

# Ethical dilemmas during field studies of emerging and disruptive technologies – is our current state of knowledge adequate?

A report under the SSHRC Knowledge Synthesis Grant on: How can emerging technologies be leveraged to benefit Canadians?

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## Preamble and key messages

Ethics has long been an essential part of the planning process for techno-centric research with human participants. Canada is one of the two countries which have implemented a single, trans-disciplinary national policy with respect to the ethical conduct of research with human participants – an approach that helps ensure a high degree of consistency in the application of ethical principles. 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 research institutions such as universities. These institutions are then responsible for implementing and enforcing the guidelines set in the TCPS2; a process most researchers are accustomed to in the form of applications for approval of research protocols by their institutional Research Ethics Boards (REB).

In recent years however, the process of formal ethics review has become more difficult within fields that study humans' interaction with emerging technologies. Researchers in fields such as Human-Computer Interaction (HCI) are increasingly conducting research outside the controlled environment of laboratory studies, or with vulnerable user groups, which pose new "ethical dilemmas". This is only expected to increase and diversify, as new technologies are emerging such as mobile devices, intelligent personal assistants, or interactive assistive applications. Not only such technologies are evolving rapidly, but their contexts of use and their users (especially marginalized populations) are constantly being redefined.

In the synthesis work reported here we aimed to analyze if existing ethics policies such as the TCPS2 can provide guidance that is still relevant to the particularities of new field-based techno-centric evaluations, qualitative studies, challenging lab-based evaluations, and ethnographic observations of emerging digital technologies as used by vulnerable or under-assessed user groups. We report on various yet complementary perspectives for viewing ethics and detail the intricacies of each of these focal points. We describe research with human participants and with the use of novel technologies. Beyond this we detail dilemmas that arise within each of those categories in the emerging field of HCI as researchers attempt to leave their laboratories in search of participants in the "wild". In particular, we present bibliographic evidence to the following key points:

- KP 1.* HCI researchers are venturing into unknown 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
- KP 2.* 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
- KP 3.* 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
- KP 4.* 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
- KP 5.* Very little evidence exists of Canadian HCI researchers studying the ethical challenges of techno-centric fieldwork, especially outside lab settings or with vulnerable users

## Executive summary

The process of formal ethics review, which was once a formality, has become more challenging for techno-centric Human Computer Interaction (HCI) researchers who are venturing into unknown contexts and physical spaces while conducting fieldwork with emerging and disruptive technologies. 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. The emergence of new interactive technologies (mobile devices, intelligent digital assistants, wearable computing, 3D printing, etc.) and the use of such technologies in new contexts (e.g. marginalizes users, developing countries, accessibility, literacy) poses new ethical challenges, with HCI researchers today **lacking path dependency** to address such challenges [KP 1]. This historical ontology contributes to the reason why HCI researchers are often unable to draw on a large resource of literature from their colleagues within or outside the field to inform their research or guide their ethics application.

Existing ethical guidelines (such as the Canadian Tri-Council Policy on Ethical Conduct of Research) have allowed many HCI researchers to gain permission to conduct research in the field; however, the often unexpected and unpredictable realities of conducting fieldwork combined with the exploration of emerging technologies has led to the realization of existing “ethical vacuums”<sup>(1)</sup>. Where researchers would typically estimate possible harm for participants based on empirical measurements and past experience, many HCI researchers are left to “rely on anecdotal evidence or simply guessing” what potentially may occur in the field<sup>(2; 3)</sup>. Furthermore, HCI researchers are also expected to problem solve potential ethical dilemmas as they are occurring in the course of their fieldwork<sup>(4; 5; 6; 7)</sup>. While the unpredictable nature of fieldwork may be a common occurrence in the social sciences<sup>(8; 9)</sup>, HCI researchers have been, until recently, largely spared of difficult ethical situations.

HCI researchers who have left the comfort of their lab settings to commence fieldwork have reported various **challenges** that were **caused by uncontrolled variables** and due to the location of the research<sup>(10; 11; 12)</sup> [KP 3]. Variables that were noted as being uncontrollable in the course of field work included indirect breaches of privacy<sup>(13)</sup> and potential infringements of anonymity<sup>(14; 15; 16; 17)</sup>.

The venture into unknown contexts can also be linked to individual institutions drive for research grants and marketing or publications. The potential to gain worldwide recognition has allowed many HCI researchers to explore, for example, the development of assistive technology that is also sponsored and advertised by industry. For many HCI researchers, this push to be recognized and acknowledged in the media has caused potential ethical dilemmas such as in the case of the Google Glass trials<sup>(18)</sup> and new technology based interventions in mental health<sup>(19;20)</sup>.

