

Ethics assessment in different fields

Internet Research Ethics

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Annex 2.d.2 Ethical Assessment of Research and Innovation: A Comparative Analysis of Practices and Institutions in the EU and selected other countries *Deliverable 1.1*

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1 INTRODUCTION

1.1 Internet research

The development of the Internet and other communications technologies have seen a parallel growth in the development and use of technologically-based research methodologies.¹ In particular, the Internet has emerged as a major data resource for research across disciplines, ranging from the social sciences to arts and humanities, medical and biomedical sciences and the natural sciences.²

Internet-based research is "research which utilizes the Internet to collect information through an online tool, such as an online survey; studies about how people use the Internet, e.g., through collecting data and/or examining activities in or on any online environments; and/or, uses of online datasets or databases". Internet research encompasses research as a research tool and as a research venue. As a tool, Internet research is facilitated by search engines, data aggregators, databases, catalogues and repositories. The concept of the Internet as a venue includes places or locales such as conversation applications (e.g., Internet messaging and chat rooms), forms of role-playing games and virtual worlds (Multi-User Dungeons or MUDs), MOOs (a MUD, object-oriented), MMORPGs (massively multiplayer online role-playing games), newsgroups, home pages, blogs, micro-blogging (e.g., Twitter), RSS (Rich Site Summary) feeds, crowd sourcing applications or online course software.

Internet-based research methods can include online surveys, web page content analysis, videoconferencing for online focus groups and/or interviews, analysis of e-conversations through social networking sites, e-mail, chat rooms, discussion boards and/or blogs. The Internet as a research tool offers clear advantages including the following: recruiting and accessing some difficult-to-reach groups, in particular, those whose activities are illegal or socially unacceptable; facilitating geographical spread and richness in data collection; providing safe virtual environments for researchers to carry out interviews or focus groups and allowing for a broader range of sample. Internet research also allows for savings in costs (e.g., costs of travel, venue and transcription of interviews). Three types of Internet-based research methods can be distinguished. Passive analysis involves studies of information patterns on websites or interactions on discussion groups without the involvement of researchers themselves, e.g., the study of helping mechanisms and content of online self-help groups for a variety of diseases. Active analysis involves researchers actively intervening in a

¹ Haigh, Carol, and Neil Jones, "Techno-Research and Cyber-Ethics: Challenges for Ethics Committees", *Research Ethics Review*, Vol.3, No. 3, 2007, pp. 80-83.

² Eynon, Rebecca, Jenny Fry and Ralph Schroeder, "The Ethics of Internet Research", in Nigel G Fielding, Raymond M. Lee and Grant Blank (eds.), *The SAGE Handbook of Online Research Methods*, SAGE Publications, London, 2008, pp. 23-42 [p. 26].

³ Buchanan, E.A., "Internet Research Ethics: Past, Present and Future", in Mia Consalvo and Charles Ess (eds.), *The Handbook of Internet Studies*, Blackwell Publishing Ltd., Oxford, 2011, pp. 83-108 [p. 90].

⁴ Stanford Encyclopaedia, Internet Research Ethics, 2012. http://plato.stanford.edu/entries/ethics-internet-research/

⁵ Ibid.

⁶ Convery, Ian, and Diane Cox, "A review of research ethics in internet-based research", *Practitioner Research in Higher Education*, Vol. 6, No.1, 2012, pp. 50-57 [p. 50].

⁷ Haigh and Jones, op. cit., 2007, p. 80.

⁸ Madge, Clare, "Developing a geographer's agenda for online research ethics", *Progress in Human Geography*, Vol. 31, No. 5, 2007, pp. 654-674 [p. 656].

⁹ Eysenbach, G. and James E. Till, "Ethical issues in qualitative research on internet communities", *BMJ*, Vol. 323, No. 10, 2001, pp. 1103-1105 [p. 1103].



particular context, but without identifying themselves as such. The third method involves researchers identifying themselves as such and gathering information through a variety of approaches including online semi-structured interviews, online focus groups, or Internet-based surveys or using the Internet to recruit participants for "traditional" research.

The Internet has opened up a wide range of novel approaches to examining human inter/actions in new contexts, and from a variety of disciplinary and interdisciplinary approaches. There has been debate regarding whether Internet research raises any novel ethical challenges or if it is similar to its offline counterpart in terms of critical issues of risk and safety to the human subject. As Internet research is undertaken from a wide range of disciplines already long engaged in human subjects research (sociology, psychology, anthropology, medicine, communications studies, etc.), the general ethical demands which pertain to such research also hold for research on the Internet. However, some fundamental concepts such as that of minimal risk and public behaviour change or become ambiguous when research is conducted online. For example, the authors of the Association of Internet Researchers' Ethics Working Committee report argue that issues of privacy, confidentiality, informed consent and determining the identity of participants are made more difficult in online research. This argument is summed up by Frankel and Siang who observe:

The ability of both researchers and their subjects to assume anonymous or pseudonymous identities online, the complexities of obtaining informed consent, the often exaggerated expectations, if not the illusion, of privacy in cyberspace, and the blurred distinction between public and private domains fuel questions about the interpretation and applicability of current policies governing the conduct of social and behavioural research involving human subjects. ¹⁵

1.2 Internet research ethics: A brief history

Throughout the 1990s, disparate disciplines began in piecemeal fashion to investigate the ethical complexities and implications around the use of the Internet for research. Many researchers were of the view that uncertainty existed regarding the applicability of research ethics guidelines such as the Belmont Report to Internet research. Some disciplines, notably from the arts and humanities, argue that Internet research is more about context and representation than about "human subjects", suggesting that there is no intent – and thus minimal or no harm – to engage in research about actual persons. The ethical implications of the use of the Internet for research attracted academic interest with one of the first journal issues dedicated to Internet research appearing in 1996 in a special issue of *The Information*

¹⁰ Ess, C., and the Association of Internet Researchers Ethics Working Committee, "Ethical decision-making and Internet research: Recommendations from the AoIR Ethics Working Committee", 2002. http://www.aoir.org/reports/ethics.pdf

¹¹ Ibid.

¹² Ess and AoIR, op. cit., 2002.

¹³ Frankel, Mark S., and Sanyin Siang (for the American Association for the Advancement of Science), "Ethical and Legal Aspects of Human Subjects Research on the Internet, 1999.

https://nationalethicscenter.org/resources/187/download/ethical_legal.pdf

¹⁴ Association of Internet Researchers (AoIR) Ethics Working Group.

¹⁵ Ibid.

¹⁶ Buchanan, E.A., and C. Ess, "Internet Research Ethics: The Field and Its Critical Issues", in Kenneth Einar Himma and Herman T. Tavani (eds.), *The Handbook of Information and Computer Ethics*, John Wiley & Sons, New Jersey, 2008, pp. 273-292 [p. 274].

