

Ethics notes



May 2015

The use of mobile technology and social media is growing rapidly around the world, providing an easy platform for researchers to recruit participants for research. This technology is also a useful tool for conducting research: it is cheap, fast, and easier for researchers to recruit online. But what are the ethical implications and challenges facing researchers in this evolving area? In this issue of *Ethics Notes* we have published three commentary pieces exploring some of these issues.

Wearable technologies in health research

By Dr Luke Gemming

Wearable technologies have become a hot topic recently as both large and start-up companies have released consumer-friendly wrist-worn fitness trackers, smart watches, and wearable cameras. The rapid increase in their capabilities and range of products available, in conjunction with the associated media attention, has changed the research landscape significantly. Consequently, it is evident wearable technologies are rapidly becoming ubiquitous in society, but understanding of how these technologies are best applied in health research is still in its infancy¹.



Dr Luke Gemming

Dr Luke Gemming is a lecturer within the Discipline of Nutrition and Dietetics at the University of Auckland. During his PhD he completed a three-month research exchange to the University of Oxford where he collaborated with experts in wearable camera health research. His general interests are in the applications of wearable sensor technologies in nutrition and physical activity research, and smartphone applications to enhance the practise of nutrition and dietetics.

Wearable cameras raise unique ethical issues compared to other technologies as the images recorded can inadvertently capture third parties without consent. Wearable cameras capture point-of-view images automatically approximately every 5 to 30 seconds and will typically capture 3000+ images during a single day. The images are reviewed in a similar manner to watching a stop-motion movie, as the images are not captured frequently enough to play a fluid video; this allows an entire day to be viewed within minutes, which reveals a digital archive of an individual's daily activities and interactions from the first person perspective.

The use of wearable cameras in health research stems from the limitations of self-report, which is often prone to substantial bias^{2,3} and the ability of wearable cameras to passively record situations and health behaviours where direct observation is not feasible or cost effective. To date their applications have primarily been explored in research with small samples in a range of areas such as assisting with memory impairment⁴, enhancing methods of dietary assessment⁵, and the assessment of sedentary behaviours and physical activity¹. However, larger studies are underway.

(Continued on page 2)

(Continued from page 1)

In New Zealand, the Kids'Cam study is exploring everyday environments of approximately 200 year eight children by documenting what children see and where they go throughout the day, including at home, at school, and during most other activities. Kids'Cam is under the research programme 'Dietary Interventions: Evidence & Translation' led by the National Institute for Health Innovation, the University of Auckland, and conducted by the University of Otago⁶. Kids'Cam is one of the first studies in the world to use wearable cameras to examine health behaviours among children and is a great example of the unique data wearable cameras capture.

Understandably the notion of using wearable cameras for health research results raises eyebrows among some people, participants, and researchers. When first considered their use appears to comprise various risks, however, simple measures can ensure all ethical issues are addressed. As indicated, a common concern first raised is the privacy of third parties inadvertently captured within images. Images are often captured of people in public without consent, which is legal and commonplace; best illustrated every day during the six o'clock news. Thus, third parties present within images are not participants. However, privacy concerns of third parties need to be addressed and this is achieved by safeguarding the storage, handling and use of the images.

An ethical framework for use of wearable cameras in health research provides clear guidelines for best practise⁷ and the following procedures address most conceivable issues:

- devices should be encrypted when possible or require propriety

software to protect the images if devices are lost or stolen

- AES 128/256-bit encryption is a standard format widely used
- once images are transferred from devices, images should be stored in a restricted password-protected location/folder
- images transferred to another location should be re-encrypted first
- no efforts to identify third parties should be attempted and images should only be used for the purpose stated to participants
- researchers involved with viewing and coding images should sign ethical declarations with respect to the handling, security and use of the images
- images should not be published or reproduced in any form without participant consent or that contain third parties (as third parties have not provided consent)

Information for participants is also important. Participants need to be aware of public and private locations where photography may be undesirable or prohibited without consent. Participants should also be given ample opportunity to review the images in private, if requested, and to delete any image they do not wish to disclose. Lastly, participants need to be aware that if a crime is witnessed researchers will be obliged to report the crime to the relevant authorities.