It could be suggested that one solution to rising ethical dilemmas for HCI researchers in the field would be the assistance of **multi-disciplinary collaborators** [KP 2]. Baker & Warburton (2015) suggest drawing

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<sup>1</sup> Buchanan, 2015

<sup>2</sup> Busch, et al, 2016

<sup>3</sup> Taherian, Davies, & Owens, 2015

<sup>4</sup> Kazemian, Munteanu, & Penn, 2016

<sup>5</sup> Slegers, Duysburgh, & Hendriks, 2015

<sup>6</sup> Vines, et al, 2016

<sup>7</sup> Waycott, et al, 2015

<sup>8</sup> Baker & Warburton, 2015

<sup>9</sup> Phillips, 2014

<sup>10</sup> Davis & Waycott, 2015

<sup>11</sup> Gora, 2015

<sup>12</sup> Hughes, et al, 2015

<sup>13</sup> Hughes, et al, 2015

<sup>14</sup> Busch, et al, 2016

<sup>15</sup> Davis & Waycott, 2015

<sup>16</sup> Gora, 2015

<sup>17</sup> Hughes, et al, 2015

<sup>18</sup> McNaney & Vines, 2015

<sup>19</sup> Estrada, Wadley & Lederman, 2015

<sup>20</sup> Orłowski, et al, 2015

on techniques from the field of sociology. Alternatively, the addition of medical collaborators, care workers or clinicians could be seen as useful for research located within hospitals<sup>(21; 22)</sup> or care homes<sup>(23; 24)</sup>, or when developing 'health' or 'wellbeing' apps of various forms<sup>(25; 26)</sup>. Educational psychologists could be useful in assisting researchers working with vulnerable students<sup>(27; 28; 29)</sup> or when the potential for exposing vulnerability exists<sup>(30)</sup>.

However, the addition of multi-disciplinary collaborators can also create ethical dilemmas for researchers<sup>(31; 32; 33; 34)</sup> who find themselves dependent on staff for access to residents<sup>(35)</sup> or proxies for participants<sup>(36; 37; 38)</sup>. Some researchers are faced with ethical dilemmas when collaborators have access to the findings of their research such as phishing studies conducted for employers<sup>(39)</sup> and when participants and their care workers or family are present at the same time as sensitive material is revealed<sup>(40)</sup>. Ethical dilemmas may also include the identification of non professional or substandard levels of care by hospital staff<sup>(41)</sup> or when employees are found to place the security of their employer at risk<sup>(42)</sup> and finally when employees are not in the proper condition to be working<sup>(43)</sup>. Finally, some researchers may even face ethical dilemmas when they choose not to collaborate with law enforcement when illegal activities are revealed<sup>(44; 45; 46; 47; 48)</sup>. While the decision to work strictly within one discipline or with research-oriented practitioners may assist with feasibility, it could be argued that it is not representative of real world situations<sup>(49)</sup>.

The methodology training many HCI researchers have undergone 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**<sup>(50; 51; 52; 53; 54; 55; 56; 57)</sup> [KP 4]. In particular, HCI researchers have noted the impact of witnessing sensitive discussions on their well being<sup>(58; 59; 60)</sup> and their concern for their participants at the recognition of publishing sensitive stories<sup>(61; 62; 63)</sup>. Many HCI researchers required an exit strategy for their own well being at the end of the study to deal with issues of guilt<sup>(64; 65)</sup>.

We conclude this summary with an observation on the relative scarcity of Canadian-lead research within the field of ethics as pertaining to techno-centric fieldwork (by way of little bibliographic evidence). In

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<sup>21</sup> Buchanan, 2015

