

# THE ETHICS OF RECRUITING, RETAINING AND TRACING RESEARCH PARTICIPANTS ONLINE

Research Summary

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# Executive Summary

This report presents a summary of findings from the project, 'The ethics of recruiting, retaining and tracing research participants online'. This project was funded and conducted by La Trobe University between 2016 to 2018. The research aimed to identify what online strategies were used to recruit, retain and trace participants in research, what concerns researchers and HREC members had about using the internet to recruit, retain and trace research participants, and what information researchers and HREC members used to guide decisions about the ethical appropriateness of online research. The research was conducted in three phases: (1) scoping review of the literature in parent, child and family research; (2) qualitative interviews with eight public health researchers and seven HREC members; and (3) online survey of 401 researchers and/or HREC members in Australia.

Most articles in the scoping review reported using the internet to recruit participants, primarily via websites, email and social networking sites, with few reporting online retention or tracing. Several ethical considerations were identified, such as protecting privacy and confidentiality, obtaining informed consent, and disparities in internet access. Ethical issues specific to engaging minors online were also identified, including obtaining parental consent, verifying participant age, and children's vulnerability online. Five professional guidelines on internet research ethics were identified in the scoping review, although few academic articles cited these guidelines. In the interviews, all researchers had used the internet to engage research participants (mostly for recruiting), and all HRECs had reviewed internet research proposals. Tracing participants via the internet was less common, and views on its ethical appropriateness varied. Ethical concerns and challenges pertaining to participant privacy, confidentiality and anonymity were reported, as were protecting vulnerable participants, gaining informed consent and the rapid pace of technological change. Both groups reported a lack of clear guidance for ethical decision-making. Researchers and HREC members used a similar range of resources to guide decision making in online research, including the National Statement and institutional guidelines, as well as informal resources such as their own experience and advice from colleagues. Survey findings demonstrated that Australian researchers and HREC members shared similar concerns and attitudes towards using the social media to recruit, retain and trace participants. Neither groups were very confident in identifying the ethical issues of engaging participants via social media, and few had participated in social media-specific ethics training. Resources used to guide decision-making reflected those identified in the interviews.

From these three phases, our findings show that researchers use a range of online platforms to engage research participants, and that there are benefits to these approaches compared to conventional offline methods. However, online research raises a number of ethical concerns and 'grey areas', particularly around what is considered private versus public data, and what is possible versus ethical. Engaging research participants online introduces complex ethical issues, requiring researchers and HREC members to be familiar with this technology and aware of its risks and limitations. Both researchers and HREC members were keen for guidance on the ethical use of the internet and social media when engaging participants in research, demonstrating a need for greater awareness of available resources and further training and support.

# Introduction

Researchers increasingly use the internet, through websites, email, social media (e.g. social networking sites, blogs, forums) and other online applications, to recruit, retain and trace research participants. For example, researchers can initiate contact and invite potential participants into a study by advertising study information on Facebook or via email (recruit) [1, 2]. In longitudinal research, researchers can maintain contact with participants by posting study updates on project websites or directly to participants via Facebook (retain) [3]. Researchers can also find and re-establish contact with participants in longitudinal research who have been lost to follow-up by searching for individuals' names on internet search engines or social networking sites (trace) [4].

While the internet offers an opportunity for researchers to efficiently and cost-effectively make and maintain contact with participants on a large scale, current ethical guidelines in Australia provide little or no guidance on its use and it is unclear how researchers and human research ethics committees (HRECs) make decisions about the ethical appropriateness of engaging research participants online. This project, funded by La Trobe University, investigated the ethics of using the internet to recruit, retain and trace participants in research, across three phases:

- Phase 1: Scoping review of literature in parent, child and family research
- Phase 2: Qualitative interviews with HREC members and public health researchers
- Phase 3: Online survey of HREC members and researchers

The research aimed to answer the following research questions:

1. What online strategies are currently being used to recruit, retain and trace participants in research?
2. What concerns do researchers and HREC members have about using the internet to recruit, retain and trace research participants?
3. What information do researchers and HREC members use to guide their decisions about the ethical appropriateness of using the internet in research?

# Methods and Results

## SCOPING REVIEW

The scoping review was conducted to identify the ethical concerns associated with using the internet to recruit, retain and trace participants in research, and to identify the resources that guide internet research ethics. The review focussed on parenting, child and family research published between 2006 and 2016 which had used the internet to recruit, retain or trace participants. Six academic databases were systematically searched, identifying 65 articles that met the inclusion criteria.