¹⁸ Stanford Encyclopaedia, Internet Research Ethics, 2012. http://plato.stanford.edu/entries/ethics-internet-research/



Society. In 1999, the American Association for the Advancement of Science (AAAS) convened a workshop on "Ethical and Legal Aspects of human Subjects Research in Cyberspace", intended to "explore the relevant issues and lay the groundwork for further involvement in these matters by professional and online communities, research institutions and government agencies"19. To this day, the AAAS report remains a benchmark to which the Internet research ethics (IRE) literature refers. The increase in the use of Internet research in medical and biomedical contexts was consolidated in the founding of the Journal of Medical Internet Research in 1999. With the increase of scholarly attention and a huge increase in the number of Internet-based research protocols, professional societies began to draft statements or guidelines, or addenda to their extant professional standards. ²⁰ In 2002, the Association of Internet Researchers (AoIR) Ethics Working Group released a report on "Ethical Decision-Making and Internet Research". The American Psychological Association released a report of the Board of Scientific Affairs' Advisory Group on the Conduct of Research on the Internet.²¹ In 2003 and 2004, three major books on Internet research ethics²² were published, incorporating in-depth analysis of the ethical issues outlined by Frankel and Siang and AoIR and "building on the development of IRE as a discrete field, with its own evolving research base". 23 The field of IRE ethics gained further momentum in 2006 with the appearance of the first publication of the International Journal of Internet Science, followed in 2008 by the International Journal of Internet Research Ethics.

Academic disciplines, ranging from arts and humanities, to social sciences, to medical and health-related disciplines are all represented in the IRE literature.²⁴ In their study of US-based institutional review boards (IRBs), Buchanan and Ess found that the majority of the research reviewed by the IRBs came from the social sciences, followed by medicine and health, with a small percentage coming from the arts and humanities.²⁵ While many researchers focus on traditional ethical principles, concepts of Internet research ethics do depend on disciplinary perspectives as illustrated earlier in the view of Internet research as being more about context and representation rather than human subjects.²⁶

2 VALUES AND PRINCIPLES

Internet Research Ethics (IRE) is defined as "the analysis of ethical issues and application of research ethical principles as they pertain to research conducted on and in the Internet".²⁷ In the following section, we describe the philosophical foundations of IRE, focusing on those ethical values and principles most often discussed in the ethical literature.

As Buchanan observes, "In order to get to the current dialogue of Internet research ethics, it is important to contextualise the discussion in the larger framework of research ethics, which as

¹⁹ Frankel and Siang, op. cit., 1999.

²⁰ Stanford Encyclopaedia, Internet Research Ethics, 2012. http://plato.stanford.edu/entries/ethics-internet-research/

²¹ Kraut, R., J. Olson, M. Banaji, A. Bruckman, J. Cohen and Mick Couper, "Psychological research online: report of board of scientific affairs' advisory group on the conduct of research on the internet", *American Psychologist*, Vol. 59, No. 2, 2004, pp. 105-117.

²² Buchanan, 2004; Johns, Chen and Hall, 2004; Thorseth, 2003 (see section 8).

²³ Buchanan, op. cit., 2011, p. 91.

²⁴ Ibid

²⁵ Buchanan and Ess, op. cit., 2009, p. 46.

Stanford Encyclopaedia of Philosophy, "Internet Research Ethics", 2012. http://plato.stanford.edu/entries/ethics-internet-research/
27 Ibid.



a strict discipline, has a relatively brief history". The modern traditions of codified, formalised research ethics stem from the Nuremburg Code, released in 1947 in response to medical experimentation atrocities perpetrated by Nazi doctors during World War II. The Nuremburg Code influenced the development of the World Medical Association's Declaration of Helsinki in 1964 on Ethical Principles for Medical Research Involving Human Subjects. The aftermath of the decades-long Tuskegee clinical study led to the formalisation of ethics review in the United States.

The US issued formal regulations protecting human subjects in medical and biomedical research in the National Research Act in 1974; the creation and establishment of institutional review boards (IRBs) followed and the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research published *Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, known as the Belmont Report.²⁹ As a policy statement, the Belmont Report remains to this day the single most important document to use as an ethical base for subject research.³⁰ The Belmont report identifies three core principles for research involving human subjects, namely respect for persons, beneficence and justice.³¹

Similar statements, using analogous principles of respect for persons, beneficence and justice emerged out of Canada in the late 1970s and policies were embedded under the Tri-Council Policy Statement's Ethical Conduct for Research Involving Humans. Regulatory frameworks in Europe such as the European Union's various directives, in addition to national policies, form the basis for human subjects work and include the EU Data Privacy Protection Acts, the Research Council of Norway and its National Committee for Research Ethics in the Social Sciences and Humanities, the United Kingdom's NHS National Research Ethics Service and the Research Ethics Framework of the Economic and Social Research Council (ESRC) General Guidelines. Australia's National Health and Medical Research Council's Statement on Human Experimentation governs Australian research ethics programmes including, since 1986, social and behavioural research. India adopted its set of medical ethical guidelines in 1980 in its "Indian Council of Medical Research", revised and updated in 2000.32 The Forum for Ethical Review Committees in Asia and the Western Pacific (FERCAP) was established in January 2000.³³ Research ethics committees (RECs) in Africa have a varied existence. RECs in South Africa, for example, date to 1966 at the University of Witswatersrand, while other African countries are still in the process of developing programmes and training.³⁴

IRE in Western countries emerged initially from models of human subject research and human subject protections in the life sciences (i.e., medical ethics, bioethics, etc.) and social sciences (e.g., psychology).³⁵In addition, the work of the AoIR ethics committee sought insight and guidance from three sources including (1) professional ethics, including the Association for Computing Machinery Code of Ethics and Professional Conduct; (2) ethical codes in the social sciences and humanities, with humanities scholars arguing that human

³⁰ Buchanan, op. cit., 2011, p. 84.

²⁸ Buchanan, op. cit., 2011, p. 84.

²⁹ Ibid.

³¹ http://videocast.nih.gov/pdf/ohrp belmont report.pdf

³² Buchanan, op. cit., 2011, p. 84.

³³ Stanford Encyclopaedia of Philosophy, op. cit., 2012.

³⁴ Buchanan, op. cit., 2011, p. 84.

