

Chapter 12 Field studies of interactive technologies for marginalized users: a Canadian ethics policy perspective

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Abstract

Human-Computer Interaction (HCI) is increasingly employing fieldwork to evaluate and study emerging technologies (e.g. mobile devices, digital assistants) or new contexts of use (e.g. vulnerable or digitally-marginalized users). This has posed new ethical dilemmas for the researchers designing and conducting them, such as unplanned participation in research by caregivers; discovery of substandard professional conditions at the fieldwork site; research site collaborators indirectly accessing materials that may expose the privacy of vulnerable participants. The presence of such dilemmas and the difficulty anticipating ethical traps during fieldwork has often made the increasingly-formal ethics review process more difficult.

We present here a synthesis of case studies of interactive technologies for marginalized users, aiming to provide researchers and practitioners with additional sources of guidance as they tackle ethical dilemmas in conducting techno-centric fieldwork with marginalized users such as older adults. We argue that the core source of these dilemmas is often not the disruptive nature of these technologies, nor their deployment in sensitive settings. Instead, we offer a policy-based interpretation of these case studies along dimensions that highlight methodological challenges facing HCI researchers that transcend the specificity of the deployed technologies, and discuss lessons learned as applicable to the practice of HCI fieldwork with marginalized users in general and older adults in particular.

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Highlights

- HCI research is increasingly employing fieldwork to study and evaluate interactive technologies
- Many deployments of technology are with vulnerable, digitally-marginalized, or underrepresented users
- Such new context of studying emerging technologies in situ have posed ethical dilemmas for HCI researchers
- The source of many such dilemmas is the gap between the body of practice in HCI and the body of knowledge and policy guidelines interpretation with respect to the ethical conduct of research with human participants
- We present a policy-based interpretation of several case studies that may help new researchers and practitioners avoid the ethical traps that exist between the knowledge and practice of HCI research and the available guidelines.

Biographical Statement

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Munteanu, Stephanie has conducted extensive research investigating the Canadian Tri-Council policy frameworks that regulate ethics in research for human computer interactions of vulnerable and marginalized groups with emerging and disruptive technologies.

12.1 Introduction

Traditional approaches to researching and developing interactive digital technologies typically have a component involving human participants. This usually takes the form of summative studies such as those used to validate the design of an interface (e.g. usability evaluations), or formative studies such as research on understanding the complex (social, economic, etc.) factors influencing the use of technology or research methods for collecting user requirements that inform the design of various interfaces. More recently there is renewed interest within fields such as Human-Computer Interaction (HCI) in a wider range of qualitative methodologies, especially in the formative stages of research. Many are ethnographic in nature and drawn from disciplines such as anthropology or sociology of technology. For example, Contextual Inquiry (Holtzblatt & Jones, 1993) is a method that was proposed more than two decades ago, yet has seen little use outside the collection of user and design requirements in workplace settings. While ethnographic (and more generally, qualitative) approaches have been historically present in HCI research (Suchman, 1987), the past two decades have been dominated by summative evaluations of interactive technologies, most often in the form of controlled experiments (Barkhuus & Rode, 2007).

In recent years these ethnographic approaches drawing from several disciplines (social sciences, critical theory, feminism, etc.) have started seeing a wider renaissance across HCI research (Bardzell & Bardzell, 2011), especially for under-represented users (Schlesinger, Edwards & Grinter, 2017). This may be partly due to an increase in the diversity of technological developments, but also due to many new domains of application. Research within these emerging application areas focuses on understanding the support needs of marginalized or under-represented users and designing interactive assistive technologies for them; for example, applications in support of older adults (Baecker, Moffatt, & Massimi, 2012; Neves, Franz, Munteanu, Baecker, & Ngo, 2015) or for people with various abilities (Bigham, 2014; Mandryk & Birk, 2017; Gerling, Mandryk, & Kalyn, 2013; Flatla, Andrade, Teviotdale, Knowles, & Stewart, 2015). Within these research spaces, qualitative field methods are emerging as a useful methodology both in the formative (inquiry) and summative (evaluation) stages (Axtell, 2017).

As HCI researchers are increasingly conducting research outside the controlled environment of laboratory studies, or with vulnerable user groups, one of the challenges is that of new ethical dilemmas (or moral panics, a term first coined by Cohen (1972) – later used by van den Hoonaard (2001) in the context of the formal ethics application process, or more recently as techno panics as suggested by Cows & Schroeder (2015). While there is not a single or comprehensive definition of what an ethical dilemma is, the examples captured by van den Hoonaard (2002) and later by Sadownik, Munteanu & Xu (2016) indicate that an ethical dilemma may occur when the research encounter an (often unexpected or unplanned)

situation in which the formal ethics policies or guidelines contradict the reality of the research – for example, when complying with the guidelines may expose the participants to increased harm, or when the lack of policy guidance puts the research in a situation to choose between compromising the outcomes of the research or the well-being of participants (including researchers as participants). This is only expected to increase and diversify, as new technologies are emerging such as wearable devices, intelligent personal assistants, or interactive assistive applications. Incorporating ethics in the design of such research studies is increasingly complex and often bureaucratic (Haggerty, 2004).

