e- Ethics@Nottingham: Ethical Issues in Digitally Based Research

Briefing and Good Practice Guidance by Professor Tom Rodden on behalf of the University Research Ethics Committee

Digital technologies are an everyday part of our lives and with over 2 billion internet users it comes as no surprise that the digital is playing an increasing role in research that involves human subjects either as a subject of research or as tool of to support the undertaking and analysis of studies. This includes the recording of on-line activities, the use of the Internet for surveys, the logging of digital data, the study of on-line social environments and the digital capture and storage of media and human records. The facilities provided by digital technologies have started to allow new questions about human activities and endeavours to be posed but digital technologies also raise ethical and societal issues that need to be considered as researchers increasingly exploit digital technologies.

The area of e-ethics has emerged as a distinctive domain reflecting on the critical issues of human oriented research using digital technologies. It is important that researchers at Nottingham develop an understanding of the current debates and emerging principles in what is often a complex and rapidly changing domain. This document summarises some of the more critical issues and emerging questions that need to be considered when undertaken work in this area. A resource page summarising the key organisations, resource portals and critical documents is available at www.someaddress.com.

The ethical issues surrounding on-line research are not particularly different from any research involving users and research needs to be undertaken in relation to existing university and subject specialist guidelines. Much of the current debate in e-ethics centres on how these map over to on-line research and what risks arise in undertaking this research. This briefing considers three areas of e-ethics that impact researchers at Nottingham.

- **Research on the Internet** exploring how on-line activities supports a range of human endeavours.
- **Research through the Internet**, which exploits the connectivity and scale of the Internet to support studies
- **Digital research records** including the capture of material and keeping records in a manner that is consistent with the assurances given to users.
Research on the Internet

A vibrant community of researchers have sought to understand online activities and how these activities link with everyday activities. This has included a broad range of on-line environments (e.g. virtual worlds, social network sites, twitter, blogs, chatrooms, on-line conferencing) and how they may be used across a broad set of domains including healthcare, learning, business engagement and entertainment. Often fundamental human issues such as trust & identity lie at the core of these investigations making it critical that they are undertaken in a manner that is sensitive to the ethical issues involved.

The need for informed consent and the right of the individual to withdraw hold as just as much on-line as they do in physical environments. However, the nature of on-line environments is more ambiguous than their physical counterparts. On-line environments may be accessible to many millions but are often accessed by individuals from private settings (their home), they are available from many countries rather than located within a single physical jurisdiction, they allow much more fluid notions of identity and presence. The very ambiguity surrounding the nature of on-line environments and the reasonable expectation of members of these environments makes it critical that the issues of consent and withdrawal are treated appropriately. When considering research on the Internet researchers and ethics panels should consider a number of critical questions. ¹

1. Where does the inter/action, communication, etc. under study take place?
2. What ethical expectations are established by the nature of the venue?
3. Who are the subjects/ authors / creators of the material and/or inter/actions under study?
4. How far do extant legal requirements and ethical guidelines in the researchers’ professional bodies “cover” the research?
5. What are the reasonable ethical expectations/assumptions of the authors/subjects being studied?
6. What ethically significant risks does the research entail for the subject(s)?
7. How far do extant legal requirements and ethical guidelines in the countries implicated in the research apply?

Research through the Internet

Internet based facilities now offer convenient access to subjects/participants and approaches that were previously impractical can now realistically be achieved using on-line tools (e.g. on-line survey tools), communication facilities (e.g. Skype) and social network sites (e.g Facebook, Twitter). These facilities also embed key choices in method and approach within their design and in the terms and conditions associated with their use that raise challenges for researchers and ethics groups.

Gathering participant data through on-line tools is subject to the same ethical principles of informed consent, privacy and rights of withdrawal as other forms of research. A key issue is ensuring that the assurances given to participants are aligned with the terms and conditions associated with on-line tools. When exploiting internet tools (e.g. survey facilities, applications on social networking sites) to gather information from participants, researchers and ethics panels should consider a number of critical questions:²

1. Is the type of data considered sensitive (e.g., health, medical, sexual, political)?
2. Does the tool’s privacy policy contradict local policy? If so, how will the contradictions be resolved?
3. What measures are in place to safeguard data at the site of data collection?
4. Must participants/subjects furnish personally identifiable data to the tool provider in order to complete the instrument for research? If so, how will such data be used?