³⁵ Buchanan, E.A., and C. Ess, "Internet Research Ethics: The Field and Its Critical Issues", in Kenneth Einar Himma and Herman T. Tavani (eds.), *The Handbook of Information and Computer Ethics*, John Wiley & Sons, New Jersey, 2008, pp. 273-292 [p. 274].



beings online should be viewed as amateur artists or authors who are producing a work that generally requires only copyright protection and social scientists arguing that human beings online should be viewed as "subjects" to be protected according to the standard human subjects protections of anonymity, informed consent, etc.; and (3) information and computing ethics.³⁶

Contemporary ethical frameworks in IRE include deontology and utilitarianism. Utilitarianism is a species of consequentialism – referring to a family of moral theories that assert that the wrongness of actions is wholly determined by the consequences³⁷ – which holds that our sole duty is to maximise utility, where this is understood as the happiness or welfare of individuals affected by the action. Thus, research should proceed, if taking account of all the risks and benefits. This is likely to produce more utility than not going ahead.³⁸ Deontological theories, on the other hand, insist on an absolute protection of basic rights and protections, regardless of the benefits of the research.³⁹ Deontological ethics emphasises the importance of duties, for example, to respect the wishes of individuals (by obtaining consent before involving them in research) or avoid harming them (by not sacrificing their lives or interests for the benefit of others). These duties or rules place constraints on the ways in which we may treat people. 40 Buchanan and Ess suggest that these distinctions have proven useful in the development of IRE in two ways in particular. 41 First, these distinctions help researchers and those without formal training in ethics to make sense of their ethical experience and intuitions. Second, these distinctions contribute to highlighting important differences between national and cultural ethical traditions, thus stimulating the development of pluralistic approaches to IRE.

A number of political scientists and ethicists have observed that research ethics in the Anglo-American sphere (United States and the United Kingdom) follows the utilitarian tradition, while European researchers are rooted in deontological approaches.⁴² The concept of ethical pluralism is emerging as a core framework and philosophical approach from which to conceptualise Internet research ethics.⁴³ The ethical-decision making document released by the Association of Internet Researchers⁴⁴ emphasises ethical pluralism, which stresses the importance of the recognition of different traditions of ethical decision-making across nations and cultures.

Contemporary ethical approaches also include feminist and communitarian approaches that emphasise the ethical importance of personal relationships and care between researchers and those engaged as "subjects". Capurro and Pingel, for example, propose a guideline of best practice in online research ethics which includes online researchers' awareness of gender biases within different cultural contexts, the "creation of an atmosphere of social

³⁷ Baggini, Julian, and Peter S. Fosl, *The Ethics Toolkit: A Compendium of Ethical Concepts and Methods*, Blackwell Publishing, Massachusetts, 2007.

⁴² Buchanan and Ess, op. cit., 2008, p. 276.

³⁶ Ibid.

³⁸ European Commission, European Textbook on Ethics in Research, Brussels, 2010, http://ec.europa.eu/research/science-society/document_library/pdf_06/textbook-on-ethics-report_en.pdf ³⁹ Ibid.

⁴⁰ Buchanan and Ess, op. cit., 2008, p. 276.

⁴¹ Ibid.

⁴³ Buchanan, op. cit., 2011, p. 87.

⁴⁴ Ess et al., op. cit., 2002

⁴⁵ Ess, Charles, "Internet research ethics", in Adam Joinson, Katelyn McKenna, Tom Postmes and Ulf-Dietrich Reips (eds.), *Oxford Handbook of Internet Psychology*, Oxford University Press, Oxford, 2007, pp. 487-502.



responsibility of online researchers as well as of their patrons with regard to utility and usability of their research, particularly with regard to the weakest members of society, including whole societies as weakest members or non-members of the online world"; and respect for bodily identity as affected by research on digital identity.⁴⁶

These ethical approaches come closer to utilising forms of the 'Golden Rule", i.e., pushing researchers to consider how they would feel if they were treated in the same way they propose to treat their subjects. Responses to specific ethical issues in research can be viewed quite differently, depending on which of these frameworks is taken as the most important. As Buchanan and Ess note, even though arguments *against* applying human subjects protections models to online contexts won out in the 1990s, these models predominate in contemporary discussions of IRE and the three extant ethical guidelines specific to ethical issues in online research, i.e., those of the AoIR, the American Psychological Association and the National Committee for Research Ethics in the Social Sciences and the Humanities (Norway) (see section 6). Moreover, as these models are underpinned by both national and international declarations of human rights, these models stress protecting the integrity and dignity of human persons first of all by emphasising rights to informed consent, privacy, confidentiality and anonymity. The right to privacy is reinforced in philosophical discussions of information ethics in particular, e.g., privacy is viewed as instrumental to the development of the human being as a free and rational being and as a participant in a democratic society.

3 ETHICAL ISSUES

The IRE literature of the last decade and a half has focused on several topics that arise most frequently in online research.⁵⁰ These topics are presented as discrete issues but as Buchanan and Ess observe "the specificity and characteristics of Internet technologies and especially of interdisciplinary research online mean that IRE issues are usually intertwined and consequently more complex".⁵¹ The issue of privacy is one such example. In discussions on privacy in Internet research ethics, the focus seems to be on the distinction between public and private spaces online with implications for whether informed consent is necessary. At the same time, privacy and concern about the protection of personal data is inherent in discussion about the steps required to ensure anonymity and confidentiality although the emphasis on privacy appears somewhat implicit.

3.1 Anonymity and confidentiality

Confidentiality is generally a strict requirement put on those handling others' personal data with strict legal requirements in place in many jurisdictions.⁵² Researchers are not permitted to use or share potentially identifiable personal data and the use of personal data for certain purposes has to be authorised by the participant.⁵³ While the requirement of confidentiality is

⁴⁶ Capurro, Rafael, and Christoph Pingel, "Ethical issues of online communication research", *Ethics and Information Technology*, Vol. 4, Issue 3, 2002, pp.189-194 [p. 194].

⁴⁷ Ess, op. cit., 2007.

⁴⁸ Buchanan and Ess. op. cit., 2008, p. 277.

⁴⁹ Ibid, p. 277.

⁵⁰ Ess, op. cit., 2007.

⁵¹ Buchanan, and Ess, op. cit., 2008, p. 277.