Although the use of wearable cameras in health research is still emerging, their adoption for personal use and by police forces, security personnel, and other occupations around the world suggests the ethical issues and etiquette regarding their use is likely to be an evolving subject going forward.

For example, devices with wireless data transmission are becoming more prevalent, which allow real-time video streaming (a feature already on many new smartphones). Real-time point-of-view video has obvious benefits for some professions (e.g. security), but also potential in research. Systems for real-time behaviour analysis have been prototyped that could allow real-time behaviour change interventions⁸. Thus, if proven feasible, procedures to best handle real-time data will be paramount to protect people's privacy. ■

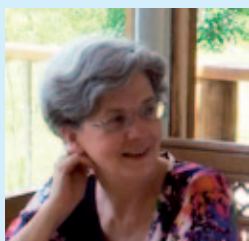
References

1. Doherty A R, Hodges S E, King A, Smeaton A F, Berry E, Moulin C J A, et al. (2013) Wearable cameras in health: The state of the art and future possibilities. *Am J Prev Med*. 44(3): 320-3.
2. Stone A A, Bachrach C A, Jobe J B, Kurtzman H S, Cain V S (1999). *The Science of Self-report: Implications for Research and Practice*. Psychology Press.
3. Gemming L, Jiang Y, Swinburn B, Utter J, Mhurchu C N (2014). Under-reporting remains a key limitation of self-reported dietary intake: an analysis of the 2008/09 New Zealand Adult Nutrition Survey. *Eur J Clin Nutr*. 68(2): 259-64.
4. Browne G, Berry E, Kapur N, Hodges S, Smyth G, Watson P, et al. (2011). SenseCam improves memory for recent events and quality of life in a patient with memory retrieval difficulties. *Memory*. 19(7): 713-22.
5. Gemming L, Rush E, Maddison R, Doherty A, Gant N, Utter J, et al. (2015). Wearable cameras can reduce dietary under-reporting: doubly labelled water validation of a camera-assisted 24-hr recall. *Br J Nutr*. 113: 284-91.
6. Dietary Interventions: Evidence & Translation (2014). Available from: <https://diet.auckland.ac.nz/content/kidscam>.
7. Kelly P, Marshall S J, Badland H, Kerr J, Oliver M, Doherty A R, et al. (2013). An ethical framework for automated, wearable cameras in health behavior research. *Am J Prev Med*. 44(3): 314-9.
8. Moynagh B, Gurrin C, Albatel R, Tengqi Q (2014). Real-time behavioural analysis using Google Glass. Proceedings of Measuring Behavior, 27-29 August 2014, Wageningen, Netherlands.

Ethical participant recruitment using social media: Issues and some preliminary suggestions

By Professor Paula M C Swatman and Dr Chandana Unnithan

The fundamental principle that people who take part in research projects should be willing and informed participants evolved in a response to experiments (predominantly medical and psychological) undertaken during the 20th century where participants were anything but willing and informed. As human research ethics (HRE) evolved during the 20th century, it focused initially on the protection of participants involved in medical research. In 1999, the Australian National Statement on Ethical Conduct in Human Research (the 'National Statement') made it clear that the guidelines applied to people involved in research of any kind – biomedical or social.



Professor Paula Swatman

Professor Paula Swatman has been an information systems academic since 1988 and has worked in ICT and, in particular, e-business for 25 years, holding chairs in both Australia and Germany. Paula has an Adjunct Chair in the School of Engineering & ICT at the University of Tasmania, where she supervises a small number of PhD students. She has been the Chair of the Tasmanian Social Science Human Research Ethics Committee since the start of 2012 and has a particular interest in the ethical issues associated with online research and social media, an area in which she has been publishing for several years now.



Dr Chandana Unnithan

Dr Chandana Unnithan has been an academic in Australian universities for 15 years, with a portfolio intersecting information systems, project management, and work integrated learning. Her research focuses on the social facets of technology implementation; using social media for citizen engagement and enhancing public health; and the progress of Women in ICT. She is part of the United Nations Action Team that advocates the use of spatial technologies in public health and on the programme committee for the Grace Hopper Celebration for Women in ICT initiative.