Historically, HCI research has held an ergonomics and cognitive focus, and this has led to the use of controlled experiments as a frequently-employed method of empirical investigation – with e.g. usability evaluations playing a most central role (Greenberg & Buxton, 2008). Ethnography and field research have often been employed as methods to elicit design requirements (Millen, 2000). While ethnography has always been an integral part of HCI (Dourish, 2006), it is only recently that HCI researchers are more visibly and more widely embracing a broader context of such field methods – a trend that is not without disciplinary criticism (Crabtree, Rodden, Tolmie, & Button, 2009). In this chapter we are focusing on the area within HCI that is considered techno-centric in its goals (e.g., formative or summative studies that are relevant to interactive technology), has broadened its methodological approach to include qualitative fieldwork, and yet does not benefit from an extensive history of such research. As we will elaborate later, it is this particular intersection where our previous research on ethics in HCI (Sadownik et al., 2016) has identified significant knowledge gaps with respect to the application of ethics guidelines. This chapter focuses on this intersection, and offers a reflection on its applicability to techno-centric research with older adults (as an example of a marginalized user group). This is presented through an analysis of several relevant case studies, anchored in interpretations of ethics guidelines that may guide techno-centric HCI researchers in avoiding similar ethical traps. While this analysis is grounded in interpretations of policies and ethical guidelines (in a way, a top-down perspective), a different, more reflective and bottom-up perspective is offered in another chapter of this book (Waycott & Vines, 2018, in this volume).

We should clarify that by techno-centric fieldwork or more broadly, techno-centric summative or formative studies, we mean (field) studies involving human participants where technology is a core focus. Summative studies may involve the evaluation of a previously-developed interactive technology (such as an interface), either in situ or in a controlled environment. Formative studies may provide the foundations for later development of interactive technologies, in a wide range of forms; for example: understanding users' current practices (and drawing design requirements from this), engaging users in design, or

understanding the human, social, cultural, economic factors affecting users' complex interaction or relation with existing technology.

12.2 Background

Many national, regional, professional, or funding bodies implement different approaches to ensuring that research with human participants is conducted in an ethical manner. Canada alongside Australia are the two countries which have implemented a broad comprehensive and trans-disciplinary national policy with respect to the ethical conduct of research with human participants – an approach that helps ensure a higher degree of consistency in the application of ethical principles. In Canada this takes the form of the Tri-Council Policy Statement (TCPS2, 2014), which applies to all research with human participants that is conducted at publicly-funded institutions. Similar regulatory approaches exist elsewhere although these differ in scope or in its applicability. In the United Kingdom, research involving human subjects is carried out under the governance of various bodies (professional organizations, universities, the National Health Service - NHS) and their policy statements (Ethical Guidelines for Good Research Practice by the Association of Social Anthropologists of the UK and the Commonwealth). In the United States the ethics guidelines are less centralized (e.g. specific to each university), although the biomedical-focused Common Rule regulates all federally-funded research and as such most universities observe its principles (Millum, 2012).

While ethics has long been a focus of HCI research (Mackay, 1995; Chalmers et al., 2011), the process of formal ethics review, which was once a formality for traditional lab-based HCI research, has become more challenging as HCI researchers are now venturing into unfamiliar contexts and physical spaces while conducting fieldwork with emerging technologies. Some of these challenges are not new in fields such as sociology or anthropology. However, the rapid evolution of interactive technologies, their new contexts of use, their increasingly-diverse users (especially marginalized populations), and renewed interest in situating these within qualitative field work represent a significant departure from the process of formal ethics review many techno-centric researchers were accustomed to (Munteanu et al., 2015).

There is evidence that the HCI field is adapting to the ethical challenges prompted by the changing nature of the evaluations and field studies, as we have surveyed in our previous work (Munteanu et al., 2015). However, we have also illustrated in this aforementioned survey examples of our own prior work and of several of our colleagues which suggest that HCI fieldwork, especially with marginalized or under-represented users, “often does not fit traditional or static ethical templates”. In our prior policy analysis and case study synthesis (Sadownik et al., 2016) we have identified several knowledge and practice gaps that highlight how either current ethical guidelines do not address the new challenges emerging from

techno-centric fieldwork or the applicability of such guidelines faces barriers related to the researchers' expertise. These gaps have been captured in an interpreting framework which we will detail in the next section, and which we will use to guide our discussion of new ethical dilemmas as relevant to techno-centric fieldwork with marginalized users.

12.3A Framework for Interpreting Ethical Dilemmas

We are grounding our analysis of ethics case studies within the guidelines provided by the Canadian TCPS2. This is motivated in part by the researchers' own training in and prior research of this policy, but primarily by TCPS2 being extremely broad in its trans-disciplinary applicability, while at the same time emphasizing flexibility with respect to how ethics principles apply to different research fields (Millum, 2012). This framing has been chosen not only due to the authors' location but primarily because Canada (alongside Australia) is one of the very few countries with a comprehensive national policy that all publicly-funded institutions must follow. While this chapter references the Canadian guidelines, the principles are universal, and thus we hope that researchers in other countries can draw upon the case studies presented here when solving their own techno-centric ethical dilemmas. For this, our mentions of the Canadian guidelines are described in terms of the principles and interpretation guides contained in TCPS2, with pointers to specific articles used only for bibliographic reference purposes.

In Sadownik et al. (2016), we have proposed a framework of knowledge gaps with respect to identifying and mitigating the ethical dilemmas arising from the broadening of techno-centric fieldwork to new domains and new technologies. This framework has been developed by conducting a thematic analysis over a large collection of case studies of ethical dilemmas. The thematic analysis was guided by the ethical principles outlined in TCPS2. The case studies consisted of 118 papers which described, as the central focus of the paper, an ethically-relevant case (e.g., field study, online ethnography, controlled experiment in sensitive settings). These case studies have been collected from several relevant HCI workshops, predominantly the 2015 and 2016 series of Workshops on Ethical Encounters in HCI, held in conjunction with key conferences in this field (Waycott et al., 2015, 2016; Davis & Waycott, 2015b). A detailed description of the methodology used to identify the case studies and to construct the interpretation framework is given in Sadownik et al. (2016).