⁵² Felzmann, H., "Ethical Issues in Internet Research: International Good Practice and Irish Research Ethics Documents", in C. Fowley, C. English and S. Thouseny (eds.), *Internet Research, Theory and Practice: Perspectives from Ireland*, Research-publishing net, Dublin, 2013, pp. 11-32 [p.20].



closely related to that of anonymity, they are not identical notions.⁵⁴ Confidentiality is concerned with the issue of assessing and sharing personal information only on the authorisation of the person concerned, while anonymity is concerned with ensuring that the person whose data is being used is not identifiable to others from the research data.⁵⁵ Confidentiality is also closely linked to the requirement for security of data storage.⁵⁶

As for onsite research, online research should respect the anonymity of respondents and ensure the confidentiality of information provided by research participants. However, online research introduces additional items of concern with regard to confidentiality and anonymity. These issues include the secure storage of data, data transmission and the protection of subjects' identities. Buchanan et al. argue that the language of traditional consent documents and protocols do not fit online research: "Risks and harms should be presented in appropriate language, such as 'There are potential risks of data loss, data manipulation, or unauthorized access by outside parties in the form of research. All appropriate precautions will be taken to ensure the security and integrity of the data'."⁵⁷ Hence boilerplate phrases such as "No others will have access to the data" which inherit the standard means of storing data on pieces of paper physically located in a locked cabinet in a locked researcher's office - give very little detail regarding the methods used to secure data.⁵⁸ Statements informing subjects about the location of the stored data, the duration of storage and accessibility of the data are significantly different in Internet research.⁵⁹ Increasingly, applications made to IRBs contain language such as: "Data files that contain summaries of chart reviews and surveys will only have study numbers but no data to identify the subjects. The key [linking] subject names and study identifiers will be kept in a locked file."60 Aycock et al. observe that, while such statements are more explicit about the protection of data given the risk of disclosure of subject identities, lack of certainty still persists regarding issues such as the meaning of a "locked file", the quality of the password required to open the file, and so on. 61 The transmission of data also has to be addressed – in an internet study, there is a small but real possibility that data will be intercepted by a third party.⁶² Options for securely transmitting data include the use of encryption and secure socket layer (SSL) protocols, the use of identifying labels that are meaningless to anyone but the researcher and the separate transmission of identifying information and experimental data. 63 Data must also be protected while it is being processed – as it has to exist in decrypted form in order to be of use to the researcher – and securely destroyed when it is no longer needed.⁶⁴

⁵⁴ Felzmann, op. cit., 2013.

⁵⁵ Ibid

⁵⁶ Felzmann, op. cit., 2013.

⁵⁷ Buchanan, Elizabeth, Aycock, John, Dexter, Scott, Dittrich, David and Erin Hvizdak, "Computer Science Security Research and Human Subjects: Emerging Considerations for Research Ethics Boards", *Journal of Empirical Research on Human Research Ethics: An International Journal*, Vol. 6, No.2, 2011, pp. 71-83 [p. 77]. ⁵⁸ Aycock, John, Elizabeth Buchanan, Scott Dexter and David Dittrich, "Human subjects, agents or bots: current issues in ethics and computer security research", *Financial Cryptography and Data Security, Lecture Notes in Computer Science*, Vol. 7126, 2012, pp. 138-145 [p. 142].

⁵⁹ Buchanan et al., op. cit., 2011, p. 77.

⁶⁰ Ibid.

⁶¹ Aycock et al., op. cit., 2012, p. 142.

⁶² Nosek, Brian A., Mahzarin R. Banaji and Anthony G. Greenwald, "E-Research: Ethics, Security, Design, and Control in Psychological Research on the Internet", *Journal of Social Issues*, Vol. 58, No. 1, 2002, pp. 161-176 [p. 165].

⁶³ Ibid, p. 165.

⁶⁴ Nosek et al, op. cit., 2002.



Subject anonymity is another issue relating to confidentiality.⁶⁵ Offline identity can, to some degree, be subsumed in the volume of data that is generated by questionnaires or even interviews or focus groups.⁶⁶ However, online research must contend with the strength of "cyber-identity".⁶⁷ Some users choose to use their real names, while other choose pseudonyms, screen names, avatars, masks, to name just a few.⁶⁸ Although the real life identity is in most cases hidden to researchers, it does not mean that the use of pseudonyms is unproblematic.⁶⁹ For instance, as Kraut et al. observe, one cannot take for granted that the pseudonyms used by individuals to both mask and express their identities online render their conversations anonymous, as subjects may select pseudonyms that contain part or all of their real names or disclose information that publicly links their pseudonyms to their real identities.⁷⁰

Indeed, the protection of participants' online identities may require greater caution than might usually be the case for offline research.⁷¹ Even seemingly anonymous snippets of text in a blog or online forum may be traced back to individual posters through the use of search engines.⁷² This happened on a large scale when America Online (AOL) released a dataset of some 20 million search terms from 650,000 anonymised users for the purposes of research: journalists and others were able to link some individuals to strings of search terms.⁷³ Thus, the researcher must carefully consider how and to what degree she should preserve anonymity. An additional consideration is that pseudonyms may function similarly to real names and so should be treated in the same way as real names. 74 Moreover, people care about the reputation of their pseudonyms⁷⁵ and may consider reference in research to their original pseudonyms as intrusive as real-life identification.⁷⁶ Conversely, personal investment in an online persona may have the opposite effect; changing screen names in a report may detract from the "reality" or "reputation" of the participant.⁷⁷ The AoIR report suggests that obligations to protect anonymity, privacy, confidentiality, etc. vary depending on whether participants are best understood as "subjects" (as is characteristic of the social sciences) or as authors (as is characteristic of the humanities). 78 If participants are best understood as subjects (e.g. they participate in chatrooms, MUDs or MOOs), then greater obligations to confidentiality, etc. follow. On the other hand, those subjects understood as authors intending for their work to be public (e.g., in e-mail postings to listserves, public webpages, blogs, etc.) necessitate fewer obligations. Indeed, as a number of commentators have observed, authors of blogs or webpages may intend to act as public agents online and may not want subject confidentiality. ⁷⁹ Thus, to *not* use direct quotations and specific names in research would be

⁶⁵ Madge, op. cit., 2007, p. p. 659.

⁶⁶ Haigh and Jones, op. cit., 2007, p. 81.

⁶⁷ Ibid

⁶⁸ Buchanan and Ess, op. cit., 2008, p. 279.

⁶⁹ Felzmann, H., "Ethical Issues in Internet Research: International Good Practice and Irish Research Ethics Documents", in C. Fowley, C. English and S. Thouseny (eds.), *Internet Research, Theory and Practice: Perspectives from Ireland*, ©Research-publishing net, Dublin, 2013, pp. 11-32 [p.20].

⁷⁰ Kraut et al., op. cit., 2004, p. 109.

⁷¹ Battles, Heather, T., "Exploring ethical and methodological issues in Internet- based research with adolescents", *International Journal of Qualitative Methods*, Vol. 9, No. 1, 2010, pp. 27-39.

⁷² Kraut et al., op. cit., 2004, p. 109.

⁷³ Halavais, Alexander, "Open up online research", *Nature*, Vol. 480, 2011, pp. 174-175 [p. 174].

⁷⁴ Bruckman, Amy, "Ethical Guidelines for Research Online", 2002a. http://www.cc.gatech.edu/~asb/ethics/
⁷⁵ Ibid

⁷⁶ Felzmann, op. cit., 2013, p. 21.