¹ These are derived from the Association of Internet Researchers Ethics Guide - http://aoir.org/documents/ethics-guide/ this guide provides a range of protocols and consent forms based on these guidelines.
² These are derived from Buchan, E et al “Online survey tools: ethical and methodological concerns of human research ethics committees” available from the digital library at http://internetresearchethics.org/
5. Does the company providing the tool assume responsibility if data are lost or exposed during a security breach? What mechanisms are in place from the company to alert researchers and participants in the event of data loss or intrusion?

6. Does the company sell its data to third parties, and if so, how are data protected? How will ongoing consent be assured, if new participants are added and contacted by the tool agent?

7. Does the company store the data on its own servers?
   - Where are the servers housed, e.g., are they under the purview of EU law and regulations?
   - How long will the data be stored on the servers, and does this contradict the time frame indicated by professional bodies or institutional policies?
   - What happens to the data after the researcher completes his/her work on the tool? How are the data destroyed?
   - How will cross-border data be handled. e.g. IP addresses are considered by one country to fall under privacy regulations?

Digital Research Records
The secure storage and management of digital research records associated with human participants represents one of the most significant issues in on-line research. The accessibility of digital records means that considerable benefits may arise from the effective use and sharing of this data but this needs to be undertaken in a manner that is consistent with best ethical practices including informed consent and the legal frameworks surrounding personal data. The capture, storage and sharing of human participant data may be subject to a number of significant pieces of legislation including:

- Data Protection Act 1998
- Freedom of Information Act 2000
- Human Rights Act 1998
- Statistics and Registration Services Act 2007
- Environmental Information Regulations 2004

Researchers should be explicit about the purposes for which research data will be used. As part of gaining informed consent researchers should take into account any future use of data, such as the sharing, preservation and long-term use of the research. Research should:

- Inform participants how research data will be stored, preserved and used in the long-term
- Inform participants how confidentiality will be maintained, e.g. by anonymising data
- Obtain explicit informed consent for any data sharing and include a means of withdrawal.

When anonymising digital data researchers should pay particular attention to:

- relational data, where relations between variables in related datasets can disclose identities
- geo-referenced data, where identifying spatial references such as point co-ordinates also have a geo-spatial value

A growing number of researchers are gathering information about users activities through digital traces and records. This is an area of considerable debate at present as to how users may be informed about the gathering of this information and provided with a means of withdrawal. Researchers should

- Provide a means of informing participants that this information is being collected and a means to opt out of the recording of this information

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3 UK Data Archive (2009) Research ethics and legislation relevant to data sharing. www.data-archive.ac.uk/create-manage/consent-ethics/legal
Offer participants a means of viewing recorded information in a manner that is human legible understandable by participants
Provide participants with a means of withdrawal including removing the elements of the recorded data that correspond to them

Best practice and some simple guidelines
In addition to considering these critical questions and legal implications a number of simple principles of best practice are worth following when engaging with on-line and digitally based research. 

In preparing documentation for any ethical review process researchers should be explicit about the nature of the on-line environment and their access to it. They should:

- State whether the online environment is considered public or private.
- State whether they have obtained permission from the list owner or site administrator to recruit subjects from, or post messages on the site.
- Obtain permission to use archived data from a list or site. (Permission may be verified by an e-mail from the list owner or administrator.)
- Describe how subjects should be identified in any reports, whether by use of their screen names or pseudonyms.

When undertaking the research researchers should inform the subjects that there is no completely secure interaction online and instigate protocols to ensure security and privacy of the data. They should:

- Include a statement on the limits of security on the informed consent document. A suitable example that relates to keeping collected data confidential and the risk/benefit of participation in the study would be.
  "As an online participant in this research, there is always the risk of intrusion by outside agents, i.e., hacking, and therefore the possibility of being identified."
- Keep collected data in an encrypted format on a secure server and ensure that the data and identifiers are kept apart. Ideally, on different servers.
- Provide a forum for participants to ask questions online before consenting to participate in a research project.
- Provide an on-line contact point for any enquires about the research and a means of raising concerns they may have about the research process.

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4 These are drawn from a range of sources including the Association of Internet Research Guidelines and material from the digital library at http://internetresearchethics.org/