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Research ethics for mobile sensing device use by vulnerable populations

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ABSTRACT

Devices equipped with sensors to track mobility, such as through Global Position Systems (GPS) and accelerometery, are increasingly being used for research. Following Canadian, US, and International guidelines there is a need to give special consideration when conducting research with vulnerable populations. This paper examines specific ethical concerns for conducting research with mobile sensing devices for use by vulnerable populations, considering aspects of both research design and research process. Drawing on insights from feminist design and aligned fields, such as participatory design and action research, we contend that any research design and process for working with vulnerable populations must be developed in collaboration with the particular groups and communities who are part of the research. As part of this process of collaborative research, we discuss risks in terms of the lack of control over data associated with choosing commercial devices, as well as practicality and obtrusiveness of devices for the wearer. We also discuss the significance of informed consent and refusal and issues relating to security and safety during research. As part of the collaborative research design and process, we argue that participants should be given as much control over their data as possible. Based on this discussion, we provide recommendations for researchers to consider, which are broadly relevant for research using mobile sensing devices but particularly significant in relation to vulnerable populations.

Devices equipped with sensors to track mobility, such as through Global Position Systems (GPS) and accelerometery, are increasingly used for research (Jankowska et al., 2015; Kerr et al., 2011). These devices collect detailed personal and health information about individuals and create new ethical concerns. Many researchers, for example, have pointed to potential breaches in privacy and confidentiality involved in storing, displaying, and disseminating spatial data that has not been adequately anonymized (Boulos et al., 2009; Brownstein et al., 2006; De Montjoye et al., 2013; Seidl et al., 2016). At the same time, using mobile sensing devices allows researchers to track diverse spatial and mobility patterns to understand their association with health risks, including among vulnerable populations.

The study of spatially linked health risks is often done through neighbourhood research and using administrative boundaries (zip/postal codes or census tracts) and GIS mapping. These methods rely on static spatial contexts that do not capture travel or activity beyond the location of analysis, which can be examined using mobile sensing devices (Duncan et al., 2016). The use of mobile sensing devices also works to eliminate recall bias and error common to other methods aimed at tracking travel and movement such as travel diaries and web-based mapping (Duncan et al., 2018; Jakopanek et al., 2014). GPS tracking also allows for measuring health-risks associated with social and physical environments where other forms of measurement are not practical or ethical, such as examining the cigarette smoking behaviours of adolescents (Wiehe et al., 2008).

Because of these advantages, research using mobile sensing devices is being used to examine population health in relation to spatial context among vulnerable populations, including people who inject drugs, men who have sex with men (MSM), Black MSM, transgender women, and low-income housing residents (Duncan et al., 2014, 2016; 2018; Goedel et al., 2017; Landovitz et al., 2012; Mirzazadeh et al., 2014; Tamura et al., 2017). We define vulnerable populations as a "subgroup or subpopulation who, because of shared social characteristics, is at a higher risk of risks" (Frohlich and Potvin, 2008, p. 218). These populations often include groups marginalized in relation to ability, gender, sexuality, race, or class, or intersections of categories that can compound the risk of risks (Crenshaw, 1989, 1991). Research has examined the relationship between neighbourhood noise with body mass index and blood pressure based on GPS-defined activity space to evaluate risks in relation to cardio-vascular disease for low-income housing

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residents (Tamura et al., 2017, 2018). Researchers have also argued that the use of mobile sensing devices could help inform HIV prevention efforts (Duncan et al., 2018a,b; Goedel et al., 2017; Mirzazadeh et al., 2014), harm reduction practices in relation to drug injection (Mirzazadeh et al., 2014), and to monitor patients with dementia (Lin et al., 2012).