⁷⁷ Buchanan and Ess, op. cit., 2008, p.279.

⁷⁸ Ess and AoIR report, op. cit., 2002.

⁷⁹ Madge, op. cit., 2007; Buchanan and Ess, op. cit., 2008.



considered infringement of copyright.⁸⁰ "In order to respect individuals who share their ideas on public lists, the names of those participants should be properly attributed."⁸¹ Indeed, in their study of an online lesbian activist site, Bassett and O'Riordan argue that the decision to disguise online identity in order to protect participants may function to reinforce broader social marginalisation of the lesbian community.⁸²

The distinction between public versus private data is blurred in many types of internet communications with implications for the treatment of confidentiality and anonymity. ⁸³ Internet researchers cannot fall back on a simple classification of data as public or private but have to carefully assess the particular characteristics of their research area and the specific attitudes that participants are likely to have to the use of their data. ⁸⁴

3.2 PRIVACY

One central issue in Internet research ethics is the distinction between public and private spaces online, with attendant implications for whether or not informed consent is required.⁸⁵ In traditional research ethics, individual informed consent is not necessary for the use of material that is in the public domain, while research that is carried out outside the public domain is considered private and requires permission from the originators of the data for any use of that data.⁸⁶ However, it can be difficult to clearly differentiate between what should count as private and public information with regard to information gathered online.⁸⁷ Data from message boards and chat rooms is publically accessible for years after it has been posted and may be viewed in the same way as a newspaper archive.⁸⁸ However, as Eysenbach and Till argue, there may be important psychological differences online and people participating in an online discussion group cannot always be assumed to be "seeking public visibility"⁸⁹. Thus, the dichotomy of private and public sometimes may not be appropriate and online communities may lie in between.⁹⁰

There is evidence that participants in public chat rooms may still consider such venues to be private spaces and may react as if someone has violated their privacy. King illustrates this with a quote from a member of an Internet e-mail discussion group, who on discovering that their notes were the subject of research made the following remark: "When I joined this, I thought it would be a support group, not a fishbowl for a bunch of guinea pigs. I certainly don't feel at this point that it is a safe environment, as a support group is supposed to be, and I

⁸⁰ Madge op. cit., 2007, p. 660.

⁸¹ Madge, 2007, op. cit., p. 660.

⁸² Bassett, Elizabeth H., and Kate O'Riordan, "Ethics of Internet research: Contesting the human subjects research model", *Ethics and Information Technology*, Vol. 4, No. 3, 2002, pp. 233-247.

⁸³ Felzmann, op. cit., 2013, p. 20.

⁸⁴ Ibid.

⁸⁵ Convery, Ian, and Diane Cox, "A review of research ethics in internet-based research", *Practitioner Research in Higher Education*, Vol. 6, No.1, 2012, pp. 50-57 [p. 51].

⁸⁶ Felzmann, op. cit., 2013, p. 16.

⁸⁷ National Committee for Research Ethics in the Social Sciences and the Humanities (NESH-Norway), "Research ethics guidelines for internet", 2003. https://www.etikkom.no/In-English/Publications/Internet-research-/

⁸⁸ Eysenbach, Gunther, and James E Till, "Ethical issues in qualitative research on internet communities", *British Medical Journal*, Vol. 323, 2001, pp. 1103–1105 [p.1104].

⁸⁹ Ibid, p.1104.

⁹⁰ Eysenbach and Till, op. cit., 2001, p. 1104.



will not open myself up to be dissected by students or scientists." Similarly, in their study of how individuals in online chatrooms reacted to a variety of consent conditions, Hudson and Bruckman found that participants in public chatrooms acted as if their privacy had been violated when they were made aware of the fact that they were being studied.⁹²

Questions of privacy – and related questions about the necessity of consent – often deal explicitly with the concept of "reasonable expectations". Both the AoIR and the American Psychological Association argue for the importance of taking into account the assumptions of those being studied. The American Psychological Association states that an expectation of privacy depends on implementation details – along with legal regulation and social norms – such as the number of people who subscribe to particular online settings, whether membership is restricted or open, whether the forum has posted explicit recording policies and so on. Similarly, Eysenbach and Til identify measures that can be used to estimate the perceived level of privacy: (i) the requirement for some form of registration in order to gain access to a discussion group; (ii) the number of (real or assumed) users of an online community and; (iii) the individual group's norms and codes and target audience, often specified in the "frequently asked questions" of an online community. So

3.3 Informed consent

Informed consent is one of the cornerstones of research ethics and stipulates that research participants must be fully informed about the purpose, methods and intended possible uses of the research, what their participation in the research involves and what risks, if any, are involved. It is potentially easier to ensure that the participant is fully informed in face-to-face contexts than it is in the online environment. As the authors of the NESH report argue, the challenge in obtaining informed consent in an online context stems from the lack of interactivity and specifically, visual cues that a researcher can read from to ensure that participants have an adequate understanding of the information communicated to them. Conversely, Walther contends that researchers in an offline context are faced with the same challenge and indeed, that the "eyeballing method" is not any more efficient.

In most regulatory frameworks, the waiving of informed consent is a possibility, in addition to the possibility for modification of the standard processes of obtaining informed consent, if approved by a research ethics board.⁹⁹ Different forms of Internet research require different approaches to the consent process.¹⁰⁰ Bruckman argues that online information may be used by the researcher without consent if it meets the following conditions: (1) it is officially,

⁹¹ King, Storm A., "Researching internet communities: proposed ethical guidelines for the reporting of results", *The Information Society: An International Journal*, Vol. 12, 1996, pp. 119-127 [p. 122].

Hudson, James M., and Amy Bruckman, "Using empirical data to reason about internet research ethics", in H. Gellersen et al. (eds.), ECSCW 2005: Proceedings of the Ninth European Conference on Computer-Supported Cooperative Work, Paris, 18-22 September 2005,, pp. 287-306 [p. 298].
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⁹⁴ Kraut et al., op. cit., 2004, p. 110.

⁹⁵ Eysenbach and Till, op. cit., 2001, p. 1104.

⁹⁶ Eynon, Fry and Schroeder, op. cit., 2008, p. 29.

⁹⁷ National Committee for Research Ethics in the Social Sciences and the Humanities (NESH-Norway), op. cit., 2003.

⁹⁸ Walther, Joseph, B., "Research ethics in Internet-enabled research: Human subject issues and methodological myopia", *Ethics and Information Technology*, Vol. 4, No. 3, 2002, pp. 205-216 [p. 212].

⁹⁹Stanford Encyclopaedia of Philosophy, "Internet Research Ethics", 22 June 2012.