The National Statement has undergone a number of reviews since 1999: a major update in 2007 and, since then, a series of smaller revisions to individual chapters or topics, preceded by an issues paper and a request for feedback from interested parties – including members of the more than 200 Australian Human Research Ethics Committees (HRECs) and the institutional ethics and integrity administrators who make the HRE process work.

One of the most difficult things for any formal process is keeping up with rapid technological change. A disruptive technology, such as social media, has the potential to make a workable and effective system seem outdated and hard to use in a matter of months! Social media and social networks have become an integral part of every aspect of life, both personal and professional. Business, government, and community organisations are using social media to access their stakeholders, and

users increasingly trust social media advertisements (Sensis, 2014). It is no surprise that researchers want to know what's happening in (and to) this space – and find it easier to recruit participants from the general population via Facebook or Twitter advertisements than they do via the more traditional print media.

The assurance of participant privacy and, where appropriate, anonymity

(Continued on page 4)

(Continued from page 3)

are among the most critical issues for an HREC. However, the growing popularity of social media as a venue for recruitment of participants and a location for meeting, interacting with and observing people has made it far more difficult for ethical researchers and HRECs to ensure these important protections are still being effectively applied, particularly in terms of how participants are recruited (Buchanan, 2012).

The issues facing researchers using social media to recruit participants or gather data fall into six categories (Swatman, 2014):

1. **Recruitment of participants:** in contrast to traditional 'push-based' recruitment, social media requires a 'pull' strategy. Potential participants are notified of an opportunity – and can discuss the offer with others, modify it, or post it in other online venues before responding so that researchers lose control of the invitation, with privacy and anonymity being affected. In addition, it can be difficult to know who has really responded to an invitation posted on social media – are your 'adult' participants all really over 18?
2. **Privacy/anonymity/confidentiality of participants:** social media spaces are generally thought of as being public – but is the space a researcher is using to recruit participants, gather data on opinions, or observe online interactions perceived as private by its users? Are they aware they are being observed and, if so, would they consent to this? In addition, much so-called 'anonymous' research is actually traceable: most online survey software defaults to collecting IP addresses and most tweets contain identifiers.
3. **Consent:** informed consent is the *sine qua non* of ethical research and obtaining consent from adults is relatively straightforward in most cases, via links from social

networking sites to more private and secure online environments. But ...

- a. **Age verification:** there is no effective method of ensuring a participant's age or level of maturity from an online invitation, e.g. are all Facebook users really over 13?
- b. **Documentation:** how can you be sure who really provided that parental consent you obtained via social media?

4. **Representativeness of social media:** researchers surveying a 'representative' group of people may unthinkingly select an environment such as Facebook or Twitter because it is so easy to collect active, enthusiastic responses. While Facebook is used by a huge proportion of the population – Sensis (2014) found 97 per cent of their respondents had Facebook accounts – there is no guarantee that all these people are active users, or are willing to consider invitations to participate in research. And Twitter, while awash with comments, is by no means truly representative of the general population.

5. **Data sharing/data storage:** chapter two of the *Australian Code for Responsible Conduct in Research* (the Australian Code) requires researchers to ensure their data are securely stored within their home institution. Yet most social media sites, owned by US corporations, store data on US-based servers – placing research data in breach of the federal *Australian Privacy Act* and making them vulnerable to access under US legislation such as the *Patriot Act* or the *Foreign Intelligence & Surveillance Act*, or even the European Convention on Cybercrime which permits access to US data owned by foreign nationals.

6. **Terms of service/end-user licence agreements:** social media users click on terms of service they rarely read to gain access to their preferred online environment. Foxnews

(2010) reported a British gaming company which mischievously included the "immortal soul clause" in its terms and conditions, allowing the company to claim customers' souls as an April Fool joke – but few noticed the clause. Researchers who store anything relating to their project (apart from a recruitment advertisement) on social media will find the site owns that copy of their data.