There is a need to give special consideration in relation to vulnerable populations when conducting research using mobile sensing devices (Fuller et al., 2017; Haley et al., 2016; Nebeker et al., 2017). Guidelines for ethical conduct, including the Canadian Tri-Council Policy Statement 2, the United States Belmont Report, and the World Medical Association's Declaration of Helsinki similarly indicate the need to give special consideration and attention to vulnerable populations (Canadian Institutes of Health Research et al., 2014; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978; World Medical Association, 2013). Yet, guidelines regarding research design and practice for using mobile sensing devices with vulnerable populations have not been examined in detail.

Researchers have sought to examine the acceptability and feasibility of using mobile sensing devices with specific vulnerable populations, including different groups of MSM (Duncan et al., 2016, 2018), transgender women (Goedel et al., 2017), people who inject drugs (Mirzazadeh et al., 2014), and low-income housing residents (Duncan et al., 2014). Feasibility assessments in these studies centre on the extent to which participants wear the mobile sensing devices and for how long, and whether sufficient data are collected and devices are returned. Acceptability assessment examines concerns raised or experienced by participants such as fear of losing the device and comfort while wearing or using the device. We see such consultations with participant populations as an essential part of conducting research using mobile sensing devices. However, we also consider broader ethical concerns often not addressed in studies that centre solely on feasibility and accessibility, even as these studies ask participants to use the devices as part of this assessment. We thus provide a scaffold for researchers to consider before conducting research with vulnerable populations using mobile sensing devices. As such, we do not focus on any one specific population, but provide examples where certain concerns might apply.

This paper builds on the discussion initiated by Fuller et al. (2017), which examines ethical concerns for conducting research using mobile sensing devices relating to consent, privacy and confidentiality, and mitigating risk. The authors also argue that ethical concerns for research with vulnerable populations are understudied, need to be determined *a priori*, and that participant populations need to provide feedback on the technologies used for the study and be provided with multiple device options. The Connected and Open Research Ethics (CORE) group at the University of California San Diego has also examined ethics review board perspectives on research using mobile sensing devices, as well as produced a checklist for researchers to use when considering using digital technologies for research (Nebeker et al., 2015, 2018; Touros and Nebeker, 2017). The checklist asks researchers to evaluate their use of digital technologies for health research with respect to privacy, risks and benefits, access and usability, and data management (Nebeker et al., 2018). This paper provides context and recommendations for these evaluations with respect to vulnerable populations.

1. Background

We consider research as consisting primarily of three stages: research design, research process, and data storage and dissemination, and focus our discussion on the first two stages. Researchers should, however, continually examine guidelines and methods that are developed for appropriate data storage and anonymization of data for sharing and dissemination. This paper is based on a non-systematic survey of existing literature relating to research ethics and mobile sensing devices, a great deal of which focuses on ethical problems around and how to adequately anonymize data (e.g. De Montjoye et al., 2013; Gambs et al., 2010), as well as research using mobile sensing devices with vulnerable populations. We also draw on our collective research expertise and experience relating to mobile sensing device research, mobility and population health, and feminist technology studies. These insights are also supplemented by the participant observations of the first author who wore three mobile sensing devices (Fitbit, Apple Watch, and GENEActiv devices) for 1 week as a participant in a population health research project. These experiences provide insights into some of the concerns of using mobile sensing devices, but are also shaped by the privileges of being a cis-gendered middle-class white woman. This paper is thus additionally guided by the principles of feminist technology design.

Feminist design is a growing field, which builds on research from human-computer interaction, feminist technology studies, and related social science fields. The goals underlying feminist design include creating designs that include diverse users and contexts of use, and are sensitive to the power dynamics and unintended consequences of design (Bardzell, 2010; Breslin and Wadhwa, 2014; Cassell, 2002; Jaroszewski et al., 2018; Rode, 2011). Increasing research in feminist design focuses on examining the operation of intersecting power relations such as those relating to gender, race, class, and ability, questioning what norms are reproduced through the design, development, and use of technologies, as well as who is included or excluded in these designs, and who benefits (Costanza-Chock, 2018; Keyes, 2018; Scheuerman et al., 2018; Schlesinger et al., 2017). The issues raised in this paper are read through this lens, considering ethical problems at both micro or individual and macro or social levels.