Our theoretical framework is anchored by four Key Points (KP). These points represent distinct aspects of the gaps that exist between the knowledge and practice of HCI research and the available policy guidelines. Each of these KPs represents a theme that encompasses several types of ethics dilemmas, with each dilemma being carefully measured against the TCPS ethics guidelines, regardless of the country where the research was conducted. We summarize here these key points and provide examples of the types of ethical dilemmas

representative of those points, as means to contextualize the analysis presented in the rest of this chapter. In the next section we use this framework to interpret and discuss new case studies as applicable to marginalized user groups such as older adults.

KP 1: Lack of Path Dependency.

HCI researchers are venturing into unfamiliar contexts and physical spaces with emerging technologies in fieldwork where they lack path dependency and cannot draw on a large resource of literature from their colleagues.

(Sadownik et al., 2016)

This KP is grounded in many case studies brought forward by HCI researchers that present situations where there is little prior knowledge about how to handle such new contexts. Among the examples of representative ethical dilemmas is that of the conflict between protecting participants' privacy and respecting Terms of Service which requires disclosure of identifiable information (Bica et al., 2016). Another example of an applicable case study is that of "contextual" ethics – unexpected situations in the field that differ from the initial protocol that was formally approved – such as that illustrated by the cessation of studies with well-being apps, especially as focused on mental health (Buchanan, 2015), which may cause undue harm to participants. Such situations were rarely encountered in HCI in the past or reflected extensively in HCI literature. As such most researchers lack the prior knowledge or experience to anticipate them.

KP 2: Multi-disciplinary Collaborations.

HCI researchers are attempting to test their research in areas that require multi-disciplinary collaborators and either have difficulty coordinating research interests or lack participating collaborators.

(Sadownik et al., 2016)

As HCI research is increasingly looking at how to design interactive applications that provide benefits to their users such as related to health, collaborations across disciplines and between academia and industry are becoming commonplace. This has the potential to create situations of conflicting roles between researchers, practitioners, and other stakeholders. One of the most illustrative examples is that of collaborations with mental health professionals, e.g. the dissonance between researchers and clinicians in their support of mental health apps based on an understanding of duty of care (Estrada, Wadley, & Lederman, 2015) or in the researchers' limited ability to provide online support for the intervention technology at all times as expected by practitioners (Singh, Kaur, Sajjanhar, & Cross, 2015).

KP 3: Unpredictable Variables.

HCI combines the world of working with humans and working with computing devices, an environment that combines both the uncontrolled and the controlled variables; however, many researchers are methodologically more accustomed to controlled experiments and thus prefer to conduct these within laboratory settings.

(Sadownik et al., 2016)

In our synthesis study (Sadownik et al., 2016) we have identified a pattern of HCI researchers facing unpredictable situations in their fieldwork. Some of these stem from working with participants in uncontrolled environments (a situation which e.g. ethnographers are familiar with), while some are caused by the unpredictable use of technology in such settings. Example case studies are the unexpected triggering of negative emotions in participants (Gerling, Lineman, Waddington, Kalyn, & Evans, 2015), trauma (Yoo, 2016), or even conflict between participants (Kazemian, Munteanu, & Penn, 2016).

KP 4: Training Background.

Many HCI researchers have a training that prepares them for controlled experiments in computer science or hard sciences but subsequently leaves them unprepared to deal with the challenges of multidisciplinary research in the social sciences or soft science research due to the potential for subjectivity and uncontrolled variables.

(Sadownik et al., 2016)

Our prior case study synthesis indicated that many HCI researchers' backgrounds leaves them unprepared to deal with several unexpected situations in the field. One of the most common such situations is that of researcher-as-participant. For example, sensitive settings in which many researchers felt the need to comfort their participants when privy to upsetting conversations (Davis et al., 2015), or in which the emotional impact of building a relationship with participants caused many HCI researchers to feel a range of negative emotions when the study ended (Dee & Hanson, 2016).

12.4 Case Studies of HCI Research with Marginalized Populations: Policy Reflections

As described in Sadownik et al. (2016), our initial survey analysed papers that presented ethical dilemmas within HCI research. For the analysis presented in this chapter, we have added papers from two new workshops: the 2017 edition of the Ethical Encounters in HCI

Workshop (Waycott et al., 2017) and the 2015 Workshop on Ethics for Studying Sociotechnical Systems in a Big Data World (Fiesler et al., 2015), held at the ACM SIGCHI Conference on Computer-Supported Cooperative Work and Social Computing (CSCW). The entire collection of papers (totalling close to 250 papers) were then independently analysed, for the purpose of identifying which of the ethical dilemmas described in these papers are specific to techno-centric fieldwork with marginalized populations. This resulted in a total of 88 case studies of such ethical dilemmas. These case studies were then classified according to the broader dilemmas they represented, using the same labels as in our report (Sadownik et al., 2016), e.g. “blurring of boundaries between researchers and participants”, “blurring of boundaries around data use”, “exposing of participants’ personal situations”, “need to make unpredictable, individualized changes to research protocol”, “multi-party responsibility in health-related research”, “ethically correct but violating civil or commercial agreements”. A further, higher-order analysis then mapped these into the four KPs that define our theoretical and policy framework. We should note that the addition of the case studies relevant to marginalized users is not meant as a validation test for the framework proposed in Sadownik et al. (2016); instead, we are using this framework merely as a structure to guide our policy interpretation and discussion of ethical dilemmas.

