more consideration was needed to

clarify their role. Much depends on the individual situation; the researcher ‘must decide on a case-by-case basis whether the distressing information demands a response, if a response or intervention is indeed a possibility’ [9]. From the researcher’s perspective, coping with distressing interview content can be very stressful and disturbing whether it arises in email or face-to-face encounters. MJ may need to arrange some debriefing support, especially if she has not previously undertaken work with adults who have acquired serious disabilities.

Concerns about distressing content lead into considerations of privacy and the ways in which this may be compromised by the research. Participants will need to be assured that the information they provide will be treated in confidence and that they will not be identified in any reports or documents. This may be particularly important for those seeking legal redress or who are engaged in other forms of litigation, such as access to their children, in which their current mental state and abilities may be subject to assessment. Those attempting to rebuild their lives may also not want others to know about their thoughts and experiences. Finally, participants may want to express criticisms of services, their families and carers but, at the same time, wish to avoid jeopardising relationships with people on whom they depend. MJ will need to establish the level of assistance that individuals require in order to contribute their views and experiences. In some instances, additional software or hardware may be necessary to enable individuals to use a computer independently.

### **What role might the REC play in enabling MJ to address these ethical concerns?**

The impact of email and the internet is still very new and, consequently, there are as yet no definitive guidelines for researchers [8]. Constructive dialogue between researchers and REC members is, therefore, essential in developing good practice and ethically-sound research. REC members may feel rather overwhelmed by the technicalities of conducting a project of this kind and worry that they are not sufficiently computer-literate to give an opinion. Such feelings are reasonable but not altogether well-founded. The REC members’ central focus is still the rights and well being of the participants and the ethical issues inherent in the design. Participant information remains crucial; it is not the format that matters but the content. Free and informed consent is essential; how it is recorded, providing that some permanent format is used, matters less.

Thus, from the REC members’ perspective, constructive dialogue is rooted in the principles of research governance which remain the same, irrespective of the research design. In this instance, these principles are to be applied flexibly and creatively.

REC members will need to have open minds, and a willingness to engage with novel approaches whilst bearing in mind that their advice and opinion will carry weight for the future as a contribution towards consensus on good practice in this type of research.

### What concerns might the REC have about data management in this proposed research?

Data management will, in many respects, differ little from that in other research projects. The nature of the data to be collected, how they will be stored, who will have access to them, how they will be used and destroyed are routine topics for consideration in any ethical review. The difference here is that MJ is planning to do a series of interviews in New Zealand and then compare the outcomes with those conducted in the UK. It is not clear whether this work is to run concurrently with the UK project or as a later extension but the MJ her colleague will need to follow the procedures for research governance that pertain in New Zealand. Data collection and management in the UK is governed by the Data Protection Act 1998. Sharing data between researchers within the European Union is fairly safe in that all member states have to comply with regulations governing the processing and movement of data [10](Directive 95/46/EC). New Zealand has had legislation about privacy since 1993 and the Office of the Privacy Commissioner [11] regularly produces guidance on how data should be handled. In both countries REC members may wish to satisfy themselves about the

ways in which data will be shared via the internet and ensure that adequate arrangements are in place.

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