Many goals of feminist design align with those of participatory design (van der Velden and Mörtberg, 2014) and decolonizing design (Tunstall, 2013), including a dedication to emphasizing collaboration and coproduction with participant and user communities as means of critiquing and reconfiguring the power structures between researchers/designers and participants/users. Another aligned approach, which public and population health researchers may be more familiar with, is action research, which also shares underlying goals where “researchers work explicitly with and for people rather than undertake research on them” (Meyer, 2000, p. 178). Feminist design and aligned fields are focused on developing more just and equitable practices in relation to marginalized groups, cultural practices, values, and forms of knowledge production. These fields thus offer insights for research design practices with vulnerable populations.

Following the principles of feminist design, we contend that any research design and process must necessarily be developed in collaboration with the particular groups and communities who are part of the research. This collaboration entails work with communities before conducting research testing the feasibility and acceptability of using devices. In the case of Indigenous groups these communities may also have their own guidelines for ethical review and practices, which researchers must follow (Assembly of First Nations, n.d.; First Nations Information Governance Centre, 2018; Inuit Tapiriit Kanatami, 2018). Within this framework, we consider issues of device choice, informed consent, and security and safety during research, which we see as necessary for researchers to consider in collaboration with research participants when using mobile sensing devices with vulnerable populations.

2. Device choice

An important issue relating to the use of mobile sensing devices for research is what device to use. Options include widely available commercial devices such as Fitbit or Apple Watch, or devices designed specifically for research such as those developed by GENEActiv. The device chosen must be able to measure the mobility of the research participants. For example, different styles of walking that include walkers or canes may affect the reliability and validity of data with certain devices. The use of devices that cannot measure these types of mobility may thus exclude certain populations altogether in participating in mobile sensing research.

Additionally, we assume in this paper that researchers will follow the proper methods to adequately anonymize data for dissemination in order to preserve participant confidentiality. It is, however, impossible to make the same assumption with regards to commercial entities. Researchers must balance the risk of using commercial devices – and the concomitant lack of control over data – with the obtrusiveness of the device for participants during research. These are issues that apply to any study using mobile sensing technologies, as seen in the Digital Health Decision-Making Checklist, which asks researchers to consider how "the technology can be tailored to the end user" and how "technology is accessible to diverse populations," as well as to review privacy policies and terms of conditions when commercial devices are used (Nebeker et al., 2018). We unpack some key facets of these points for researchers to consider and address in using the checklist and evaluating their projects when planning to conduct research with vulnerable populations.

2.1. Commercial devices

Commercial entities have previously released confidential spatial information when sharing data collected through their devices and applications, even when the data was anonymized. In January 2018, for example, when the fitness tracking app Strava released a set of heat maps showing the activity of users, they also accidently released the location of US military and intelligence installations (Hern, 2018). More generally, releasing spatial information, even in an anonymized format, has the potential to reveal sensitive locations and user habits. De Montjoye et al. (2013), for example, showed that spatial data based on mobile phone connections with particular antennae allowed individuals to be uniquely identified with as little as four to eleven data points and "little outside information is needed to re-identify the trace of a targeted individual even in a sparse, large-scale, and coarse mobility dataset" (De Montjoye et al., 2013, p. 4). Information can also often be inferred from missing or omitted data, an issue which is discussed further below in relation to informed consent (Fuller et al., 2017). Anonymized spatial data may identify neighbourhoods and sites, which could put particular locations associated with participants and vulnerable groups at increased risk of stigma. Similarly, this data can reveal spatial data and mobility patterns of groups such as women or children at risk of stalking, domestic abuse, kidnapping, or sex trafficking, as well as undocumented migrants and other groups targeted by law enforcement (Scott-Railton, 2018).