<sup>22</sup> Hughes, et al, 2015

<sup>23</sup> Dee & Hanson, 2016

<sup>24</sup> Ramos, & van den Hoven, 2015

<sup>25</sup> Buchanan, 2015

<sup>26</sup> Estrada, Wadley & Lederman, 2015

<sup>27</sup> Andalibi & Forte, 2016

<sup>28</sup> Gora, 2015

<sup>29</sup> Ng, 2015

<sup>30</sup> Gerling, et al, 2015

<sup>31</sup> Buchanan, 2015

<sup>32</sup> Davis & Waycott, 2015

<sup>33</sup> Dee & Hanson, 2016

<sup>34</sup> Gora, 2015

<sup>35</sup> Dee & Hanson, 2016

<sup>36</sup> Estrada, Wadley & Lederman, 2015

<sup>37</sup> Gora, 2015

<sup>38</sup> Taherian, Davies, & Owens, 2015

<sup>39</sup> Busch, et al, 2016

<sup>40</sup> Davis & Waycott, 2015

<sup>41</sup> Buchanan, 2015

<sup>42</sup> Busch, et al, 2016

<sup>43</sup> Wadley, et al, 2015

<sup>44</sup> Gora, 2015

<sup>45</sup> Prichard, Spiranovic, & Lueg, 2015

<sup>46</sup> Steinberger, Schroeder, & Lindner, 2015

<sup>47</sup> Strohmayer, & Comber, 2015

<sup>48</sup> Yoo, Nathan, & Friedman, 2016

<sup>49</sup> Orłowski, et al, 2015

<sup>50</sup> Andalibi & Forte, 2016

<sup>51</sup> Bica & Anderson, 2016

<sup>52</sup> Davis & Waycott, 2015

<sup>53</sup> Dee & Hanson, 2016

<sup>54</sup> Di Fiore & D'Andrea, 2016

<sup>55</sup> Estrada, Wadley & Lederman, 2015

<sup>56</sup> Gora, 2015

<sup>57</sup> Kazemian, Munteanu, & Penn, 2016

<sup>58</sup> Andalibi & Forte, 2016

<sup>59</sup> Stevenson, & Taylor, 2015

<sup>60</sup> Strohmayer, & Comber, 2015

<sup>61</sup> Bica & Anderson, 2016

<sup>62</sup> Davis & Waycott, 2015

<sup>63</sup> McKay, & Buchanan, 2015

<sup>64</sup> Dee & Hanson, 2016

<sup>65</sup> Di Fiore & D'Andrea, 2016

our main report we have included a detailed policy analysis of the current version of the Tri-Council Policy Statement (TCPS2, 2014) and showed its applicability to solving ethical dilemmas within fields such as HCI. While TCPS2 may benefit from being updated to reflect new realities of techno-centric fieldwork, an extensive careful interpretation of relevant articles in TCPS2 demonstrated that it can still provide guidance to such research studies. Therefore, our key point [KP 5] serves as a call to action for Canadian HCI researchers to become actively engaged in research on the ethical issues surround techno-centric fieldwork – the synthesis captured in this report suggests that this is strongly needed.

*NOTE: All references included in this executive summary can be found in the bibliography included with the main report.*

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# 1 Background

There are many different lenses from which to view the term ethics, and a plethora of research ethics boards (REBs), research fields, institutions and industry practices that apply their own unique ethical standards. Although the universal purpose of every REB is to ensure that all human research subjects are protected (Weijer, 2001), their applications can vary widely, even between institutions located within the same country (Warrell & Jacobsen, 2014). Noted sociologist Gresham Sykes (1922-2010) is reported to have commented over forty years ago that, "review committees represent such a wide variety of intellectual fields that they are incapable of reasonable judgement in specialized areas" (Schrag, 2011, p. 120). In many ways, REB's are responsible for reviewing contexts, and what is acceptable in one context may be viewed as a violation in another (Nissenbaum, 2004; Walther, 2002; Wright, 2011). Canada alongside Australia are the two countries which have implemented a 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. Such institutions are then responsible for implementing and enforcing the guidelines set in the TCPS2; a process most researchers are accustomed to in the form of applications for approval of research protocols by their institutional REB. Previously published reviews have focused on earlier versions of the tri council policy (1998) document (McDonald, 2009) – our focus in this report is on the current TCPS2 (2014) document.

In recent years the process of formal ethics review has become increasingly difficult within fields that study humans' interaction with emerging technologies (Munteanu, Molyneaux, Moncur, Romero, O'Donnell, & Vines, 2015; Waycott, Morgans, Pedell, Ozanne, Vetere, Kulik & Davis, 2015). While this can partly be attributed to the bureaucratization of the application and review process, there is increasing evidence that new "ethics dilemmas" are emerging which pose additional challenges to researchers (van den Hoonaard, 2001, Munteanu, 2015, Waycott, 2016). While ethics has long been an essential part of the planning process for techno-centric human subject research (Mackay, 1995), new practice-based methods can more dynamically affect all aspects of ethically conducting the research: privacy, confidentiality, consent, harm and risks, trust and authority (Mok, Cornish, & Tarr, 2015; Waycott et. al., 2015). Researchers in fields such as Human-Computer Interaction (HCI) are increasingly conducting research outside the controlled environment of laboratory studies, or with vulnerable user groups. The commercialization and invention of new emerging technologies (Gouvea, Linton, Montoya, & Walsh, 2012) such as mobile devices, intelligent personal assistants, or interactive assistive applications are only expected to increase and diversify. Not only are such technologies evolving rapidly, but their contexts of use and their users (especially marginalized populations) are constantly being redefined. Therefore, researchers "should be prepared for situational ethical dilemmas and be supported in developing a range of tactics and sensitivities to respond to them in the field" (Vines, McNaney, Holden, Poliakov, Wright & Olivier, 2016, p. 2)

In the synthesis work reported here, we aimed to analyze how existing ethical guidelines such as the TCPS2 (2014) can provide guidance that is relevant to the particularities of field-based techno-centric evaluations, qualitative studies, challenging lab-based evaluations, and ethnographic observations of emerging digital technologies as used by vulnerable or under-assessed user groups. We report on various yet complementary perspectives for viewing ethics and detail the intricacies of each of these focal points. We describe research with human participants and with the use of novel technologies.

Beyond this we detail dilemmas that arise within each of those categories in the emerging field of human computer interaction (HCI) as researchers attempt to leave their laboratories in search of participants in the “wild”. Finally, we consider the impact on researchers who have not profited from an abundance of conceptual frameworks (Guillemin & Gillam, 2004) to assist them in completing ethics protocols and estimating harm, while also considering the value of reflexivity (Allmark, Boote, Chambers, Clarke, McDonnell, Thompson, & Tod, 2009; Guillemin et. al., 2004; Hewitt, 2007; Jeanes, 2016, Le Dantec & Fox, 2015; Waycott et. al., 2015) in creating relationships between researchers and those they wish to study.