Most articles reported using the internet to recruit participants, primarily via websites, email and social networking sites, with few reporting online retention (12%) or tracing (10%). The majority (60%) of reviewed articles did not discuss ethics beyond general consent or approval procedures. Forty percent acknowledged one or more key ethical concerns of engaging participants online. Some concerns were specific to engaging participants in family and child research online, such as the challenges of obtaining parental consent and verifying participant age, and children's online vulnerability. Other concerns were applicable when engaging any research participant online, including privacy, confidentiality and anonymity; informal consent and assessing participant comprehension; and disparities in internet access. Articles commented on the

complexity of separating public and private domains online, particularly for social networking sites and online communities that encourage users to share information. Online research increased the risk of participants' inadvertently revealing their involvement in a study and increased the risk of deductive disclosure of a participants' identity if quotes from online communities were published. Some issues were not confined to online research but were applicable to any human research that lacked direct participant-researcher interaction. However, engaging participants online inflated risks and introduced new challenges due to the 'visible', far-reaching and dynamic nature of online platforms, especially social media.

Very few (5%) articles cited internet-specific ethical guidelines in the design or conduct of their research. A general internet search identified five professional guidelines that focus on internet research ethics:

- Markham and Buchanan (2012) *[Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee](#)* [5]
- British Psychological Society (2013) *[Ethics Guidelines for Internet-mediated Research](#)* [6]
- Secretary's Advisory Committee on Human Research Protections (2013) *[Considerations and Recommendations Concerning Internet Research and Human Subjects Research Regulations](#)* [7]
- The Norwegian National Research Ethics Committees (2014) *[Ethical Guidelines for Internet Research](#)* [8]
- Clark, Duckham, Guillemin, Hunter, McVernon, O'Keefe et al. (2015) *[Guidelines for the Ethical Use of Digital Data in Human Research](#)* [9]

## INTERVIEWS WITH RESEARCHERS AND ETHICS COMMITTEE MEMBERS

In Phase 2, semi-structured interviews were conducted with eight public health researchers and seven HREC members to explore the key ethical issues concerned with using the internet to recruit, retain and trace participants in research. Participants were asked about the research they were involved in (researchers) or had reviewed (HREC members) that used the internet to engage participants, their understanding of the potential ethical issues concerned with using the internet to engage research participants, and what informed their decision-making about the ethical appropriateness of using the internet in research. Thematic analysis of data involved a four-stage process described by Green and colleagues [10] to identify key themes. Five key themes were identified: internet use and its effectiveness; ethical concerns; ethical decision-making; HREC challenges; and resources.



### Internet use and its effectiveness

All researchers had conducted research using the internet, across a variety of platforms (e.g. Facebook, email, dating applications). Most had used the internet to recruit participants, and some had also used it to retain participants in longitudinal research. A small number of researchers conducting longitudinal research were using Facebook to trace participants who had been 'lost' to follow-up. All HREC members had reviewed internet research proposals, mostly relating to the use of Facebook to recruit participants. None had reviewed a proposal requesting to trace research participants via the internet, and views about the appropriateness of this varied.

### Ethical concerns

Both researchers and HREC members reported on the usefulness and effectiveness of the internet as a research tool, but also the ethical complexities. Both groups identified a need for guidance and support. Researchers acknowledged that engaging participants via the internet is "not black and white" with ethical "grey areas". They reported a tension between what was possible and legal, and what was ethical. Both groups reported ethical concerns such as maintaining participant privacy, confidentiality and anonymity; protecting

vulnerable participants; and gaining informed consent. Additionally, researchers reported a lack of clear guidance about the ethical use of the internet in research as an issue.

### **Ethical decision-making**

For researchers, decisions about the ethical appropriateness of using the internet in their research relied on several factors. These included the sensitivity of the topic, participant age and vulnerability, what participants had consented to, and minimising harm and participant burden. There was a suggestion that ethical processes were not keeping pace with technology – that meant researchers could not maximise the tools available to them, at the speed they were required. Further, a perceived lack of familiarity with internet research meant that researchers decided to ‘stay safe’ with their methodology rather than risk ethics committees rejecting their research proposal. HREC members described decision-making about the use of the internet in research as sometimes being “subjective”, “difficult” and “not black and white”. To assist ethics committees with decision-making, they expressed a need for additional training on internet research, or alternatively, having a HREC member who was familiar with internet research and/or the various platforms.

### **Challenges for HRECs**

HREC members also identified several challenges of reviewing internet research ethics proposals, such as:

- Adapting to the pace of technological change, the number of platforms and what they all do;
- Juggling large workloads (particularly those who served on the HREC on a voluntary basis) with the amount of research required to understand the proposals;
- A lack of ethics training opportunities specific to social media in research.