With little control over what data commercial entities release and the extent of their efforts to anonymize that data, there is also increased risk that participants could be identified through linked data (Bonchi et al., 2011; Narayanan and Shmatikov, 2008). In this case, data from two or more sources are linked together, enabling statistical or definite de-anonymization of the data and identification of individuals. Moreover, commercial devices collect multiple types of information, including from sensors for GPS, heart-rate, accelerometer, altimeter, and gyroscope. Not all of this information is always required for research, but it is nonetheless all collected and shared with and by the commercial entities who produce these devices. Some devices have also been shown to emit unique IDs that could allow a third-party to track a particular user within a given space, such as a shopping mall (Hilts et al., 2016).

Commercial entities may additionally be located in, or conduct business in, the United States (US), making the data they collect subject to the Uniting and Strengthening America by Providing Appropriate Tools Required to Intercept and Obstruct Terrorism (USA PATRIOT) Act of 2001. The majority of Canadian internet traffic additionally routes through the US (Clement and Obar, 2015). Recently, the United States-Mexico-Canada Agreement (USMCA) will also change data localization laws and policies in Canada. Where provinces such as British Columbia and Nova Scotia require sensitive health information to be localized within the province, the USMCA restricts these policies, creating less certainty of where data associated with commercial devices is stored (Office of the United States Trade Representative, n.d.; Geist, 2018).

The location and flow of data, particularly through the US, may further increase the risk for populations who are targets for surveillance by police and other law enforcement agencies such as refugees, undocumented migrants, and profiled population groups. In particular, personal data are increasingly being used for algorithmic assessments including for credit scores, risk assessments in parole hearings, hiring, or determining rental eligibility (Angwin et al., 2016; Merchant, 2018; Waddell, 2016). In these forms of assessment, data from a variety of sources, which may include mobile sensing devices, are evaluated according to particular measurements and by an algorithm to attribute a score or level of risk to a particular individual. These forms of assessment also disproportionately negatively affect vulnerable groups (e.g. Eubanks, 2018). While research devices may not be registered to an individual, if research participants connect the research device to a personal device such as a smart phone, the research data collected through these devices may also be inadvertently shared with a variety of companies and other entities. Participants are unlikely to read companies' privacy policies and terms of service and may not understand the meaning of these terms, which may similarly pose a challenge for researchers (Reidenberg et al., 2014). Data are additionally used to train algorithms in creating categories and classifications for assessment in ways that have been shown to be both problematic and biased in relation to gender, race, and other systems of inequality (Costanza-Chock, 2018; Buolamwini and Gebru, 2018; Eubanks, 2018; Keyes, 2018; Noble, 2018).

In their analysis of the consequences of classification, Geoffrey Bowker and Susan Leigh Star (1999) discuss how in South Africa during the apartheid, a person's racial classification – which had implications for where they could live, go to school, and numerous facets of their lives – could be determined or changed based on who they spent time with or their association with particular stereotypically racialized activities such as playing soccer. While this example is thankfully no longer relevant, mobility data that could capture where an individual spent time or who they associated with would have had a clear impact on their racial classification, in addition to providing broader population data about the mobility "characteristics" of different racial categories that would have been used and analyzed by these algorithms in creating the classification criteria. Current practices of predictive policing in the United States operate on similar logics, drawing on historical and spatial crime data to target specific locations for policing, while also using the data about particular individuals for surveillance (Stop LAPD Spying Coalition, 2018). Similarly, practices of "big data blacklisting" that include classifications such as the No Work, No Vote, No Citizenship, No Fly lists, as well as the Terrorist Watchlist flag suspicious data with a range of impacts on the rights and freedoms of particular individuals (Hu, 2016).