The case studies we discuss here have been selected based on their potential relevance, applicability, or similarity to gerontechnology fieldwork – as older adults can be often considered marginalized with respect to representation in techno-centric research. We discuss in this section how these case studies represent different types of ethical dilemmas (according to our interpretation framework), the context in which these occurred, the type of marginalized users, the case authors’ own reflection and resolution if presented in the respective paper, and the specific guidelines in TCPS2 that may have provided a resolution or mitigation for the dilemma. In some case studies the ethical dilemmas could have been avoided or mitigated by a careful interpretation of ethical guidelines – these are often cases where the researchers may not have the extensive training to handle such complex situations (KP4: “Training Background”), or the research protocol may have been methodologically grounded in more traditional HCI practice (KP3: “Uncontrolled Variables”). In many other cases these dilemmas were outside researchers’ control, especially during the “static” planning stages due to the field setting (KP2: “Multi-disciplinary Collaborations”). In these multidisciplinary cases TCPS2 often offers comprehensive guidance, although this may be limited in scope to a Canadian policy context. However, given the multidisciplinary view of ethics that Canadian policy takes (Millum, 2012), a reflection on how this particular policy document can guide the interpretation of the ethical dilemmas discussed here could serve as an invitation for other ethics bodies to consider adopting similar guidelines or interpretation. Additionally, we hope that the reflections captured in this paper will invite further

refinements of existing policy document or updates capturing the emerging challenges faced during techno-centric fieldwork with marginalized users.

We structure this section along four subsections, each mapping into one of the four KPs of our interpretation framework. Each subsection is further structured along the type of ethical dilemmas representative of that KP. The most representative case studies are discussed in greater detail, with all other cases being listed as bibliographic references, annotated with the type of dilemma they represent, the type of marginalized users and context, and the ethics guidelines that may address these.

In our own HCI research with marginalized and under-represented users we encountered numerous similar situations such as those categorized here. We have described the ethical dilemmas raised during our work, as well as the approaches we took to address them, in prior publications (Munteanu et al., 2015). Here we reflect on some of the case studies and ethical dilemmas identified in the broader literature from an ethics guideline perspective as well as from our personal perspective on conducting such research. We then discuss the lessons learnt from these dilemmas and from the approaches taken in addressing them, in particular as these may apply to broader contexts of techno-centric fieldwork with under-represented users such as older adults.

12.4.1 Lack of Path Dependency

Issues of contextual ethics that the formal process overlooked

Buchanan (2015) raises the ethical dilemma of completion of studies in which participants used an app that was beneficial to them, such as for their wellbeing. Benefits arising from technological interventions are often withdrawn upon completion of the study. However, the need to continue the intervention post completion of the research study is in fact the norm in other fields (e.g. medical). In TCPS2 this is covered under Ch. 3.1 “Incentives” and Ch. 11.1 “Psychotherapy”, discussing how the intervention should continue after the research study has completed, if it is beneficial for participants. However, one of the challenges faced by HCI researchers is that of long-term software maintenance of such apps. This is even more common as most of the emerging, cutting edge research in HCI happens in academia as part of graduate students’ thesis work. We have discussed this in our prior ethics research (Munteanu et al., 2015) illustrating the case of a mobile phone extension supporting blind users’ text entry on mobile devices (Southern, Clawson, Frey, Abowd, & Romero, 2012) – in this particular example, the system could not be given to participants beyond the study completion due to the lack of software support after its creator’s graduation, while the blind participants indicated that they would have preferred to continue using the device (and possibly benefit from its assistive capabilities). We have experienced a similar case of withdrawing possibly-beneficial technology from study participants in one of our projects on assistive technologies for older adults (Wu & Munteanu, 2018). In our project we have

designed a mobile interface that connects to wearable body sensors and allows users to visualize changes in their long-term falling risks. The design was implemented through a mobile prototype that was evaluated through a field deployment where participants used the device for several weeks— although the prototype was still in early stages, participants indicated that they would have liked using it past the very short feasibility testing period.

Prichard, Spiranovic & Lueg (2015) and Steinberger, Schroeder & Lindner (2015) discuss how consent forms create a record of participation in research and may pose threats to confidentiality – this overabundance of privacy concerns could lead to underrepresenting vulnerable populations. This may be less of a concern in traditional HCI research that focuses on testing the usability of an app – recruitment strategies often incentivize participation through financial compensation. However, as ethnographic research is becoming increasingly common in HCI, participation in user requirement studies such as contextual inquiries requires clear enrolment criteria. These can indicate that a participant belongs to a certain group which may carry social stigmas. We are experiencing this in many of our current investigations, e.g. research on older adults’ financial budgeting practices or on their knowledge about Internet scams – our participants often enrol as they struggle with these topics. Policies such as TCPS2 provide guidance on this, for example through provisions for not requiring consent to be documented or even elicited in the first place (Chapter 3.7A - Alterations to Consent Requirements and Chapter 3.12 - Consent shall be documented).