The Social Science HREC had, over a period of two years, received an increasing number of applications including recruitment, data gathering, or observation via social media and felt it would be valuable to see how effective the National Statement's guidelines were in this brave new world. Together with a colleague who specialises in content analysis, we reviewed anonymised data from 63 applications (out of a total 657) which had used social media in some way during the previous two years, analysing patterns via Leximancer™ and, happily, discovered that:

- informed consent was used exclusively in all projects
- Facebook was used only to generate interest in a project (though no researchers had discussed the issue of possible modification or re-posting of their advertisements)
- the only online surveys used Facebook Messenger, which provides for more secure data transmission. ■

References:

- Buchanan, E (2012). Social media, research, and ethics: Challenges and strategies, the Rockefeller University Center for Clinical and Translational Science Webinar Series, New York, Accessed 30 July 2012 from: <http://www.uwstout.edu/faculty/buchanane/>
- Foxnews (2010). 7,500 online shoppers unknowingly sold their souls, 15 April 2010: <http://www.foxnews.com/tech/2010/04/15/online-shoppers-unknowingly-sold-souls/>
- Sensis (2014). The ageing face of social media, URL <http://about.sensis.com.au/Media-Releases/?ItemID=1255>, Accessed 22 September 2014.
- Swatman, P M C & Unnithan, C (2014). Ensuring the privacy of social media-based research participants: Best practice for HRE, Australasian Ethics Network Conference, Sydney, 3–5 December: https://aenconference.com/Home_Page.html

Research, ethics and the challenge of social media

By Dr Bev Turnbull

The scope of social media is multifaceted, pervasive, influential, and here to stay. Its ease of access, versatility and speed has enabled the creation of virtual communities and opportunity for private or public comment. It has changed the way information is created, shared, disseminated and utilised. In doing so, it has created new opportunities but also challenges not only for researchers and also for ethics committees.



Dr Bev Turnbull

Dr Bev Turnbull is a Senior Lecturer and Chair of the Human Research Ethics Committee at Charles Darwin University, Australia. Her areas of expertise and research interests include mentoring and scholarly productivity; bio-ethics and end of life issues; teaching practice; practitioner practice; and women's health issues.

Social media has considerable potential for health research, for example, health promotion messages, health education for health professionals, dissemination of and sharing of research results, and as a way of tracking disease trends. Mychasiuk & Benzies (2011) advocate the use of Facebook as an effective means of improving participant retention in longitudinal health studies since a Facebook profile usually remains constant, in contrast to addresses, contact numbers and employment details which do not. It is extremely popular, potentially data rich, free and easily accessible (D'Arcy & Young, 2012).

Prasad (2013) identifies social media as an opportunity with the potential to provide evidence-based credible patient information, at the same time flagging that the plethora of sites may confuse and obfuscate. Social network sites are also targeted as marketing sites for those with vested interests in health messages and health products with the potential for overt marketing of health

products, including pharmaceuticals. McKee (2013) notes also the risk of dissemination of information that is non-evidence based or that contradicts best practice guidelines.

Increasingly, social network sites are seen as a way to obtain participants for research and to engage them in dialogue. Social network sites have potential as large data pools for research in a variety of fields such as psychology, sociology, and computer technology. However, just because a user shares ideas or provides data via social networks does not mean that data provided should be automatically collected or shared, and published by researchers. The multiple connections between social network site users lead to tensions between what a participant is willing to provide and share and how this may be represented or misrepresented.

Despite many seeming advantages, Facebook illustrates such tensions. Potentially it offers a more effective

way to collect social and political data from a much wider opinion pool, since those most informed about particular issues do not necessarily reflect the opinions of the general public. Twitter offers another option to garner social opinion; however, here too issues around how much users wish to share arise. The quality of and depth of data obtained can be questionable, and this can be seen in the plethora of media comment (at least in Australia) that Tweets attract. Similar to injudicious emails, social media commentary may well end up where one least expects.

Anonymity is an essential right in research because of its relationship with trust, which is linked to provision of information and well informed consent. These challenges are amplified in use of online media. A key problem with the use of social network sites for research is that of how to control the dissemination of information and how to address privacy and confidentiality. The following case study of an Honours project illustrates this:

Honours projects provide a rich training ground for future research skills. While original research is not anticipated, projects are expected to be sufficiently robust and to address ethical principles. Psychology Honours students at my local university found themselves constrained by their ability

(Continued on page 6)

(Continued from page 5)



HRC Twitter page, <https://twitter.com/hrcnewzealand>

to attract sufficient participants for their research projects resulting too often in a homogenous participant pool, and at times response numbers with insufficient power for effective analysis. Survey questionnaires are commonly used not only due to time (semester) constraints but because their use facilitates application of theory to practice; use of validated survey tools, statistical analysis, and opportunity to design and craft a plain language statement. 2012 saw the first applications proposing Facebook as a method of participant recruitment directing potential participants to a secure survey link advertised through Facebook.