Beyond state surveillance and policing, there is also increasing use of an individual's data from mobile sensing devices by insurance companies to provide premiums related to healthy lifestyles, as well as to assess the risk of various populations (Capgemini, 2016; Thompson Reuters, 2018). While these programs currently operate to provide privileges to certain individuals, they also build on past logics of redlining by insurers and financial institutions that denied services to residents in particular neighbourhoods or communities. In addition to the direct effect on individuals, redlining reproduced the socio-economic vulnerability of populations in these areas (Davidow, 2014; Massey and Denton, 1993). To our knowledge, the combination of micro and macro ethical concerns associated with the use of data for algorithmic decision making and surveillance have not been addressed in population health research using mobile sensing devices, including those working with vulnerable populations. As mentioned above, research participants may link their data from mobile sensing devices with personal digital devices, sharing their personal and mobility data with commercial and other entities. The ultimate point being, researchers have little to no control over how commercial entities use, store, and disseminate the data collected with their devices, and based on historical and current practices this data can pose risks for vulnerable populations. Research drawing on principles of feminist design must consider these micro and macro ethical effects in relation to vulnerable groups in the use of mobile sensing devices.

2.2. Device obtrusiveness

Researchers should also consider the practicality and obtrusiveness of the particular device that is chosen for research. This includes considering how long the device needs to be worn, how often, for how long participants must interact directly with the device, and the types of interactions. Commercial devices that are widely used might be preferred where there is a risk of harm to the participant for being identified as a research participant. For example, in a study of people who inject drugs, some participants suggested that if their dealers learned of the devices it could put them at risk (Mirzazadeh et al., 2014). Research practices, such as labelling devices, can also make them more obvious, regardless of whether a commercial or non-commercial device is used.

Obtrusiveness, however, may vary depending on the diversity of participants according to gender, religion, or ethnic groups. For example, women's clothing often does not have sufficient, or any, pockets or belt loops to attach, easily carry, or hide some devices. Uniforms or dress codes for work, or cultural or religious norms, may also prevent the use of certain devices, where these devices may be categorized as jewellery or items such as wrist-watches could get caught in machinery. Vulnerable populations may be excluded from participating in studies relying on mobile sensing devices altogether if they cannot wear the devices, or these devices may put individuals at increased risk of job loss or social and religious sanctions.

Devices may also be obtrusive to participants themselves. Schukat et al. (2016) suggest that participants may become more anxious about their health or addicted to these devices, including developing hypochondria or anxiety. Devices without displays may prevent participants from self-monitoring, where there is risk to participants in relation to mental health. A gendered analysis of one mobile sensing device (the Jawbone UP3) also discusses how different devices reproduce binary gender norms, including through aesthetic and through the data interface. This and many devices only allow for the input of binary sex classifications, making “the device unfriendly to gender non-conforming users” (Cifor and Garcia, 2019). Researchers should also consider how these devices may rely on assumptions about binary sex and gender in the analytic data they present, particularly when conducting research with nonbinary and trans individuals.

Research with men who have sex with men in New York and the Deep South and transgender women in New York, however, has found a high acceptance of the use of mobile sensing for research in terms of issues such as ease of use, comfort wearing, and concerns such as theft (Duncan et al., 2016, Duncan et al. (2018a,b; Goedel et al., 2017). These studies assess concerns through surveys before and after, and sometimes during, the study-use of mobile sensing devices. Duncan et al. (2018a,b, p. 3063), however, also shows a small increased proportion of strongly agree/agree responses to “The GPS (irritated my skin or was) seems uncomfortable to wear” and “I am worried about my safety wearing the GPS.” Close collaboration with participant groups before and during the use of these devices would provide more in-depth insights into the mundane and daily challenges with using these devices that contribute to these responses and the overall obtrusiveness of devices.

Based on the issues discussed above, in relation to commercial devices and device obtrusiveness, we propose the following recommendations:

1) Researchers should conduct literature reviews specific to the population being studied and work with participant groups throughout the research design process, including discussing device choices and possible risk. Participants should also be offered choice as to the type of device used for research, particularly when participants may represent various or intersecting vulnerable groups.
2) Devices should be discretely labelled for research, in locations that cannot be seen when devices are worn.
3) When commercial devices are chosen, researchers should review the company privacy policies and terms of service to determine what information is collected and with whom this information could be shared, which should be relayed to participants as part of the informed consent process.
4) Researchers should collaborate with legal scholars or counsel and their research ethics board when additional expertise is needed in reviewing company policies and terms of service.
5) Researchers should monitor data storage and sharing laws and policies, and practices of using mobile sensing device data in algorithmic forms of assessment.
6) Researchers should continually re-evaluate the risks of using mobile sensing devices, particularly commercial ones, for research.