This report collects and synthesizes a wide range of accounts of fieldwork or ethically-challenging research as appearing in various HCI-based publications. Many of these are conducted in Canada, in countries with a similar national governing body for research ethics (Australia), in countries with similar policies effected by several professional bodies (United Kingdom), or in countries with similar principles that are however implemented independently at institutional levels (USA). We have opted to include such countries because they conduct similar research in the field of HCI as many Canadian researchers do, and therefore we can reasonably expect that Canadian researchers may encounter similar challenges. In fact, many of the literature sources referenced in the report are by Canadian researchers in collaboration with international partners – such collaborations are very common in HCI. Because of this, the accounts captured in this study are carefully measured against the Tri-Council Policy Statement (2014) regardless of the country where the research was conducted. These accounts are reviewed under the scope of TCPS2 (2014) verifying not only its application of core principles, but also their adherence to specific principles and guidelines identified in various sections of the TCPS2 (2014). The literature reviewed in this synthesis captures qualitative studies and considers both the potential for harm for participants and for researchers.

## 2 Methodology

The initial approach to the literature review began by surveying published journal articles available through the institutional library system (University of Toronto, which indexes several leading scholarly databases) and bibliographic database aggregators such as Google Scholar. Search words for online searches included phrases such as, “emerging technologies”; “ethical dilemmas in research”; “human computer interaction ethics”; “Personal and ubiquitous computing”, “Tri-Council policy review”.

In total, 118 articles and/or position papers were reviewed and considered, 35 were taken directly from the CHI 2015-2016 Ethical Dilemma workshops (Waycott, 2015 and 2016) where contributors were asked to write specifically about the topic of ethical dilemmas experienced during fieldwork in human computer interaction. When discovered, similar publications that completed a meta-analysis on ethical concerns in HCI were also reviewed as a comparison (Buchanan, Aycock, Dexter, Dittrich, & Hvizdak, 2011; Punchoojit & Hongwarittorn, 2015).

Approximately one quarter of the surveyed articles were discarded. Papers that were discarded fell into four categories: 1) the paper reflectively considered technology, after it was built and the implications of some of its design qualities 2) the paper reviewed the fallibility of technologies for the general public in terms of privacy but not directly related to researchers ethical dilemmas using the technology in a study 3) the paper considered Canadian ethics policies prior to 2014 that were no longer relevant with the

TCPS2 document and 4) the paper reviewed the use of the Internet in research settings with vulnerable participants that would not require an ethics protocol to be submitted.

Once key papers, relevant to Human Computer Interaction were located, such as Waycott et. al., 2015; Vines et. al., 2015; and Munteanu et. al., 2015, subsequent searches for specific authors listed were completed. Other sources were considered relevant based on their overall theme, the dilemmas experienced while conducting qualitative studies, and the acknowledgement of power relationships and identities of the Other (Juritzen, Grimen & Heggen, 2011).

As relevant articles were scanned, researchers made additional notes of authors who were referenced and where possible the researcher reviewed each article individually to confirm quotations and conceptual notions suggested by the primary reference. Examples of these instances include Waycott et. al., 2015 reference to Allmark et. al., 2009; Guillemin et. al., 2004 and Hewitt, 2007 when suggesting "Social interactions are unpredictable. This requires researchers to adopt a reflexive awareness of the ethical issues that occur during the research process, to consider their implications for the research and to plan an appropriate course of action" (p. 1519). Another example included Vines et. al., 2016 reference to Guillemin et. al., 2004 and Miller and Bell, 2002 when suggesting that "it is necessary to distinguish between procedural and anticipatory ethics and emergent ethics in practice" (p. 2). Finally, Chang & Gray's (2013) reference to Vavoula and Sharples (2008) paper questioning how vulnerable participants can "consent to disclosing information about events they currently do not know when, where, and under what circumstances, will take place?" (p. 150).

When an author was referenced, the article was retrieved and reviewed for accuracy and included in the bibliography as a reference that informed the study. Position papers that were published through the CHI 2015-2016 Workshops hosted by Waycott, Vines, and Munteanu provided a large base of data to draw from. A list was compiled of Canadian HCI researchers at institutions situated across Canada and a survey was completed of published papers that were made available on each researcher's home or publications page. In many cases, researchers were asked to confirm if the noted publications represented the completeness of their work and challenges with ethical dilemmas. Canadian HCI researchers were contacted and individually asked to inform the study and literature review by providing relevant papers published or presented on the topic of ethical dilemmas experienced while conducting fieldwork with human participants.

The report began by classifying information into four general areas: 1) Ethics as relevant to human participants 2) Ethics in techno-centric fields such as HCI 3) Ethical dilemmas 4) Ethical dilemmas in techno-centric fields such as HCI. References were given careful consideration as to whether the ethical procedure was general in nature for all human participants or specific to techno-centric fields. The same consideration was given to referenced ethical dilemmas. Once this sorting was completed, the references were further divided into five conceptual areas of consideration. In particular, the researcher considered under each of the four general headings whether the referenced ethical protocol or dilemma was directly related to the 1) author's concern about the potential for harm to the participant or researcher 2) If the reference was a procedural or conceptual ethical concern 3) problems directly related to the researcher completing a qualitative study instead of a quantitative one 4) a requirement or lack of sensitivity and finally 5) if the noted concern was related to dealing with ethics review boards when researching human participants or related to the use of novel technologies for techno-centric fields.