Following ethics clearance a student used their own Facebook account to advertise a survey. A 'friend' then posted the survey on the local newspaper's Facebook page, which then went viral. The result was a public dialogue regarding the quality of the survey among participants and 'friends' whose identities and views were clearly visible. A complaint was lodged from a member of the general public and the survey link was promptly removed from the newspaper's Facebook page.

However, in the space of several hours, 150 participants had accessed the survey.

Social media has blurred the boundaries between private and public information. Despite the very public nature of social media, participants will vary regarding what they view as public and private. The distinction in social media is harder to make, and people's privacy concerns do not remain static over time (Henderson, Hutton & McNeilly, 2012). There is no doubt we can harness social media to locate participants, and also to conduct dialogue with them (consider blogging, journaling), but issues around confidentiality and anonymity need thoughtful consideration.

These issues are the same for traditional research, but are less apparent and easier to unintentionally (or otherwise) transgress with social media. The infamous T3 Facebook project is one example. Transparency surely should underpin all research, yet where an IP address is collected it is relatively simple for a skilled operator to trace the originator. Privacy settings are not absolute; once information is posted on the Internet

it is very difficult to remove content material. Recruitment via social media does change relationships – since individuals recruiting may also be participants. O'Connor (2013) suggests this indicates a more peer-to-peer relationship between the recruiter and the recruited. Therefore, there is a need to identify how the power of social media will be ethically harnessed early in the research process to ensure that enthusiasm and passion for a project do not replace sound judgement in seeking to use social media to facilitate research.

Requests to our ethics committee to use social media as part of research are increasing. Students as researchers are particularly enthusiastic users of social media, however, enthusiasm and innovation may need to be tempered. In 2015 the question is no longer should researchers be permitted to use social media, but rather what are the key ethical issues around its use and how can researchers and ethics reviewers best address these. Questions that might be considered include: Is there a cultural shift occurring in what people consider to be an informational risk? Do social network users fully comprehend what participation may mean? Whose responsibility should it be to ensure participants understand what privacy settings are available to them? For universities the current challenge is to develop responsible guidelines for ethical review and research practice. ■

References:

- D'Arcy A & Young T (2012). Ethics and social media: Implications for sociolinguistics in the networked public. *Journal of Social Linguistics*, 16:4, pp. 532-456.
- McKee R (2013). Ethical issues in using social media for health and health care research. *Health Policy, Elsevier*, DOI: <http://dx.doi.org/10.1016/j.healthpol.2013.02.005>.
- Mychasiuk R & Benzie K (2011). Facebook: an effective tool for participant retention in longitudinal research. *Child: care health and development*, Blackwell Publishing, DOI: 10.1111/j.2214.2011.01326.x.
- O'Connor D (2013). The apomediated world: Regulating research when social media has changed research. *Journal of Law, Medicine and Ethics*, pp. 470-483.
- Prasad B (2013). Social media, health care and social networking. *Gastrointestinal Endoscopy*, 77, 3: 492-495.

Ethics Summer Studentships

Three students were awarded HRC Ethics Summer Studentships in 2014/2015. The purpose of the studentship is to enable a student to train during the summer break with a research team and have the opportunity to explore ethical issues that face New Zealand. Below are the brief reports of the projects.



Timothy Pilkington

The University of Auckland

(Supervisor – Associate Professor Martin Wilkinson)

The moral status of incompetent persons' interests

The aim of the paper is to provide ethical grounds for administering life-saving treatment to Alzheimer's patients despite the patient's clear prior directive to the contrary. Despite their confusion and frequent incoherence, Alzheimer's patients can be committed to values. They possess a will that can be steadily directed at certain aspects of their own lives deserving our respect. Their will might take a different direction than it did before the disease, and significant differences in what they value might emerge. Such differences might be over trivial matters, but they may concern fundamental questions such as whether their lives should continue. In discussing this issue the researcher offered an account of the moral status of such patient's current clearly discernible interests in cases concerning life and death. He assessed the degree of autonomy possessed by these patients, the nature of the interests that they possess, and the kinds of goods they are capable of experiencing in an attempt to reach a conclusion regarding what is owed to these patients in such circumstances.