3. Informed consent

The process of informed consent is closely related with device choice, as the consent process necessarily includes discussing information about the types of data being collected and who that data are being shared with, including commercial entities when using commercial devices. As mentioned above, even if data are not being used for research, a variety of information is collected by many of these devices. The Digital Health Decision-Making Checklist (Nebeker et al., 2018) includes a column for researchers to address whether all points of the checklist are addressed as part of the informed consent process, as well as the research protocol. As Fuller et al. (2017) point out, however, participants may not be aware of the detail and scope of information that researchers and others can infer from the data collected from these devices. GPS maps, even when anonymized, can show patterns of movement and likely general locations of a participant's home and work. Fuller et al. (2017) also discuss how information could easily be inferred from missing data.

For example, studies of the acceptability and feasibility of using mobile sensing devices with MSM and transgender women include sample maps of a participant's GPS tracks (Duncan et al., 2016, 2018; Goedel et al., 2017). While data within the participant's home zip code are hidden and the map shows only outlines of zip-code areas, areas are readily identifiable based on landmarks. More detailed information could reasonably be gleaned with more sophisticated methods of comparison or by those who would also have specific knowledge and targeted interest in certain locations, such as law enforcement. Police have historically targeted MSM, including raids of bath houses and bars in New York (one of the more common locations for these studies) and elsewhere in the United States and Canada. In this way, mobility data has the potential to highlight areas used by vulnerable groups that are targets of attention by law enforcement or of harassment and discrimination and contribute to practices such as predictive policing, discussed above. As such, information about commercial devices and the risks associated with access to data by commercial entities are particularly relevant for any groups where the interception of data by law enforcement and authorities is a risk. This risk is compounded with the potential for identifying sensitive sites by inference, or identifying individuals through linked data. Discussing these risks is a necessary part of points such as “what data are shared is specified,” “with whom data are shared is stated,” and “associated risks are potentially known” in the checklist and the informed consent process (Nebeker et al., 2018).

As highlighted above, many vulnerable groups including visible minorities and economically disadvantaged populations have been subject to disproportionate surveillance by government bodies (Browne, 2015; Proulx, 2014). Emerging perspectives in the social sciences on ethical approaches to digital technologies and data, as well as on the decolonization of research and surveillance, additionally centre on *control* of data by participants (Amrute, 2018; Peake, 2015). As anthropologist Sareeta Amrute argues in speculating about "What would a techno-ethics look like?", "The conditions of providing data and the obligations set out for doing so need to be worked out in concert with the communities who produce that data" (Amrute, 2018). Control by participants over data requires information about when data are recorded and transmitted/transferred to researchers. Is all data downloaded at once by the researcher directly from the device at the completion of the study? Is data continuously transmitted from the devices to the researchers? Are participants responsible for transmitting the data once a day or once a week? Control also includes information on how participants can stop data collection for a period of time, in addition to the option of full withdrawal from the study which is commonly included in the informed consent process (Nebeker et al., 2016). Can participants simply take the device off? Is GPS data still collected even when devices are not being worn? Is there a power button that users can control? What information can researchers infer even when data are not being collected (Fuller et al., 2017)?

More generally, critical race and indigenous studies scholars have emphasized that collaboration with participant groups who have control over that participation includes the potential of refusal where participants may decline participation and refuse that certain research or information be shared in support of the self-determination of vulnerable groups (Benjamin, 2016; Simpson, 2007; TallBear, 2013). As Ruha Benjamin explains in examining instances and possibilities for refusal in genomics research, "the potential of refusal not only to negate colonial forms of knowledge production but also to create new, more equitable relationships between researchers, subjects, and the state is vital for conceptualizing a postcolonial feminist bioethics" (Benjamin, 2016: 4). For example, in discussing the design process developed through ethnographic research with marginalized groups using the mobile tracking app *Tinn*, which tracked users' experiences with tinnitus, Bryce Peake argues that decolonization necessitated the inclusion in the app of the option for participants to delete a period of data used for research, providing them with a measure of control over the data researchers had access to (Peake, 2015).