In a study that presents a different perspective on participants’ enrolment in a research study, Talhouk & Thieme (2016) discuss how financial compensation may coerce vulnerable people to participate. The authors also suggest that these may lead to such participants not being fully motivated, which may affect the accuracy of the data collected in the study. This is a topic covered in guidelines such as TCPS2 under the “Incentives” provisions. While we have observed similar cases in our prior work with younger vulnerable groups (Munteanu, 2012), in our many studies aggregating several hundred older participants we have in fact experienced the opposite. However, we have observed other consequences stemming from this very strong intrinsic motivation to participate (as opposed to the extrinsic motivation discussed in Talhouk & Thieme, 2016). For example: participants’ may be very eager to share many personal details beyond what is needed for the study, which has its own problems as discussed in Davis & Waycott (2015); participants may engage in the study’s activities more meticulously than needed (sessions that normally take 2 hours sometime last up to 4, simply because of participants’ willingness to contribute to the research); or participants taking many additional steps to “prepare” for the research study (e.g., preparing snacks for the researchers).

No empirical basis to estimate possible harm and rely on anecdotal evidence or simply “guessing”

Over-sharing of personal details occurs during studies with other vulnerable groups, as discussed by Hodge et al. (2017). In this case, teenagers’ shared experiences about violent video game play can create problems with respect to the need to alert their parents about possible psychological conditions. While TCPS2 contains clauses for handling such situations (under “Duty of Care”), the fact that such conditions are only revealed because of the technology that is studied presents researchers with a more difficult dilemma – especially when complying with “Duty of Care” necessitates informing third-party individuals. In our research with older adults this is a common situation, which sometimes can be more easily addressed through dialogue with the participant (e.g. we have provided contact information of relevant therapists during our study on risks of falling). However, we found this more difficult to do in situations where participants were in denial about the observed problem, and contacting a family member or caregiver was not possible due to the participant still being in full capacity to consent (as it happened during our study of budgeting practices which revealed information that made the researchers worried about the participants financial wellbeing).

Researchers’ concerns about participants’ wellbeing is quite common; however, there is very little precedent in HCI fieldwork to inform us how to address this. In the research discussed in Dee & Hanson (2016), in the context of studies within care homes with older adults, researchers’ own emotional wellbeing was affected by the participants’ stories or circumstances.

Moral dilemmas

While most researchers are careful in their narrative descriptions of participants, there are significant potentials for mislabelling when larger data sets are involved (e.g. in studies with computational components, especially if labelling is algorithmic). This can pose ethical conundrums of a moral nature, especially for marginalized users, as discussed in Leavitt (2015). Automatic algorithms could place particular individuals into groups that they don’t belong or don’t identify with. This is particularly relevant for older adults – a group often subjected to (sometimes intentional) mischaracterization. Unfortunately, ethics guidelines do not provide adequate coverage in guiding researchers (especially those from computing disciplines) on this matter, although several provisions tangentially cover this. For example, in TCPS2, Chapter 5- “Identifiable information”, especially Article 5.7- “Data linkage” provides recommendation about dealing with data that may reveal personal details about participants, including from algorithmic cross-linkages across multiple data sources (such as from several studies, which may inadvertently expose information about participants that is not part of the initial research protocol. More applicable to the matter of misrepresentation is Chapter 5.5A- “Consent and secondary use of identifiable data”, which discusses how

researchers should ensure that data obtained from participants (directly or indirectly) should be used in such a manner that respects the participants' wishes about the use of such data (whenever it is practical to have these wishes known).

The promise of anonymity

Preserving the anonymity of participants is a central tenet of ethics principles. However, unexpected situations in the field, combined with researchers' lack of experience in handling such situations, can lead to difficulty in handling anonymity. For example, Bipat & Wilson (2017) discuss how vulnerable users' lack of technology/social media experience, especially with regard to understating ephemeral vs. persistent content that may be used in research, can lead to difficulties in upholding anonymity or fully providing informed consent with respect to the use of participants' data in the long term. This is a topic where some guidance is provided in TCPS2 under Chapter 5.5 "Impracticable" consent section (e.g. raising additional privacy concerns if seeking consent) and as a general balance of risks vs anonymity (under Chapter 5 "Anonymized Information" articles). This is an issue that we have also encountered in our work with older adults, such as in Axtell (2017) – many participants did not have an understanding of the technical aspects of how their digital pictures are stored "in the cloud", and their understanding varied greatly across users. This ranged from perceptions of complete lack of privacy despite some privacy controls existing within such services, to perceptions of security (with respect to irreparable loss) as being weaker than physical storage of paper pictures. It is thus to be expected that complex privacy controls in a digitally-complex setting such as that of many ethnographies of online communities for marginalized users may not be fully understood by these users either.

12.4.2 Multi-disciplinary Collaborations

Obtaining informed consent directly from a vulnerable participant

HCI is a truly multidisciplinary field, drawing methods and approaches from several disciplines. However, recently the use of ethnographic fieldwork with vulnerable groups has drawn HCI researchers into also collaborating across disciplines or working closely with other stakeholders that may have different backgrounds. To a minimum, this poses technical challenges with respect to solving an ethical dilemma, such as during clinical trials of digital technologies, where HCI researchers need to handle consent within the context of a clinical setting, which may be complicated by the use of medical jargon in relevant documents (Rodger, Davidson, & Vines, 2015). This is common in research with older participants as well; for example, for most of our studies we recruit with the help of our collaborating agencies, institutions, or private companies, which requires additional precautions to be taken to ensure consent is informed (including working with our partners to make sure the language used in the study documents they hand to participants is appropriate). Ethical guidelines provide extensive information for such cases, mostly drawing from the medical domain. For