 $[\]label{lem:http://plato.stanford.edu/entries/ethics-internet-research/$^{100}\ Ibid.$



publicly archived, (2) no password is required for archive access, (3) no site policy prohibits it and (4) the topic is not highly sensitive. If informed consent is necessary, there are various ways of obtaining it. Consent may be obtained electronically if subjects are aged 18 or over, the risks to subjects are low and the online consent form takes people through each subelement step by step. 101 Research involving minors requires parental consent on paper (sent to the researcher via paper mail or fax) or by telephone if the research is low risk. 102 If the research is not low risk, parental consent should be obtained in a face-to-face interview. 103 Given that the researcher may not be able to determine whether a subject has understood the informed consent statement, online research may necessitate additional pretesting of these statements than research conducted in other venues. ¹⁰⁴ In order to increase the likelihood that subjects are granting truly informed consent, researchers can ask for feedback from subjects regarding their level of understanding, for example, by requiring a "click to accept" for each sub-element of an online consent form or administering short guizzes to establish that a subject understood. 105 Kraut et al. argue that these procedures for research involving competent adults may not be appropriate for other vulnerable groups such as children and the mentally handicapped. 106 It is in such cases that the problem of verifying identity is particularly salient. They go on to recommend procedures that researchers can put in place in order to more reliably distinguish children from adults, by, for example, having subjects enter information that is generally only available to adults (e.g., credit card numbers).

The evolving nature of online research is underlined by the fact that these approaches to consent are being promoted as good practice, rather than hard standards, with no clear indications as to how characteristics such as age – easily hidden online – can be satisfactorily established by researchers. ¹⁰⁷

The role of gatekeepers of online fora for consent is another concern. Gatekeepers play an important role in determining researchers' access to particular populations. For online research, Bruckman suggests that the permission of the group's gatekeeper is only required in cases where a vulnerable or under-age population is involved or if a gatekeeping element is explicitly required by a posted site policy. 110

The ability to withdraw from research at any time is a central element of informed consent. However, early withdrawal from a study is a threat to adequate debriefing. This is particularly problematic for Internet research as subjects can more easily leave online settings. In order to counteract early withdrawal, Kraut et al. recommend that researchers

¹⁰³ Bruckman, op. cit., 2002a.

¹⁰¹ Bruckman, op. cit., 2002a.

¹⁰² Ibid.

¹⁰⁴ Kraut et al., op. cit., 2004, p. 113.

¹⁰⁵ Ibid., p. 113.

¹⁰⁶ Kraut et al., op. cit., 2004, p. 113.

¹⁰⁷ Haigh, Carol, and Neil Jones, "Techno-Research and Cyber-Ethics: Challenges for Ethics Committees", *Research Ethics Review*, Vol. 3, No. 3, 2007, pp. 80-83 [p. 81].

¹⁰⁸ Felzmann, op. cit., 2013, p. 19.

¹⁰⁹ Ibid., p. 19.

¹¹⁰ Bruckman, op. cit., 2002a.

Nosek, Brian A., Mahzarin, R. Banaji and Anthony G. Greenwald, "E-Research: Ethics, Security, Design, and Control in Psychological Research on the Internet", *Journal of Social Issues*, Vol. 58, No. 1, 2002, pp. 161-176 [p. 162].

¹¹² Kraut et al., op. cit., 2004, p. 115.



arrange their study so that subjects are sent to a debriefing site automatically at the end of a session and debriefing material can be customised to their behaviour. 113

3.4 ETHICAL ISSUES IN SOCIAL MEDIA AND CLOUD COMPUTING

Facebook is a massive domain in which millions of interactions take place each day. Given that such a large number of interactions are being made and recorded digitally, it is unsurprising that researchers from many fields in the humanities and the physical and social sciences have exploited this rich source of data. Wilson et al. have identified 412 articles in the domain of Facebook research in the social sciences alone. However, there are various ethical issues that need to be considered when using social network site (SNS) data. In particular, these sites raise questions about privacy as many of their users seems to assume a level of privacy that is not available to them within the network. This leads to the ethical conundrum as to whether or not users' expectations of privacy should drive researchers' efforts to protect privacy, while more legalistic approaches would argue that researchers are bound only by relevant laws and the privacy statements of the websites themselves.

Zimmer outlines the problems using the fallout from a study carried out by a group of researchers - in which they publicly released profile data from the Facebook accounts of an entire cohort of college students from a US university - as a case study with which to articulate "a set of concerns that must be addressed before embarking on future research in social networking sites, including the nature of consent, properly identifying and respecting expectations of privacy on social network sites, strategies for data anonymization prior to public release, and the relative expertise of institutional review boards when confronted with research projects based on data gleaned from social media." 119

Cloud computing is a relatively recent trend in Information Technology that moves computing and data away from desktop and portable PCs into large data centres, with applications delivered as services over the Internet as well as to the cloud infrastructure. Examples of cloud applications include web-based email and calendaring services provided by Google or Yahoo, online productivity platforms like Google Docs or Microsoft Office 365, online file storage and sharing platforms such as Dropbox or Box.net and large-scale application development and data processing platforms such as Google Apps, Facebook Developers Platform and Amazon Web Services. 121 Along with businesses and consumers, researchers have started to use cloud computing platforms and services to assist in various

¹¹³ Ibid n 115

¹¹⁴ Henderson, Tristan, Luke Hutton and Sam McNeilly, "Ethics and online social network research-developing best practices", *Proceedings of BCS HCI 2012 Workshops HCI Research in Sensitive Contexts: Ethical Considerations*, 2012, BSL.

¹¹⁵ Wilson, Robert E., Samuel D. Gosling and Lindsay T. Graham, "A Review of Facebook Research in the Social Sciences", *Perspectives on Psychological Science*, Vol. 7, 2012, pp. 203-220.

¹¹⁶ Henderson et al., op. cit., 2012, p. 1.

¹¹⁷ Buchanan and Ess, op. cit., 2008, p. 282

¹¹⁸ Ibid, p. 283.