As the body of the report was developing, five key themes emerged as being repeatedly referred to by researchers or as being the cause of the majority of ethical dilemmas. These key themes are summarized into the “Key summary” preamble document as key points KP 1 to 5. The first key theme considered that Human Computer Interaction Researchers were venturing into unknown 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 (*KP 1*). This inability to review past approved ethical protocols forced many HCI researchers to either not venture into the field, or to make an educated guess on the protocol and reflect afterwards. The second key message recognized that many HCI researchers were attempting to test their research in areas that would benefit from the expertise of multi-disciplinary collaborators (*KP 2*). This acknowledgement that their research was not purely uni-disciplinary caused difficulties for researchers who struggled to find participating collaborators and instead ventured on their own, did not fully understand the benefit of having a collaborator, or experienced difficulty coordinating multiple members in one research team. A third key message that emerged from the literature review was the uncontrollable nature of working in the field due to variables that would normally be controlled in lab settings (*KP 3*). The fourth and last key message grounded in surveyed literature arose from the observed pattern that many HCI researchers were not prepared to always handle the unexpected interactions and relationships formed during field studies. The case studies that we have investigated suggest that this dilemma was related to having a common background in computer science and a training in methodology that predominantly prepares researchers for controlled experiments in lab settings (*KP 4*). Finally, in our survey of relevant HCI literature we have not found evidence of Canadian-lead research into studying the ethical aspects of techno-centric fieldwork, which has prompted us to suggest a fifth key message that indicates a possible lack of interest in such scholastic endeavours or even a deference to the institutional process of ethics as implemented by various REBs (*KP 5*). We thus treat this fifth key point as separate from the other four, as this one is based on lack of evidence as opposed to being thematically grounded in an extensive body of literature.

Connections to the TCPS2 (2014) document were made based on the researcher’s understanding of the ethical dilemma expressed in each of the tables with some explanation as to why particular dilemmas were applicable in multiple sections of the Tri-Council policy report.

## 3 Survey of the research space

### 3.1 Ethics as relevant to research with human participants

#### 3.1.1 Qualitative Studies

Qualitative studies and the social sciences/ humanities “have a long history” (TCPS2, 2014, Chapter 10) with researchers sharing a desire to “understand human action through systematic study and analysis” (*ibid*). In human computer interaction research however, qualitative studies are less common, and this can be attributed to specific challenges that relate to working specific user groups, for example, with vulnerable participants (Arditti, 2015). Qualitative field studies and in particular, observational studies, rely on the researchers first hand account of the phenomenon and are therefore acknowledged by researchers as a “powerful source of validation” (Angrosino & Mays de Perez, 2000, p. 674). However, research approaches to qualitative studies are “inherently dynamic” (TCPS2, 2014, Chapter 10). For these reasons, field studies have only recently emerged as a delicate nuance to the earlier clinical trials or laboratory training sessions that many HCI researchers have grown accustomed to.

As such, HCI researchers are now displaced both in location and temporal settings, finding themselves accounting for the wellbeing of participants during times of crisis and stress (Andalibi & Forte, 2016; Baker & Warburton, 2015; Bica & Anderson, 2016; Davis & Waycott, 2015; Kazemian, Munteanu, & Penn, 2016; Talhouk, & Thieme, 2016; Yoo, Nathan, & Friedman, 2016) in addition to sensitive settings (Waycott et. al., 2015) where the question of human dignity has been pushed aside (Davis & Waycott, 2015; Slegers, Duysburgh, & Hendriks, 2015; Taherian, Davies, & Owens, 2015) or being privy to confidential, private or illegal information communicated by the participants (Gora, 2015; Prichard, Spiranovic, & Lueg, 2015; Singh, Kaur, Sajjanhar, & Cross, 2015; Steinberger, Schroeder, & Lindner, 2015; Strohmayer & Comber, 2015; Thiel & Poikela, 2015; Wadley, Lederman, Alvarez-Jimenez & Gleeson, 2015; Yoo, 2016).

### 3.1.2 Procedural versus Contextual Ethics

The procedure of completing an ethics form for conducting research with human participants emerges as central focus of concern for HCI researchers as they continually reflect (Waycott et. al., 2015) upon a feeling of being unprepared for the contextual decisions that are demanded of them during field studies, from moment to moment (Buchanan, 2015; Strohmayer et. al., 2015; Taherian et. al., 2015; Waycott et. al., 2015). The intention of the ethics procedure is to consider plausible ways of reducing potential harm for participants (Weijer, 2001) and accounting for possible emotional harm or distress (Buchanan, 2015; Busch et. al., 2016). HCI researchers are now calling for ethics procedures to consider the potential for situational ethics dilemmas to arise in the field along with a contingency plan of action (Vines et. al., 2016). However, in an effort to expedite the ethical process, coupled with a lack of experience in field studies and a general lack of evidence from case studies, researchers are often presenting a “best-case scenario” on their ethics applications and making adjustments in-situ afterwards (Buchanan, 2015; Busch et. al., 2016; Taherian et. al., 2015).