Fuller et al. (2017) suggest a consent renewal process where participants are shown heat maps of their data and the type of information that can be inferred. This practice could also be used as part of the collaborative research design and prior informed consent process, where researchers use sample heat maps and work with participants to collaboratively examine what types of information will be collected and could be inferred. This practice would help ensure the education of participants into what GPS mobility data entails, as well as the education of researchers into the matrix of domination experienced by participants that affect the risks and benefits of research using mobile sensing devices (Collins, 1992; Costanza-Chock, 2018a,b). Previous research has additionally indicated that clarity in the purpose of research and the usefulness and benefits of data collection, in particular, that collection of mobility data are indeed necessary for research purposes, is significant for participants (Boonstra et al., 2018; Duncan et al., 2016, 13). Designing research in collaboration with participant groups is a key means of ensuring that research goals align with participants' interests and values.

To address these issues, we propose the following recommendations related to the process of informed consent:

1) Researchers should first ensure that data collected with mobile sensing devices is necessary for the study; surveillance of vulnerable populations should not unnecessarily be increased. In this regard, the goals and values of collecting mobility data should be developed as part of the collaborative research design process, as discussed above, and discussed with participants as part of the informed consent process.
2) Participants should be informed of and shown all types of data being recorded, particularly in the case of commercial devices, and what kinds of information are deducible from that data (e.g. mode of transportation from accelerometer, type of activity from heart rate data, locations of home and work from GPS). We suggest that researchers review the data collected with participants following the research, as suggested by Fuller et al. (2017).
3) Participants should be given as much control as possible over the collection of their data, including the potential of refusal, as well as information about how to temporarily stop data collection and when and how data are transferred.

4. Security and safety during research

Finally, researchers should consider security and safety during the research process, including the security of the data while it is stored on the mobile sensing device and during transmission and the safety of research participants. These considerations largely centre on micro-ethical concerns relating to risks to individual participants. In studying the acceptability of using mobile sensing devices among young Black MSM in the Deep South, Duncan et al. (2018a,b, p. 3063) found a statistically significant increase between their enrollment and completion surveys when participants were asked "I am (was) worried about someone trying to steal the GPS" and "I am (was) concerned that I will (would) lose the GPS." While survey responses do not explain the cause of these increased concerns, theft or loss of a device raises issues relating both to the security of data and potential harm to participants. If a mobile sensing device is lost or stolen during research, access to the mobility and other data of participants stored on the device itself by a third party could put participants at increased risk. In addition to the security of data in such cases, requirements for participants to replace lost or damaged devices may be onerous for populations with limited economic means. Duncan et al. (2014), on the other hand, offered cash incentives as part of a study into the acceptance and feasibility of using GPS devices among low-income housing residents in New York, including a generous incentive following the return of the devices, which they suggest was both appreciated by participants and contributed to the high return rate.

Security of data in transmission and stored during the research process are also important considerations for researchers. Nebeker et al. (2018) include several elements relevant to this issue in their checklist, including whether data are encrypted, whether it can be accessed by participants and researchers, and whether data can and will be transferred to individuals' EHR. As indicated above, the use of commercial devices can make data subject to broad scale surveillance. In terms of access to data, it has been suggested that it is undesirable for researchers to actively monitor and analyse data in real time to detect harm or illegal activity (Fuller et al., 2017). As suggested above, the timing of data collection should be discussed with participants as part of the informed consent process.