example, for situations such as that described in Rodger et al. (2015) where participants volunteer for a study involving interactive technology in a clinical setting, the participants may in fact believe (or hope) that their medical will improve as a result of their participation. This may require alterations to the consent document to avoid use of medical jargons in order to increase clarity with respect to the goals of the research study. Such alterations are often necessary (TCPS2 - Chapter 3.7A - Alterations to Consent Requirements), although any departure from the normal consent process must be disclosed to participants at the end (TCPS2 - Chapter 3.7B - Debriefing in the context of alterations to consent requirements). It is also recommended that researchers consult with experts (e.g. reviewers serving on their institutions' ethics boards) who may provide specific ethics guidance with respect to the use of an interactive technology that may be similar to that of medical devices and thus lead to participants' expectations of medical benefits upon enrolment in the study (TCPS2 - Chapter 11.1- Medical Device Trials).

Collaborating with non-academic stakeholders may create conflict of interest situations, such as that described by (Ramos & van den Hoven, 2015), in which stakeholders may favour highlighting certain aspects of the study (e.g., efficiency of technology) which the researchers have concerns in relation to vulnerable groups (e.g., reduced employment opportunities for caregivers). Most of our research studies with older adults are conducted in collaborations with non-academic stakeholders, and such concerns can be addressed through clauses in the formal definition of the partnership which emphasize participants' and indirect participants' wellbeing as a priority. Again, extensive research in medical and healthcare research that encountered similar challenges has led to ample ethical guidelines that are applicable to technology studies. Such challenges may include the use of technology by older adults suffering from cognitive impairments as we have often encountered in our fieldwork. This is a situation that warrants a departure from the usual consent process, as supported by TCPS2 - Chapter 3.9 - Decision making capacity, Chapter 3.10 - Consent on behalf of an individual lacking legal capacity, or Chapter 3.11 - Loss of capacity to consent. These articles provide guidance on how to conduct research with vulnerable participants who may not be in a capacity to consent, where that research (e.g., sometimes as simple as providing a tablet device with video conferencing capabilities) directly provides a benefit to the participants or to others that are affected by the same medical condition,

Tensions may exist even when stakeholders do not have competing interests. As Haimson et al. (2015) describe, researchers often need to balance the wellbeing of participants during study and the goal of an informative reporting of results, without harming members of a marginalized community. This is well covered in ethics guidelines (TCPS2 - Chapter 10.3 - observation in natural/virtual settings, Chapter 7.4 Dual Roles - articles on undue influences, power imbalances or coercion), and is common for HCI fieldwork with older adults. These

chapters include guidance on how researchers conducting such studies should take careful precautions to avoid exposing participants to risks with respect to their privacy (including through careful monitoring of the environment in which the study is conducted and the nature of the activities being studied). Additional precautions (as recommended in the “Dual Roles” section of Chapter 7.4 in TCPS2) must be taken with respect to monitoring such privacy risk factors as well as risks to loss of consent / risk of coercion when the researcher is in a potential conflict of interest position (e.g. having a professional relation to the participants, for example as a volunteer at the long-term care facility for older adults). In our own experience, we often struggle with creating stereotypical depictions of an entire user group (e.g. lacking digital technical skills). As suggested in Ringland & Hayes (2015), a more nuanced approach and researchers’ closer engagement with the community could address such issues.

The values and goals of research may be problematic when there are conflicting benefits to policy-makers, organizations and caregivers

Additional tensions may be the result of events observed by the HCI researchers in settings where they do not have professional expertise, such as healthcare (Stevenson & Taylor, 2017). The statically-planned ethics protocol cannot anticipate the interactions with (non-participant) healthcare professionals in clinical studies, and may limit researchers’ abilities to adapt to unforeseen situations emerging from these interactions. Ethical guidance for such cases can be drawn from several parts of policies such as TCPS2 (e.g., Chapter 3.7A - Alterations to Consent Requirements, Chapter 10.5 – Emergent Design (dynamic, reflective, and continuous process), Chapter 7.4 Researcher Conflict of Interest). Especially Chapter 10.5 provides useful guidance in the form of recommendation for continuous reflection on the ethical aspects of a study when there is an expectation of encountering unpredictable situations in the field (as is the case with most qualitative field research, and particularly that in sensitive settings, as we have shown in Munteanu et al. (2015)). This is a very common situation for HCI research with older adults for which the fieldwork is conducted in institutional settings (e.g. hospitals, care homes), or in interview-based research such as our work on a crowd-based app to facilitate older adults’ understanding of health info (Aly & Munteanu, 2016). In this latter example, participants have reported distrust in medical institutions based on their observed or perceived dysfunctionality. In these cases reporting such events may lead to misinterpretations or consequences for the relationship with the research partner or the collaborating community.

Health interventions (e.g. apps) and multi-party responsibility / ethics

Another ethical dilemma that can possibly arise from multidisciplinary collaborations is that of privacy concerns related to health interventions when the research has multiple parties. For example, Wadley et al. (2015) discuss the issue of vulnerable participants such as patients of mental health services who may not want to be identified as such. Often an app developed by

HCI researchers may be deployed through a healthcare provider – patients may not want to disclose mental health information beyond their immediate care provider (for example, to outside researchers), especially to those not trained in handling sensitive data. Ethics guidelines such as TCPS suggest various provisions for this type of cases; e.g. much clearer consent (Chapter 3.12 - Consent shall be documented), stronger data protection (Chapter 5.3 - Safeguarding of information), or following the duty of care (e.g., Chapter 11.1 – Psychotherapy). In our own research studies we have encountered similar situations, where some older participants were not always willing to share all aspects relevant to the study (e.g., online browsing habits, financial background information).