### 3.1.3 Sensitivity

Becoming sensitive to the needs of a participant during the course of a study demands a researcher to consider the wellbeing of participants over the outcomes of the study (Taherian et. al., 2015; Vines et. al., 2016). “Sensitive settings refer to research contexts that face human situations that can strongly influence both the researchers and the respondents due to the delicate subject of the study” (Di Fiore et. al., 2016, p. 1). Sensitivity demands a researcher to reconsider the choice of venue for participants, comfort levels of participants, stamina and break periods (Taherian et. al., 2015). Researchers have also grown in their awareness of sensitivity as it pertains to language used with and around participants (Yoo, 2016). Additionally, the need to consider sensitivity when disseminating stories about participants to broader audiences (Walther, 2002) and the potential for harm that raises has grown in awareness for researchers as well (Davis et. al., 2015). For some, the success of a study pertains to the researcher’s ability to be sensitive to their participants needs (Dee et. al., 2016).

## 3.2 Ethics in techno-centric fields such as HCI

### 3.2.1 Qualitative Studies

The added dimension of novel technologies in techno-centric fields has important implications for ethical consideration in regards to human participants. Qualitative research studies have ranged from considering social media research that looked beyond the face value of the data to conceptualize the story (Bica et. al., 2016) to opportunities to explore family spaces in regards to socio-technical interactions (Gora, 2015). The inclusivity of vulnerable groups has opened the window to using “proxies”

to gain consent as well as insight due to researcher inexperience (Taherian et. al., 2015). Alcott (2009) would caution however, "Anyone who speaks for others should only do so out of the concrete analysis of the particular power relations and the discursive effects involved" (p. 128).

Medical professionals and HCI researchers have worked collaboratively to design novel technologies to support patients (Buchanan, 2015; Stevenson, & Taylor, 2015). This approach to research with emerging and disruptive technologies is diverse in consideration of various ethical issues and relatively uncharted (Hughes, Brown, Pinchin, Blum, Sharples, Blakey & Shaw, 2015). For vulnerable populations the availability of sociotechnical interventions is affordable (Baker et. al., 2015), however, their experience with technology is lacking and therefore for many participants, IT training is necessary prior to the commencement of any study (ibid).

### 3.2.2 Procedural versus Contextual Ethics

Due to the inexperience with emerging technologies many participants and researchers find contextual ethical decision making to occur more frequently and on a case by case basis (Gerling et. al., 2015; Stevenson et. al., 2015; Taherian et. al., 2015). In particular, this became apparent through the study of "Health" and wellbeing apps (Buchanan, 2015) although young people are receptive to using technology (Wadley et. al., 2015) many health practitioners felt the recommendation for use should be considered on a case by case basis (Estrada et. al., 2015; Taherian et. al., 2015).

### 3.2.3 Potential for Harm

The potential for harm to both participants and researchers due to the use of novel technologies and in many cases with the inclusion of vulnerable populations, demanded that informed consent procedures were continually renewed at each session (Gerling et. al., 2015). In some cases, the inclusion of care or social workers was needed in order to provide a safety measure for both participants and researchers (Talhok et. al., 2016). The creation of digital footprints brought additionally concerns regarding the dissemination of personal accounts and narratives (Davis et. al., 2015). In many cases, research has shown a need for technology to be endorsed by medical institutions (Estrada et. al., 2015).

### 3.2.4 Sensitivity

Experience introducing novel technologies to potential participants has shown the value of using active participation through the use of presentations prior to the commencement of a study (Taherian et. al., 2015). Presentations have been shown to provide an opportunity for researchers to speak candidly regarding their study and help participants make informed decisions regarding their consent (ibid). Additionally, the opportunity to meet a diverse group of potential participants helped researchers to understand what specific needs might be required for participants to engage in the study and to collaborate about how best to meet individual needs (ibid).

Researchers have also identified unexpected sensitivity to their placement in vulnerable settings with participants and their undisclosed observation of interactions between medical staff, and caregivers with participants (Hughes et. al., 2015). Access to sensitive information found on social media platforms has also raised an awareness to the particular needs of HCI researchers and their participants (Andalibi et. al., 2016; Bica et. al., 2016).

### 3.3 Ethical dilemmas

#### 3.3.1 Qualitative Studies

There are several different ethical dilemmas that can arise in qualitative studies with human participants. In many cases, the ability of a researcher to connect and form a relationship with each participant allows for varying degrees of fluidity of information and sharing. Becoming a member of a particular community to gain access to participants “enables more in-depth insights” (Taherian et. al., 2015, p. 4). However, as Taherian et. al., (2015) also correctly note, this can be a double-edged sword when these immersion techniques are seen as “coercion”.

The building of rapport, once acknowledged as the sign of a quality interview, can become an “ethical conundrum” (Strohmayr et. al., 2015). Researchers are faced with a dilemma of establishing clear boundaries between themselves as researchers, and having individual authenticity, but also wanting participants to feel relaxed and comfortable speaking about personal narratives (Strohmayr et. al., 2015; Talhouk et. al., 2016). At times, revealing personal information can also expose both participant and researcher, resulting in a “reciprocal vulnerability” (Strohmayr et. al., 2015).

As the settings for each study become more intimate, dilemmas can also occur as was shown in Davis et. al., (2015) study of socially isolated housebound individuals who became accustomed to regular visits by researchers. Exit strategies become an important focal point for which researchers must address their guilt when leaving a socially isolated (Waycott, et. al., 2015) or otherwise vulnerable participant and returning to their own lives at the end of the study (Davis et. al., 2015). Relationships that are formed have the potential to also give a sense of false hope that the researcher and participant will remain close (Strohmayr et. al., 2015).

