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Short communication

Ethical implications of location and accelerometer measurement in health research studies with mobile sensing devices

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ABSTRACT

Quantification of individual behaviours using mobile sensing devices, including physical activity and spatial location, is a rapidly growing field in both academic research and the corporate world. In this case study, we summarize the literature examining the ethical aspects of mobile sensing and argue that a robust discussion about the ethical implications of mobile sensing for research purposes has not occurred sufficiently in the literature. Based on our literature summary and guided by basic ethical principles set out in Canadian, US, and International Ethics documents we propose four areas where further discussion should occur: consent, privacy and confidentiality, mitigating risk, and consideration of vulnerable populations. We argue that ongoing consent is crucial for participants to be aware of the precision and volume of data that is collected with mobile sensing devices. Related to privacy we discuss that participants may not agree that anonymized data is sufficient for privacy and confidentiality when mobile sensing data are collected. There has been some discussion about mitigating risk in the literature. We highlight that the researchers' obligations toward mitigating risks that are not directly related to the study purpose are unclear and require considerable discussion. Finally, using mobile sensing devices to study vulnerable populations requires careful consideration, particularly with respect to balancing research needs with participant burden. Based on our discussion, we identify a broad set of unanswered questions about the ethics of mobile sensing that should be addressed by the research community.

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Quantification of individual behaviours using mobile sensing devices, including physical activity (using accelerometers) and spatial location (using Global Positioning Systems [GPS], Bluetooth beacons, WIFI routers or cell phone towers), is a rapidly growing field of both research and technology (Kerr et al., 2011; Jankowska et al., 2015). Mobile sensing is defined as using the computing, sensing, and communication capabilities of mobile devices such as smartphones to enable the real-time collection of individuals' behaviours (Krenn et al., 2011; Shirer et al., 2016). The collection and storage of highly detailed data about individuals' health and spatial location requires a renewed discussion about the ethical implications of such an endeavour. We focus the scope of our discussion on location measurement and accelerometer data collection using mobile sensing devices. We do not address ethical concerns from

other mobile sensing sensors, for example voice recording from smartphone microphones (Hashemian et al., 2012).

The existing literature discussing the ethics of mobile sensing research is often focused on aspects of successful ethics applications for individual researchers, what Guillemin and Gillam (2004) call procedure ethics, rather than a discussion about ethics of mobile sensing emerging during the research process, or ethics in practice. The CORE (Connected and Open Research Ethics) Project, led by a team at UC San Diego with support by the Robert Wood Johnson Foundation (<http://thecore.ucsd.edu/>), has begun reflection and research on the ethics of mobile sensing and provides information for researchers and institutional research ethics boards, covering topics of informed consent language, data collection, and storage practices to facilitate ethical and responsible research designs (Torous and Nebeker, 2017). Related to location measurement and accelerometer data collection, Nebeker et al. (2015) in a case study of 8 Institutional Review Board ethics applications involving GPS data collection were surprised by the

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finding that IRBs generally had little ethical concern with collecting GPS location data. Individual researchers have discussed ethical concerns related to specific research projects, but these discussions are narrow and focus only on specific aspects of each project. For example, Rainham et al. (2012) suggested that ethical obligations about voluntary participation were met by providing instructions on how to turn off the device (Rainham et al., 2012). Alternatively, Wiehe et al. (2008) suggested that technical measures to mitigate unwanted access to the data and not using deception were sufficient to meet the highest ethical standards (Wiehe et al., 2008).

The CORE initiative is important and has begun a wider discussion of the ethical implications of collecting mobile sensing data for research purposes (Nebeker et al., 2015, 2016). However, we contend that as a research community we have not sufficiently discussed the ethical implications of using location measurement and accelerometer capabilities of mobile sensing devices for research. The objectives of this paper are to summarize the literature examining ethical dimensions of location and accelerometer measurement in the research context and to highlight areas where further discussion within the field and with ethicists could be useful.

1. Background

The Canadian Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (Government of Canada, Interagency Advisory Panel on Research Ethics 2014) states that ethical aspects of research involving humans includes three basic principles: *respect for persons*, *concern for welfare*, and *justice*. Similarly, the US Belmont Report outlines respect for persons, beneficence, and justice as basic ethical principles (Ryan et al., 1979). The Helsinki Declaration (World Medical Association, 1964) and the US National Institutes of Health Ethical Guidelines and Regulations (National Institutes of Health, 2010) also discuss similar basic ethical principles. We frame our discussion using the basic ethical principles common to the majority of national and international guidance for research ethics.

