Internet Research and the implications for ethical research practice
Internet Research and the Implications for Ethical research practice

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Overview

- Internet Research – What is it about?
- Challenges of ethically reviewing Internet Research
- Internet Research in Australia
- The current project
- Findings and practical implications for researchers and ethical reviewers
Research

Internet Research – What is it about?

• Internet Research defined

  • British Psychological Society (BPS, 2013) ‘Internet-Mediated Research’

• Terminology from around the globe

  • Internet Research (IR) – United States of America
  • Internet-Mediated Research (IMR) – United Kingdom
  • Internet-Based Research (IBR) – Canada
  • Internet-Derived Data (IDD) – Proposed for Australia – NHMRC Consultation Document
Research

Challenges of ethically reviewing Internet Research protocols

- Where does one look for guidance when ethically reviewing IR?
- Is IR riskier than face-to-face protocols?
- Public versus private distinction
- Informed consent
- Withdrawal
- Managing participant feedback, distress, and debriefing
- Social responsibility – just because you can, should you?
Research

The current project

• Research questions

  • What is the current status and scope of IR in Australia?
  • What processes, practices, and considerations are observed by HRECs in the ethical review of IR protocols?

• Explanatory sequential two-phase mixed methods design

  • Quantitative data via online survey of HREC members ($n=88$)
    • from across six states of Australia and representing 22 unique HRECs
    • replication [in part] Buchanan & Ess (2009) survey of IRBs in the USA
  • Qualitative data via thematic analysis (Braun & Clark, 2006) of semi-structured interviews with metropolitan and regional-based HREC Chairpersons ($n=3$)
Research

Results: Current status & scope of IR in Australia

• On average, HREC Members estimated ~ 32% of protocols they reviewed in 2015 contained some aspect of Internet Research.

• Some HREC Members estimated that the IR protocols reviewed accounted for as much as 90% of the total protocols reviewed.

• Participant report of IR protocols reviewed from across various disciplines and categories in 2015 (frequency):
  • >85% reviewed IR protocols within the social sciences discipline
  • >96% reviewed IR protocols proposing online surveys
  • >71% reviewed IR protocols proposing use of online datasets
Research

Results: HREC Practices

• HREC Members rated National Statement “moderately” helpful ($M = 3.14, SD = 0.99$) in reviewing IR protocols – some difference amongst member categories

• Over 75% of respondents reported they did not use any review tool/policy and over 90% did not use any specific IR guidelines in IR protocol review process

• Online resources, e.g., online software template for researchers limited or awareness of resources not present

• Discrepancy in requirement for submission and review of online software privacy/security information
Results: HREC practices and considerations

IR ethical training

- HREC Members reported they were *either* not aware of, or that specific IR ethical training not provided by their organisation:
  - For HREC members (79%)
  - For Researchers (>84%)

Ethical considerations associated with IR protocols

- HREC Members rated privacy; consent; data security; research with minors; and confidentiality/anonymity as top 5 considerations
# Results: Thematic Analysis

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<td>Same, but different</td>
<td>Sometimes contradictory issues to arrive at an ethical review outcome</td>
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<td>It’s a principle-driven process</td>
<td>HREC&lt;/rare utilise the National Statement guiding principles to ethically review IR protocols</td>
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<td>Theme 3</td>
<td>We all have responsibilities</td>
<td>Shared responsibilities of stakeholders involved in the ethical review and conduct of IR protocols, including HRECs, researchers, and participants</td>
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<td>Theme 4</td>
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<td>Mapping current ethical guideline requirements onto IR conduct can prove challenging; confirming identity in an anonymous space; new research spaces raise ethical considerations in new ways</td>
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Ethical challenges in IR: Consent

• Can be difficult to undertake in face-to-face situations – may be further complicated when participant remotely located from researcher

• Assessing consent was “informed” versus practicality of indicating consent.

• International collaborations and differing requirements.

“...you’re not seeing the capacity for consent, of informed consent.” (Ruth, 622).
Ethical challenges in IR: Lack of visual cues

- Confirming identity is important for inclusion and exclusion criteria (sensitive topics, and physical/health-related studies)

- If researchers are unlikely to know true identity of participants in their online research, HRECS are entrusted to make the decision if the proposed IR method is ethically sound OR an alternative face-to-face method may be more appropriate.

"You don’t really know who you’re talking to. But given the kind of research and the import of it, does it matter? Is that a risk that you can take, or not? It’s that usual balancing act.” (Bill, 451-453).
Ethical challenges in IR: Public versus Private

• Boundaries of “public” and “private” spaces in IR

• Consider perception of privacy (King, 1996).

• Schultze & Mason (2012) guide for further dimensions to determine public and private spaces.

• Implications for informed consent and risks of harm.

“You look at how private is the information...if it’s an open discussion that anyone can go in and look at, then I think it’s reasonable to assume that the participants are aware that it’s open and therefore privacy’s not an issue...you might question whether they are when you look at some of the stuff that goes on Facebook, that maybe people aren’t as aware of how public it is perhaps. If it’s closed then it’s really not all that different from a face-to-face situation where you’ve got a group of people and you can ensure that it’s kept within that group, as long as the whole group understands the confidentiality issues.” (Don, 216-219 & 221-226).
Ethical challenges in IR: Environment

- Visibility, role and level of information provided by a researcher
  - Overt or covert
  - Participant and/or observer
  - Consent approach

- Effect on individuals and group dynamics
  - Disruption to group processes
  - Access to feedback (debriefing)
  - Distress (in the event it occurs)

“I think this is one of the challenges of this environment, isn’t it? It’s this threshold where the virtual world can’t or presents some difficulties in what of the practices we have in the physical world. Things like debriefing, feedback, or even responding to people’s distress or some of those sorts of issues. I probably can’t give you the answers to them, but they’re part of the questions we’d ask, because they’re real issues that have to be considered.” (Ruth, 419-426).
Ethical challenges in IR: Data

• Treatment of data in reporting and dissemination

  • Participants as “authors” of their own knowledge versus anonymise all participants – but what about pseudonyms?

  • Re-identification issues. Big data ≠ automatic anonymity!

  Refer Zimmer, M. (2010). “But the data is already public: On the ethics of research in Facebook”. Ethics and Information Technology, 12, 313. doi.org/10.107/s10676-010-9227-5.

  “…social media is of course...blurring social boundaries. It’s creating new sets of boundaries and relationships... One of the challenges we’ve got, is to say ‘Given that that’s what’s happening, given that identity is already up for question on the Internet, how do our traditional processes, ethics, guidelines about anonymity, de-identification, are predicated on a certain model of how we identify and how we use identity in society?’. Social media especially is throwing that one up in there and seeing what comes down again. It’s different to everything we’ve ever done before.” (Bill, 608-617.)
Reflections and future directions

This research

• adds to the limited scholarly evidence
• extends previous studies through addition of a distinct qualitative phase, and an Australian perspective
• cannot be generalised beyond the study population

Future directions

• Australian definitional guidelines for what is considered to be IR, and when it is required to be ethically reviewed. Suggest this logically fits within the NHMRC National Statement
• Results suggest HREC members and researchers may be assisted from educational efforts addressing the ethical considerations and conduct of IR
• Researchers be encouraged to include a discussion of ethical considerations
Questions?