Here we assume ethical conduct by researchers, where participants will not be actively monitored without their explicit consent and researchers will work to preserve the confidentiality of participants. There are, however, examples by private companies of unethical access to real-time user data beyond the issue of sharing that data with law enforcement agencies. Real-time spatial data can be used to stalk women, for example, which presents an additional risk with the use of commercial devices. Sexual harassment in academia and medicine is also prevalent, suggesting the potential for such violations of privacy may not be limited to private industry (National Academies of Sciences, Engineering, and Medicine, 2018). In the US in 2006, approximately 10% of all cases of stalking and harassment involved the use of GPS technologies, amounting to approximately 500,000 cases (Baum et al., 2009). This proportion has likely since increased with the increased availability of these technologies. With the possibility of linking mobile sensing devices to applications with personally identifiable information, particularly with the use of commercial devices, the possibilities of those who may be able to monitor individual locations in real-time expand.

From a feminist design perspective, the affordances created by the design of these technologies and the ways these technologies may be used by the broad networks of actors involved as they are used must be considered (Wajcman, 2007). Fuller et al. (2017), for example, also propose that participant data should be given to police “if a legal writ requests data access,” and that this information be clearly disclosed to participants as part of the informed consent process (Fuller et al., 2017, p. 87). This procedure, however, might create significantly increased risk for vulnerable populations targeted by law enforcement, such as undocumented migrants and other cases discussed above. As suggested in the Canadian TCPS2, “Researchers shall maintain their promise of confidentiality to participants within the extent permitted by ethical principles and/or law. This may involve resisting requests for access, such as opposing court applications seeking disclosure” (Canadian Institutes of Health Research et al., 2014, p. 60).

The affordances of these technologies may also be used to promote the well-being of participants. For research with participants facing challenges with mental health, real-time contact information for support services was provided through the Socialise app being used for research. This information was provided based on practitioners' recommendations and participants’ interaction with the app, where their interactions indicated a need in relation to their mental health status (Boonstra et al., 2018). Relevant contact information for support services could be similarly provided to participants through these devices for a variety of vulnerable populations. The relevance of providing such information can be examined as part of the research design process in collaboration with participant groups.

To address these issues, we propose the following recommendations related to safety and security during research:

1) Data stored on the device and in transmission should be encrypted and access restricted to the participant, using best practices for data and device security.
2) The possibility and relevance of providing cash or other forms of incentives and compensation to participants should be evaluated as part of the research design process, to contribute to the mutual benefit of the research for researchers and participants.
3) Active monitoring is not desirable, as suggested by Fuller et al. (2017). The risks to confidentiality for specific vulnerable participant populations in relation to legally-compelled disclosure should be evaluated as part of the collaborative research design process, and discussed and emphasized during the consent process.
4) Contact information for relevant support services should be provided to participants as part of the initial consent process or through the devices provided to participants.

5. Conclusion

This discussion is not meant to provide a comprehensive set of guidelines for researchers to follow, but rather to continue the discussion about questions relating to ethical practice when using mobile sensing devices. Research with vulnerable populations necessitates dedication to principles shared by many ethical guidelines such as justice, respect for persons, and concern for welfare (Canadian Institutes of Health Research et al., 2014; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research., 1978). Many vulnerable populations “are typically situated at the deadly intersection of medical abandonment and overexposure” (Benjamin, 2016, p.5). The focus on vulnerable populations centres the issues “linked to one's position in the social structure,” where a broader population approach may neglect both vulnerable groups at risk and the structural causes of those risks (Frohlich and Potvin, 2008, p. 218).

We suggest researchers begin by considering questions around device choice, informed consent practices, and security and safety during research. However, many of the issues raised above relate to the overexposure by vulnerable groups to forms of surveillance that increase their risk of risks, including both micro and macro ethical issues with using mobile sensing devices. As a result, we provide recommendations drawing on insights from feminist design and aligned fields. Interweaving with these recommendations, we contend that research should be designed and conducted in collaboration with participant communities. Researchers should enable control – and the possibility of refusal – over data and research process by participants.

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