Respect for persons recognizes that all research is conducted in such a way to value participants, whether that be individuals *per se*, their data, or biological material they provide. *Concern for welfare* is concern for the quality of an individual's life. It requires researchers and ethics boards to aim to protect participants' privacy, control over information, and mitigate potential risks associated with participation in research. *Justice* is the obligation for fair and equitable treatment of research participants both within specific studies as participants, but also more broadly by not systematically excluding certain groups in research. In the case of mobile sensing this could be because certain groups may not have phones with location measurement capabilities or data plans. Generally, basic ethical principles are applied via (1) informed consent, (2) privacy and confidentiality, (3) mitigating risk, and (4) consideration of vulnerable populations. We describe and discuss how basic ethical principles are applied using informed consent, privacy and confidentiality, mitigating risk, and consideration of vulnerable populations and discuss how research involving mobile sensing devices challenges these applications. We hope this paper will create a conversation about ethics in research using mobile sensing devices.

2. Informed consent

Informed consent typically has three main characteristics. Consent is voluntary and can be withdrawn at any time. Consent must be informed. Consent is an ongoing process. The requirements for consent (and assent for research involving children) should also reflect specific considerations of the population under

study. The consent process for groups who are unable to provide informed consent may require researchers to obtain consent from a legal representative.

Consent when using mobile sensing among participants unable to provide consent has been discussed for research among patients with dementia. In this research, mobile sensing devices are being used to track individuals and minimize potential risks of falling or getting lost. Where informed consent may not be possible, and an authorized third party acts on behalf of an individual. Landau and Werner (2012) suggest that it should not only be the decision of the authorized legal representative, but that attempts should also be made by the researchers to discuss the device and consent with the participants themselves. Among the general population, we argue that the concept of ongoing consent is crucial. The volume and velocity of data being collected via mobile sensing may be difficult to convey in an initial informed consent document. For example, Fig. 1 shows one week of location data from the lead author in a heat map. The heat map was created using 20,814 data points, including time and date, altitude, latitude, longitude, and speed. Visualizing mobile sensing data gives a detailed account of an individual's whereabouts, and participants should be made aware of and approve this during data collection. The underlying technology can provide participants with the ability to pause data recording before engaging in a private activity, or delete data they do not wish to be recorded after they have been collected. The extent to which these features have been provided to participants in existing studies using mobile sensing devices is not known. However, the ability to pause recording or delete data does not entirely negate the ability of researchers to infer the location. For example, if a participant's partner does not want the phone recording data in their home they may systematically pause recording when they are at home, making it possible to estimate home location based on a consistent pattern of missing data at a certain time of day. It may also be possible to estimate when they were home with or without their partner. We believe that a consent renewal process for participants could show a heat map of the data (Fig. 1) along with the estimated location types (e.g., home, work) based on the data. We also believe that as researchers, we should not use patterns in missing data when participants pause devices to estimate location types.

3. Privacy and confidentiality

Michael et al. (2006) suggest that privacy is the most important and challenging ethical issue related to mobile sensing because devices automatically record participants' whereabouts (Michael et al., 2006). In the context of research ethics, generally consent, privacy and confidentiality, and anonymity are paramount. The currently preferred methods to protect privacy include collecting anonymized data; collecting identifiable data, anonymizing them, using a third party to store the anonymized data, and only allowing anonymized data to be used by researchers; and collecting identifiable data and de-identifying as soon as possible. We argue that privacy and confidentiality measures in place rely on a crucial assumption that may not be valid when data are collected using mobile sensing.

The crucial assumption underlying the advantage of anonymized data is that the risk of identification from anonymous or de-identified data is low. We would argue it is false to assume that anonymous or de-identified data can even be collected when dealing with location and accelerometer data from mobile sensors, given the high velocity and volume of data collected and current data analysis techniques (Rossi et al., 2015). For example, a paper correctly identified the home locations of 79% of study participants based only on a JPEG image map published in the New England

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