12.4.3 Unpredictable Variables

Enquiries that relate to participants' personal situations, potentially expose vulnerability

Researchers in anthropology and other fields mostly in the social sciences are accustomed to dealing with unpredictable situations during fieldwork. In fact, TCPS has provisions for emergent designs that specifically allow for such situations (Chapter 3.4 - Incidental Findings) This TCPS2 chapter recommends that researchers draft a plan, a priori to the conduct of the study, outlining how unexpected situations are handles – for example, that of revealing participants' personal situation (e.g., health) that may need to be disclosed to the participant. However, in HCI fieldwork unpredictability may come from the technology that is under study prompting or causing participants, especially those vulnerable, to deviate from the study protocol. For example, older participants may reveal more information about themselves in such settings, which represents an unpredictable ethical dilemma with respect to privacy when non-participants (e.g., caregivers) are also present (Davis & Waycott, 2015). We have also observed this across many age groups in our work with low literacy adults (Munteanu, 2012) where participants interacted with non-participants during sessions at a learning centre and shared information about themselves prompted by the study and by their use of the technology.

Privacy is not the only ethical aspect that needs to be carefully monitored in such situations. Vulnerable participants engaged in research that explores potentially upsetting emotional or traumatic events can cause duress for participants (Gerling et al., 2015). This can be very common for older adults as well; for example, our work on a tablet-based app that engages older adults in storytelling (Axtell & Munteanu, 2016) prompted them to engage in reminiscence – even if we have recommended they only focus on pleasant memories, participants often recalled traumatic or very sad memories, making them visibly upset .

Emotional distress can be triggered by other aspects of the technology intervention. For example, Slegers et al. (2015) report that participants becoming self-aware of their condition or situation may cause further harm as study progresses. We have observed this for fieldwork with older adults as well, especially with respect to social isolation. Even if our research is

not directly focused on isolation (e.g., research on access to health information , Aly & Munteanu, 2016), we administer social isolation scales such as the Duke Social Support Index (Koenig et al., 1993) as part of the relevant demographic data collection – some of our participants became visibly upset (crying) when realizing, unexpectedly, that their social network is very small.

Need to make individualized, unpredictable changes, to suit the needs of each of participants

HCI is increasingly using field methods such as contextual inquiry or focus groups, which may bring up additional ethical challenges. With respect to technology deployment, focus groups (and in general, group participation) may raise concerns such as difficulty adequately addressing all participants when these have mixed abilities or (digital) proficiency – this is particularly applicable to older adults. Gerling et al. (2015) discuss issues of vulnerable participants being at risk of neglect in group studies due to lower abilities, especially with respect to performing the activities of the study. The authors reflect on how researchers must ensure that all participants are cared for, but also must enact measure to handle participants' withdrawal or removal from group settings (both as consequences at individual and at group level). Several ethics guidelines cover these topics (in TCPS2: Chapter 10.5 - Research involving emergent design, Chapter 11- Duty of Care, Chapter 11.1 – Psychotherapy), which describe in detail how the study design must include provisions for care (e.g., medical) when participants are recruited from a group that is vulnerable (e.g., due to a medical condition). However, these guidelines do not directly address issues such as those emerging when the participants are made vulnerable by the introduction of a piece of technology as the subject of the study (e.g., older adults collectively learning to use a new digital tool that some may be extremely unfamiliar with).

Lack of control over data

Many ethical guidelines have very strict provisions about the use of data obtained from participants, especially if this data is identifiable or can be misused by others (e.g., “biological samples” in TCPS2). However, indirect digital data may not always be perceived by participants or researchers as identifiable. This is additionally problematic if third parties may access it (such as for processing). For example, in the context of vulnerable participants, the lack of information or transparency about how data is handled may provoke “technopanics” and prevent participants from enrolling in studies (Cowls, 2015). Such dilemmas may be addressed by some ethics guidelines, e.g., in TCPS2: Chapter 3.4 - Incidental Findings (articles on disclosure that may cause harm to participants), Chapter 5.2 - requirement to disclose information to third parties, or Chapter 5.1 - Ethical duty of confidentiality. However, these do not provide clarity on indirect data such as biometric. In our studies with older adults that involved collections of such data we have found that some participants were concerned about who (or what third party entities) may have access to data

from the wearable devices used in the field study (Wu & Munteanu, 2018), although they were not aware of the technical aspects of how such data may be used. We addressed this by providing each participant with an offline laptop for the algorithmic processing of data collected during the study.

12.4.4 Training Background

Blurring of boundaries between researchers and participants

As ethnographic fieldwork becomes increasingly used in HCI, researchers are facing situations where their technical background doesn't properly prepare them to address the often unexpected issues. For example, Davis & Waycott (2015) report being privy to vulnerable participants' life crises, such as difficult and upsetting conversations between participants and their caregivers. There are guidelines for this in ethics policies such as TCPS2 (e.g., Chapter 7.4 Researcher Conflict of Interests-Dual Roles, Chapter 11- Duty of Care, Chapter 10.3 Observation in natural environments) providing guidance on how to handle sensitive information obtained from participants, although none cover the issue of researcher-as-participant, particularly on cases where this is not planned but the researcher became inadvertently more involved in participants' personal lives. We have encountered similar cases of difficult personal situations in our research with older adults, especially during focus groups, such as when some participants asked the researcher to facilitate matchmaking. While it may become clear from an ex post facto analysis that such situations could sometimes be anticipated (and thus mitigated), in our own experience (Sadownik et al., 2016) we have found that the HCI field is often challenged by lack of proper ethics planning, grounded in existing ethics training gaps specific to this discipline. This includes attention to procedural and micro-ethics considerations during all stages of the research.