Becky Allenby

AUT University

(Supervisor – Professor Jane Koziol-McLean)

Child safety in online research with women experiencing intimate partner violence; experiences managing informed consent, confidentiality, and safety protocols in the *isafe* study

The significant co-occurrence between men's violence against female partners and child abuse and neglect is well documented. What is less clear is how child safety should be managed in family violence research with their mothers. This issue is salient to *isafe*, a New Zealand-based Internet intervention study, testing improvement in safety decisions and mental health outcomes for women. This project explored the legislative, professional, ethical considerations that fed into the development of the *isafe* child safety protocol. Hypothetical scenarios of the application of the *isafe* protocol were used to illuminate the discussion and provide a basis for future discussion.



Hayleigh Miller

University of Otago

(Supervisors – Dr Nikki Kerruish and Dr Ben Wheeler)

Newborn vitamin K prophylaxis: An analysis of information resources for parents and professionals

Vitamin K prophylaxis is a routine intervention offered to newborns to prevent vitamin K deficiency bleeding. Parents can choose to give it intramuscularly, orally or not at all. The researcher collected information materials given to parents and health professionals about vitamin K prophylaxis and analysed these with regards to completeness, user-friendliness and approach to parental consent. Considerable discrepancies were found between education materials and the researcher suggests that a standardised brochure be used throughout New Zealand to inform families on vitamin K prophylaxis and that further research should aim to find out what information parents use to make their decision. ■

Feedback on health and disability research ethics

The National Ethics Advisory Committee (NEAC) would like to thank everyone who made a submission in response to their discussion document on cross-sectoral ethics arrangements for health and disability research. NEAC received over 30 submissions from researchers, ethics committees and other organisations with an interest in ethical research. They have appreciated the well-considered responses and practical suggestions for addressing issues. NEAC is currently reviewing the submissions and intends providing advice and recommendations to Hon Peter Dunne, Associate Minister of Health later this year.

The feedback from the consultation process will also inform NEAC's comprehensive review of its *Ethical Guidelines for Observational Studies* and *Ethical Guidelines for Intervention Studies*. NEAC will be consulting on the draft revised guidelines in late 2015.

HRC Guidance Notes on Research Ethics

The HRC Ethics Committee has updated and published the HRC Guidance Notes on Research Ethics (guidance notes) in November 2014 after receiving feedback from the HRC Biomedical Research Committee, Māori Health Committee, Public Health Research Committee, and Pacific Health Research Committee.

The guidance notes are not intended as a detailed document. Its aim is to flag issues for researchers to think about. This document is available on the HRC website: www.hrc.govt.nz/ethics-and-regulatory.

Upcoming meeting dates

HRC Data Monitoring Core Committee (HRC DMCC)

20 and 21 October 2015

HRC Ethics Committee (HRC EC)

13 May 2015

19 August 2015

11 November 2015

Please note: Any submissions to the HRC EC need to be sent to Lana Lon, at llon@hrc.govt.nz three weeks before the meeting.

About Ethics Notes

Ethics Notes is not a refereed journal and does not publish full length articles. The opinions expressed are those of the writers, and do not necessarily represent the views of the HRC.

Ethics Notes can be read on the HRC website: www.hrc.govt.nz.

Contributions are welcome. All articles in *Ethics Notes* may be reprinted, provided the source is acknowledged.

If you would like to subscribe to *Ethics Notes*, or if you no longer wish to receive *Ethics Notes*, please email: ethicsnotes@hrc.govt.nz and include your name and mailing address details. Thank you.



Health Research
Council of
New Zealand

Te Kaunihera Rangahau Hauora o Aotearoa

Phone: +64 9 303 5200

Fax: +64 9 377 9988

Level 3, 110 Stanley Street, Auckland 1010, New Zealand

PO Box 5541 Wellesley Street,

Auckland 1141, New Zealand

www.hrc.govt.nz