### **Resources**

The key resource used by both researchers and HREC members to inform decisions on the ethical appropriateness of using the internet in research was the National Statement of Ethical Conduct in Human Research [11]. Although both groups acknowledged that the Statement was useful regarding broad research principles, and not for internet research specifically. While they agreed that specific guidelines about internet research would be useful, none of the researchers could identify any, even though some guidelines are publicly available (identified in the scoping review). These internet research guidelines were used by some HREC members to guide their decision-making. Researchers who had worked closely with their HREC to design their internet research strategy reported that the ethics approval process and the study ran more smoothly.

Interview findings were used to develop the broader online survey for researchers and HREC members in Phase 3.

## **SURVEY OF RESEARCHERS AND HREC MEMBERS**

In Phase 3, Australian researchers and HREC members were invited to participate in a brief anonymous online survey that aimed to explore their views and ethical concerns regarding the use of social media (e.g. Facebook, Twitter, LinkedIn, email, blogs, forums or other platforms or websites) to recruit, retain and trace participants in research. Emails were sent to all registered Australian HRECs and the research offices of all Australian universities and other research organisations, requesting dissemination of the survey link. In total, 401 respondents completed the survey, comprising 178 researchers, 94 HREC members and 129 with a dual role (researchers with HREC experience). Participants covered a range of roles, disciplines, institutions and professional experience with social media. Survey constructs were analysed by participants’ role as a researcher and/or HREC member.

HREC members were found to personally use social media less frequently than researchers. However, overall frequency of internet use, internet privacy concerns and general attitudes towards social media were similar between groups.

Respondents identified a number of ethical concerns associated with using social media to engage research participants. These concerns largely aligned with the findings of Phases 1 and 2, and included protecting participant privacy, confidentiality and anonymity; data security, storage and ownership; participant misrepresentation and verifying participant identity; response bias and sample representativeness; data quality and validity; consent procedures; accessing participant information beyond what was consented; and the potential invasion of privacy. Participants rated their level of concern regarding a range of online and offline recruitment, retention and tracing methods. HREC members were consistently more concerned about each strategy than dual role participants and researchers. Across the three groups, respondents were most concerned about tracing participants via social media and agreed that the most ethically concerning recruitment methods involve researchers using their personal social media account to promote research, snowball sampling on social media and targeted social media advertising.

Most respondents who had experience with social media research did not consider themselves very confident in identifying or knowledgeable of the ethical issues associated with engaging research participants via social media (Figure 1). Dual role participants perceived themselves to be more knowledgeable than researchers. Respondents who used the internet more frequently and had received social media research ethics training reported greater confidence and perceived knowledge.

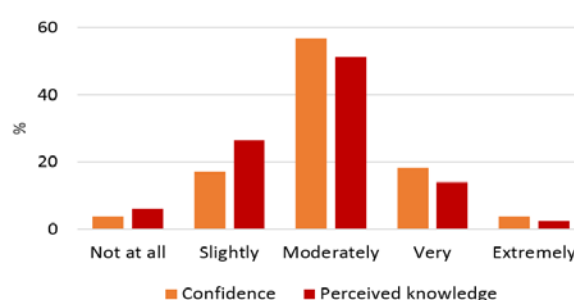


Figure 1. Confidence and perceived knowledge in identifying ethical issues in social media use in research

Respondents used a range of resources to guide ethical decision making for social media-based research, including the NHMRC National Statement on Ethical Conduct in Human Research [11], HREC colleagues or HREC chair, professional experience, and institutional guidelines or manuals. Very few (3%) referred to professional guidelines on internet research ethics (e.g. [5, 6, 9]). Few respondents (11%) had received training specific to social-media research ethics, although more dual role participants (21%) had participated in training than HREC members (12%) or researchers (2%). Many (85%) reported that they would benefit from social media ethics training.

## Conclusions

Overall, this study has contributed to our understanding of the use of the internet to recruit, retain and trace participants in research, and the ethical context in which this occurs. Findings highlight the usefulness of the internet and social media as a research tool, but also its ethical complexity. Both researchers and HREC members are keen for direction regarding the use of the internet in research, demonstrating a need for guidance, resources, training and support.

## PUBLICATIONS AND FURTHER INFORMATION

Findings from Phase 2 of this project have recently been accepted for publication in the journal *Internet Research*:

Crawford S, Hokke S, Nicholson JM, Zion L, Lucke J, Keyzer P & Hackworth NJ (Accepted). "It's not black and white": Public health researchers' and ethics committees' perceptions of engaging research participants online. *Internet Research*.

Further information about this project and forthcoming publications from Phases 1 and 3 can be found on our project website at [www.latrobe.edu.au/jlc/research/tcpp/projects/parent-engagement-project](http://www.latrobe.edu.au/jlc/research/tcpp/projects/parent-engagement-project).

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