#### 3.3.2 Procedural versus Contextual ethics

For the more experienced qualitative researcher, ethical dilemmas can be unsurprising (Baker & Warburton, 2015). Despite this lack of surprise, ethical dilemmas continue to prove challenging to even the most experienced researcher and difficult to solve by simply referring to ethics procedures (Baker et. al., 2015; Vines et. al., 2016). When research is conducted in the field, participants are studied in their environment. This can include work or professional locations and the implications of the study can be damaging to the reputation of participants (Walther, 2002), who may feel at risk of feeling exposed or embarrassed by tasks expected of them that they are unable to perform correctly in the study because of their position or professional role (Buchanan, 2015). In addition to this, the location of a study, earlier mentioned as being something to consider to ensure participants feel comfortable and are not inconvenienced, can attribute to participants “inadvertently revealing more information about themselves than they would in other settings” (Davis et. al., 2015, p. 4).

In HCI-lead studies conducted in medical or health settings, researchers have also noted that participants may believe the researcher has a medical background and may ask for medical advice or share personal medical information (Talhouk et. al., 2016). Additionally, the concept of “therapeutic misconception” arises where the participant considers the goal of the study to be therapy instead of research (Rodger et. al., 2015). This is compounded by an awareness of a participant’s complex life that would not typically be visible in other settings (Davis et. al., 2015; Gora, 2015; Talhouk et. al., 2016; Thiel et. al., 2015; Yoo et. al., 2016).

In particular cultural norms, or vulnerable populations may prove the use of incentives to be unethical and seen to encourage a desperate population to participate for monetary or medical gain (Talhouk et. al., 2016). Finally, working with vulnerable populations may mean that participants require immediate changes to the approved protocol to keep them from experiencing duress or even pain (Gerling et. al., 2015; Taherian et. al., 2015).

### 3.3.3 Potential for Harm

Both participants and researchers can potentially be harmed during a research study. Ethical dilemmas related to this area occur when researchers need to consider complex imagery, narratives or accounts that are distressing or hold lasting implications on their emotional wellbeing (Andalibi et. al., 2016; Dee et. al., 2016; Di Fiore et. al., 2016). “No one on the team considered the possibility that the research team would be psychologically affected by the stories of the residents and those who surround them” (Dee et. al., 2016, p. 3). In particular, researchers note that working with vulnerable populations, such as the elderly, created unanticipated emotional issues (ibid). The degenerative nature of the health of some vulnerable participants also impacts researchers as they interact over extended periods of time (Dee et. al., 2016; Strohmayer et. al., 2015).

Davis & Waycott (2015) discuss the difficulties researchers experience when the line between researcher and guest is blurred, causing many researchers to feel a responsibility to respond or act when a difficult or emotional experience occurs with a participant. “We entered a participant’s home as guests and strangers, but we were privy to a difficult and upsetting conversation and we felt we needed to offer support” (ibid p. 4). The potential for harm to participants can also arise when certain research situations force participants to reveal personal vulnerabilities, such as in disability studies (Gerling et. al., 2015), or when participants in politically volatile situations are participating (Yoo et. al., 2016). When researchers are surrounded by participants in a community that is malnourished and in need of medical attention or basic human rights, their action or inaction can have lifelong implications (Talhouk et. al., 2016).

### 3.3.4 Sensitivity

The topic of sensitivity for ethical dilemmas has many different subcategories. The examples highlighted above as potentially causing harm for researchers and participants raise the issue of the paramount importance of sensitivity in qualitative studies (Andalibi et. al., 2016). “It is not possible, nor desired for me to be completely emotionally removed in various phases of these studies. The challenge for me is to remain sensitive enough to conduct reliable research while also maintaining my own well being” (ibid p. 5). However, ethical dilemmas in regards to sensitivity also occur as related to concerns about patient privacy and potentially embarrassing situations that threaten the dignity of human participants (Buchanan, 2015; Strohmayer et. al., 2015) or serve as reminders of painful events (Yoo, 2016). Certain cultural or political situations can also force participants and researchers to reconsider the sensitivity of their research project (Talhouk et. al., 2016; Yoo et. al., 2016).

Kirkham (2015) believes a potential area of sensitivity concern stems from the ethical review process that often recruits non specialists to give unbiased opinions of research ethics applications and unknowingly place participants at risk through an inadequate evaluation of the project and ultimately, “failing to safeguard to the rights of participants” (ibid p. 3). “My current institution has a policy of getting non-experts to review research proposals from an ‘ethical approval’ perspective, in order to avoid potential conflicts of interest” (ibid p. 2). Additionally, Kirkham (2015) also notes that unnecessary

burdens exist regarding the investigation of certain sensitive settings thus highlighting a general criticism that institutional ethics review boards are an inadequate venue for providing on-going ethics guidance.