Managing cases that exceed HCI researchers' planned roles also involve situations that affect the researchers themselves, even if the study design does not put the researcher in a participant position. For example, coding troubling or disturbing images collected during techno-centric fieldwork with vulnerable populations may affect researchers' own wellbeing and ability to cope with such images (Andalibi & Forte, 2015). Similarly, the study may impact researchers' wellbeing when they become invested in participants' personal lives and circumstances (Dee & Hanson, 2016), especially when participants are vulnerable such as living with impairments. This can put the researchers themselves in positions of vulnerability, such as when experiencing guilt from studying participants who live in dire situations while the researcher does not (Talhouk & Thieme, 2016), or forcing the researcher to distancing themselves from the participants who experience suffering that the researcher cannot alleviate, leading to guilt and remorse for the researcher (Andalibi & Forte, 2016). In our research with older adults we have encountered numerous such situations where the

researcher felt powerless in helping participants, such as with social isolation, medical conditions, or financial burden.

Blurring of boundaries between research and treatment

Lack of training in handling such situations is also very common in what TCPS2 classifies, from an ethical perspective, as “therapeutic misconceptions”. For examples, vulnerable participants may have the false belief that the central purpose of the trial is therapeutic, and that they will personally benefit from it, even if the research is about technology (Rodger, Davidson, & Vines, 2015). This is often compounded by participants’ expectations that researchers possess medical knowledge when the technology is related to healthcare (Talhouk & Thieme, 2016) – a situation that is expected to occur more frequently as healthcare technology is increasingly becoming a core focus of research in HCI. While managing the communication with participants may mitigate such misconceptions, we have found that this is often difficult in research with older adults. For example, one of our researchers conducting usability studies in long-term care facilities was mislabelled by participants as a medical doctor, likely due to the researcher carrying a clipboard for taking notes. The researcher’s clarification of their status as a graduate student succeeded in only altering the perception to that of a medical resident. Similarly, in our project about understanding healthcare info, participants would often bring doctors’ notes and prescriptions, even if the study was a participatory design for a web interface aimed at facilitating access to general-purpose health brochures.

Blurring of boundaries around data use

Deploying technologies in studies with marginalized users can raise additional unexpected challenges. For example, unforeseen language issues or different cultural backgrounds may lead to researchers making unwitting errors when doing research in languages and cultures not their own, or researchers may bring their own preconceived notions to the conduct of the study or interpretation of data, as Majid (2015) exemplifies through the case of not interpreting religiosity in online forums as a form of social signalling. Ethical guidelines do not explicitly cover such situations, although guidance may be partly found in related provisions (e.g., TCPS2: Chapter 5.5A- Consent and secondary use of identifiable data, Chapter 2 – Risk and Benefits, Chapter 10 – Qualitative research). Although HCI researchers are trained in issues such as cultural aspects that must be factored into the design of interfaces, fieldwork that involves users such as older adults may present significant language or especially cultural divides. In our past research with older adults we mitigated this by employing research members that were native speakers of the language that our participants had, in cases where such information was available beforehand. However, in several other situations cultural differences were unexpected and posed problems with respect to being able to fully follow the desired experimental protocol in the field.

12.5 Conclusions

Researchers in Human-Computer Interaction are increasingly conducting research outside the controlled environment of laboratory studies, or with vulnerable user groups, which pose new “ethical dilemmas”. At the forefront of development and study in HCI are technologies that are undergoing innovative transformation at an unprecedented pace (e.g., increasingly capable mobile devices, machine learning to better understand and adapt to human behaviour). Additionally, such new technologies are deployed in new contexts of use – short term usability experiments but with marginalized or vulnerable users, or long term deployments in sensitive environments.

The increase use of fieldwork within HCI research with marginalized populations or in sensitive settings has raised new “ethical dilemmas” for the researchers designing and conducting such studies. While ethics has long been an essential part of the planning process for techno-centric research with human participants, the presence of such new dilemmas has often made the increasingly-formal ethics review process more difficult, as the lack of controlled environments to which tech researchers are accustomed to poses challenges in identifying potential “ethical traps” during the planning stages.

In this chapter we presented a synthesis of relevant case studies of interactive technologies for marginalized users. The evidence from these case studies suggests that the source of the ethical dilemmas present is often not the disruptive nature of these technologies, nor their deployment in sensitive settings. Instead, we have proposed the argument that it is the interplay between these aforementioned factors and the knowledge gaps with respect to the application of ethics guidelines. This interplay is visible within the space of HCI research that, while still focusing on end results such as UI designs, has broadened its methodological approach to include qualitative fieldwork, and yet does not benefit from an extensive history of such research. Our analysis of this space and the knowledge and ethics guideline interpretation challenges has focused particularly on HCI fieldwork with marginalized populations. We hope that by uncovering these gaps and challenges, and by offering interpretation of ethics guidelines as relevant to representative case studies, HCI researchers will have another tool at their disposal that can assist in avoiding the ethical traps of techno-centric fieldwork with underrepresented users.

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