¹¹⁹ Zimmer, Michael, "'But the data is already public': on the ethics of research in Facebook", *Ethics and Information Technology*, Vol. 12, Issue 4, December 2010, pp. 313-325 [p. 313]. http://link.springer.com/article/10.1007%2Fs10676-010-9227-5

¹²⁰ Timmermans, Job, Bernd Carsten Stahl, Veikko Ikonen and Engin Bozdag, "The Ethics of Cloud Computing: A Conceptual Review", 2010 IEEE Second International Conference on Cloud Computing Technology and Science. http://doi.ieeecomputersociety.org/10.1109/CloudCom.2010.59

¹²¹ Stanford Encyclopaedia, Internet Research Ethics, 2012. http://plato.stanford.edu/entries/ethics-internet-research/



tasks, such as subject recruitment, data collection and storage, large-scale data processing, as well as communication and collaboration. 122 While recent developments in cloud computing platforms have led to unique opportunities for researchers, they have also introduced ethical challenges. 123 Ensuring data privacy and security with cloud-based services is a major concern: "for researchers sharing datasets online for collaborative processing and analysis, steps must be taken to ensure that only authorised personnel have access to the online data, but also that suitable encryption is used for data transfer and storage, and that the cloud service providers maintains sufficient security to prevent breaches". 124 In addition "once research data is uploaded to a third-party cloud provider, attention must be paid to terms of service for the contracted provider to determine what level of access to the data, if any, might be allowed to advertisers, law enforcement, or other external agents."125 A more unique application of cloud computing for research involves the crowdsourcing of data analysis and processing functions, i.e., leveraging the thousands of users of various online products and services to complete research related tasks remotely. 126 The use of cloud - based platforms for this purpose can raise critical ethical issues including ensuring that sensitive research data is not accessible by outsourced labour as well as ethical concerns over trust and validity of the research process itself. 127

3.5 Institutional review boards: practices and issues

Over the past decade and a half, research ethics boards across the United States have been focusing on Internet research, evaluating studies involving online surveys, studies of how people use the Internet, online ethnography, online interviewing and uses of online datasets, databases, databanks and repositories. 128 There have been few studies investigating review boards' experiences with Internet research protocols, however. Buchanan and Ess's study of 700 US-based institutional review boards sheds light on these boards' understanding of the multiple issues involving human subjects that take place online. 129 The authors found that, of the 334 respondents, nearly half found Internet research an area of concern or importance. However, rather strikingly, the data suggest that ethics review boards may not be fully informed when reviewing online research. Sixty-two per cent of respondents did not have guidelines or checklists in place for reviewing Internet-based research protocols, while few boards were aware of extant guidelines such as the AoIR Ethical Decision-Making document. Furthermore, IP addresses, clouds and worms are not part of the standard vocabulary of human subjects' research protections. 130 Buchanan and Ess report that many boards were "unsure of who to ask", responding that "we don't know what questions to ask of the researcher" and "we rely on the IT department to advise us on such IT related issues". 131 In order for institutional review boards to be able to "provide meaningful, relevant oversight", they "must be in a position to understand technological issues and provide appropriate guidance". 132 To that end, commentators have proposed that IRBs retain an expert member

¹²² Stanford Encyclopaedia, op. cit., 2012.

¹²³ Ibid.

¹²⁴ Stanford Encyclopaedia, op. cit., 2012.

¹²⁵ Ibid.

¹²⁶ Stanford Encyclopaedia, op. cit., 2012.

¹²⁷ Ibid

¹²⁸ Buchanan et al., 2011, op. cit., p. 72.

Buchanan, E.A., and Charles M. Ess, "Internet Research Ethics and the Institutional Review Board: Current Practices and Issues", *SIGCAS Computers and Society*, Vol. 39, No. 3, 2009, pp. 43-49.

¹³⁰ Buchanan et al., op. cit., 2011, p. 72

¹³¹ Buchanan and Ess, op. cit., 2009, p. 46.

¹³² Buchanan et al., op. cit., 2011, p. 77



from an IT unit.¹³³ Institutional review boards and research ethics boards may also face jurisdictional issues.¹³⁴ For example, in Europe, Internet Protocol (IP) addresses are viewed as personal data, while this is not the case in the United States – this will have implications for the ways in which privacy and confidentiality are viewed by ethics review bodies.

4 ORGANISATIONS

The following section describes organisations that focus on or engage in ethical assessment in the area of Internet research. Of the seven organisations mentioned here, six of them have developed guidelines or some other kind of resource for those engaged in Internet research. These documents will be described in this section (rather than in the key publications section) for two reasons: (1) these documents are an integral element of these organisations' assessment agendas and aims and (2) while the organisations themselves appear to be important assessors in the area, it is not clear that (some of) the publications enjoy widespread recognition in the field.

The Association of Internet Researchers has created an Ethics Wiki¹³⁵, the purpose of which is (1) to provide a compendium of resources for ethical decision-making in Internet-related research; (2) to centralise guidelines and updates over time and (3) to build a robust and open source knowledge database. The AOIR states its commitment to ensuring that "research on and about the Internet is conducted in an ethical and professional manner". The different pages on the wiki point to the target audiences of this wiki. The "regional resources" page offers an overview of legislative and regulatory frameworks in various countries in addition to other resources to help scholars and ethics boards navigate their own region's specific requirements. The Quick Guides page includes a graphic which is "intended to provide a reference guide for researchers and research reviewers to recognize where a particular research project might fit in the internet research continuum, in what specific type of venue a project exists, what types of information/data may be derived from these contexts, and what common ethical questions have been asked within these contexts." Finally, the "case studies" page provides a template for contributions – most likely, from individual researchers – to case studies regarding a general research issue scenario and attendant ethical issues.

The Center for Information Policy Research (CIPR) at the University of Wisconsin-Milwaukee is a multidisciplinary research centre for the study of the intersections between the policy, ethical, political, social and legal aspects of the global information society. The website used to hosted an Internet Research Ethics site (the site is no longer available). The Director of the centre is Michael Zimmer, who writes and blogs on the ethics of research on social networking sites.

At the end of 2013, the British Psychological Society (BPS) issued "Ethics Guidelines for Internet-mediated Research". The document outlines some of the key issues which researchers and research ethics committees (RECs) are "advised to keep in mind when considering implementing or evaluating an IMR (internet-mediated research) study". The

¹³³ Buchanan, Elizabeth A., and Erin E. Hvizdak, "Online survey tools: ethical and methodological concerns of human research ethics committees", *Journal of Empirical Research on Human Research Ethics*, Vol. 4, No. 2, 2009, pp. 37-48; Halavais, op. cit., 2011, p. 175

¹³⁴ Buchanan et al., op. cit., p. 74

¹³⁵ See http://ethics.aoir.org/index.php?title=Main Page

¹³⁶ http://ethics.aoir.org/index.php?title=Quickguides-url

¹³⁷ http://www4.uwm.edu/cipr/about/

¹³⁸ http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf).



document also functions to aid the process of ethical decision-making in the context of specifying and implementing appropriate IMR research designs.

Lancaster University has developed a web resource on research ethics in the social sciences – which includes a web-based research section. The aim of the website is to provide a range of resources designed to help new social science researchers enhance their knowledge and understanding of the processes and practices involved in undertaking ethically sound research, as well as facilitating the provision of a set of resources for those involved in the teaching and training of ethics in social science research. While the website is largely designed for researchers working within the United Kingdom, many of the resources and general principles are also relevant to social science researchers more generally. The web-based research section addresses the ethical issues raised by using the web for data collection and addresses privacy concerns when using the Web for data storage and dissemination. This section aims to facilitate the assessment of research proposals and practices.

The British Library released a report on the use of web 2.0 in social science research.¹⁴¹ The report is the result of a three-month research project carried out as part of a joint initiative between the UK's Economic and Social Research Council (ESRC) and the British Library to enable ESRC-funded research students to work with the library on short Fellowships. The aims of the research were two-fold; one, to publicise the benefits and issues surrounding the use of new technologies in social science research and two, to report on current practice and thinking in the use of Web 2.0 technologies as social science research tools.

Brunel University London has issued guidelines for research on the Internet. ¹⁴² The guidelines are meant to "enable research to remain flexible, be responsive to diverse contexts, and be adaptable to continually changing contexts" (p.1). The report states that the different methodologies used give rise to ethical issues "over and above the University's standard research ethics guidelines" (p. 1). Brunel University endorses a number of AOIR principles to be fundamental to an ethical approach to Internet research and adopts the recommendations from the Association of Internet Researchers Ethics Committee (Version 2.0, 2012), transposed as Appendix A of the Guidelines. The recommendations relate to ethical questions in research practice.

The Research Ethics Guidebook is an online guide for social science researchers – funded by the ESRC - to ethics considerations throughout the research process, with a particular focus on the range of ethics regulatory procedures and requirements that can apply to social science research. A section on online research very briefly sets out the most fundamental ethical dilemmas encountered in online research and directs researchers, research participants and reviewers of research ethics to additional sources of information.

¹³⁹ http://www.lancaster.ac.uk/researchethics/index.html

¹⁴⁰ See http://www.lancaster.ac.uk/researchethics/7-1-webres.html

¹⁴¹ See http://www.bl.uk/reshelp/bldept/socsci/socint/web2/report.html

¹⁴² See http://www.brunel.ac.uk/__data/assets/pdf_file/0004/313798/Internet_guidelines.pdf

¹⁴³http://www.esrc.ac.uk/my-esrc/grants/RES-035-25-0065/outputs/read/8feee990-17f8-4ddd-94f3-90d357e4b4a1

¹⁴⁴ See http://www.ethicsguidebook.ac.uk/Online-research-102



5 INSTITUTIONALISATION

Insights into the degree to which ethics assessment is institutionalised in the field of Internet research were provided by an expert in Internet research ethics whom we interviewed as part of this research. The expert has been involved in the area for over a decade and a half and authored a report aimed at helping researchers to make ethics-related decisions concerning Internet research.

With regard to the institutionalisation of Internet research ethics, the expert thinks it is still at an early stage. However, he felt that Internet-based research and Internet-focused research are now built into the IRB system in the United States and are commonplace in European Commission projects. On balance, the expert thinks it is an encouraging "map" of the situation. In addition, IRBs in the United States are increasingly bringing experts on board to contribute to the evaluation of Internet research proposals. The expert named Norway as being very advanced in Internet research ethics – he felt that good infrastructure and a series of cultural factors play a role in this. Due to high levels of trust and solidarity in Scandinavian countries, there is greater sensibility regarding one's responsibility towards others.

With regard to different disciplines' involvement in Internet research ethics, the expert reported that no particular discipline is taking the lead in this regard. However, workshops given by the expert tend to be dominated by social scientists.

The expert was asked whether he sees a global Internet ethics emerging. He responded that he "would like to say yes" but reported that this is happening mostly at conference level with discussion amongst philosophers and other interested people. In the long-run, the expert is optimistic about the possibility of a global Internet research ethics. However, in the short-term, he felt that there will be problems regarding the speed of technology development, in addition to the danger of an imperialist ethics (given the fact that the Internet began as a largely western phenomenon). In regard to possible best practices in the field, the expert responded that it is difficult to predict what will happen due to the plethora of activities ongoing in Internet research and the mobility of the Internet, both of which bring new ethical challenges.

6 INTERNATIONAL FRAMEWORKS AND PROTOCOLS

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http://videocast.nih.gov/pdf/ohrp belmont report.pdf

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European Parliament and the Council, Directive 95/46/EC of 24.10.1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.¹⁴⁵

http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:en:HTML

European Parliament and the Council, Directive 2006/24/EC of the European Parliament and of the Council of 15 March 2006 on the retention of data generated or processed in connection with the provision of publically available electronic communications services or of public communications networks and amending Directive 2002/58/EC.¹⁴⁶

http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2006:105:0054:0063:EN:PDF

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7 JOURNALS AND CONFERENCE SERIES

<u>Journals</u>

- Journal of Medical Internet Research 147
- The Information Society¹⁴⁸
- International Journal of Internet Science¹⁴⁹
- International Journal of Internet Research Ethics 150
- Internet Research¹⁵¹

¹⁴⁵ In 2012, the European Commission proposed a major reform of the EU legal framework on the protection of personal data. The new proposals will strengthen individual rights and tackle the challenges of globalisation and new technologies. See http://ec.europa.eu/justice/data-protection/index en.htm.

¹⁴⁶ The Commission is currently reviewing this law.

¹⁴⁷ http://www.jmir.org/

¹⁴⁸ http://www.indiana.edu/~tisj/

¹⁴⁹ http://www.ijis.net/

¹⁵⁰ http://ijire.net/

¹⁵¹ http://www.emeraldinsight.com/journals.htm?issn=1066-2243



- Ethics and Information Technology¹⁵²
- Journal of Empirical Research on Human Research Ethics 153

Conference series

- Association of Internet Researchers Annual Conference¹⁵⁴
- Public Responsibility in Medicine and Research (PRIMER) conferences 155
- Association for Research Ethics conferences¹⁵⁶
- International Conference on Ethics in Human Research¹⁵⁷
- Asia Pacific Research Ethics Conference¹⁵⁸
- Australasian Ethics Network Conference¹⁵⁹
- World Conference on Research Integrity¹⁶⁰

8 KEY PUBLICATIONS

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¹⁵² http://link.springer.com/journal/10676

¹⁵³ http://ucpressjournals.com/journal.php?j=jer

¹⁵⁴ http://aoir.org/

¹⁵⁵ http://www.primr.org/subpage.aspx?id=4286

¹⁵⁶ http://www.arec.org.uk/

¹⁵⁷ http://www.icehr.org/

¹⁵⁸ http://www.aprec-nhg.com.sg/

¹⁵⁹ https://aenconference.com/

¹⁶⁰ http://publicationethics.org/events/3rd-world-conference-research-integrity



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