However, various movements that support the rights of human participants with disabilities, as well as research such as Alcoff (2009) and the inclusivity requirements in the TCPS2 have forced researchers to take into account and include as much as possible participants from typically marginalized or prejudiced groups. Kirkham (2015) believes that undue delays to approval for research with vulnerable groups exist, specifically people with disabilities, which he attributes to a discourse that views persons with disabilities as “objects” of charity, medical treatment, or social protection. This is in contrast to recent movements advocating for seeing persons with disabilities as “participants” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as by being active members of society (Kirkham, 2015, p. 3). Gora (2015) experienced similar concerns when advised to avoid research with children due to their classification as a vulnerable population and the role of parents as “gatekeepers” due to the social location of children. Gerling et. al., (2015) study the effect of assistive technology for disabled youth and suggest the use of case-by-case decisions with informed consent from parents and assent from study participants that is reviewed at each session.

Interestingly, McMillan et. al., (2016) voice concerns regarding the bureaucracy of completing informed consent forms for vulnerable groups that, in their opinion should be brought about through negotiation and collaboration. “The legalization of the relationship between participant and researcher with a document that casts the researcher as an untrustworthy individual engaged in a dangerous practice and the participant as a victim without agency risks causing more harm than it prevents” (ibid p. 3).

### 3.4 Ethical dilemmas in techno-centric fieldwork

#### 3.4.1 Qualitative Studies

Ethical dilemmas exist in many qualitative studies, however, there are specific dilemmas that occur for human computer interaction researchers that will be exemplified in this section. Researchers working with vulnerable groups who are enabled through the use of novel technologies have dilemmas when met by parents who hold high expectations of what their child will be able to achieve (Taherian et. al., 2015). “For technologies to support participatory consent processes and reduce possible therapeutic misconception, they must demonstrate the potential to improve both comprehension and understanding for potential participants over current models of informed consent” (Rodger et. al., 2015, p. 4). In other areas, simply the combination of a domestic situation coupled with digital content alludes to the potential for ethical dilemmas (Davis et. al., 2015). Many HCI researchers feel inadequately prepared (Dee et. al., 2016).

#### 3.4.2 Procedural versus Contextual ethics

Procedural and contextual ethics emerge in this section as specifically focused on techno-centric fieldwork such as those studying the legalities of terms of service agreements, or those related to the combination of humans, different cultural norms and computers in research.

Social media research has grown in its awareness of the intricacies involved when reusing publicly shared data (Andalibi et. al., 2016; Bica et. al., 2016). Dilemmas go far past the debate over public versus private and have emerged to consider the legalities of adhering to terms of service agreements (Bica et. al., 2016). “The legalities governing human subjects and the legalities governing social media authorship

are in conflict” (Bica et. al., 2016, p. 3). Other studies, such as Talhouk et. al., (2016) that involved incorporating technology into the provision of Antenatal Care (ANC) for refugees in rural Lebanon by providing mobile phones, questioned how the “institutionalized ethical procedures” applied to their context (p. 1). The researcher’s role was continually blurred with those of medical professionals because they were affiliated with a medical institution to conduct their research (Talhouk et. al., 2016). The blurring of boundaries coupled with the distrust of the medical system in Lebanon forced many participants to seek medical advice from the researchers (Talhouk et. al., 2016). “Previous work has found that participants often misunderstand aspects of the research endeavor in both the developing and developed world” (18 as cited in Rodger et. al., 2015, p. 2). Taherian et. al., (2015) study considering an emerging technology with a Brain Computer Interface (BCI)-Assistive Technology (AT) for people with severe cerebral palsy, who were non-verbal “encountered issues around gaining sustained participation in our project, participant burden, dissonance between consent of caregivers/guardians and assent from our participants and obtaining feedback for proxies” (ibid, p. 1). In these cases, the typical procedure of reapplying for ethics for each change to protocol was deemed impractical (ibid). Additionally, the use of “proxies” or caregivers who provide consent on behalf of non verbal participants can add to ethical dilemmas (ibid). “Two of our participants showed signs of wanting to discontinue (vocal attempts, moving their head backwards so the headset would fall off and crying) but their caregivers and teachers disagreed and tried to push on with the trials” (ibid, p. 3).

### 3.4.3 Potential for harm

As exemplified in the previous section, both researchers and participants are at risk potentially for harm during techno-centric fieldwork, the lack of training for this level of involvement and the emotional impact on researchers can be devastating (Andalibi et. al., 2016; Dee et. al., 2016).

One area of particular concern is the placing of medical information online or accessing therapy or support through online platforms (Buchanan, 2015; Estrada et. al., 2015; Møller et. al., 2016; Orłowski et. al., 2015; Wadley et. al., 2015). Confidential information is ill suited for storage on a digital platform (Singh et. al., 2015; Wadley et. al., 2015). Additionally, the notion of group support in some communities can have negative implications (Wadley et. al., 2015; Yoo, 2016). Participants may falsely believe that they are supported medically and expect immediate attention in times of crisis from their doctor (Estrada et. al., 2015). Specifically in the realm of offering online support for mental illness through group chats or forums, researchers and medical professionals worry about the additional possibility for abuse or the mirroring of behaviours (Wadley et. al., 2015). Concerns such as these can also raise censorship issues (ibid).

Offering support to participants is not a role that is expected of researchers and yet they are often placed in circumstances where their inaction is deemed to also potentially cause harm and they have a responsibility to ensure the wellbeing of participants (Kazemian et. al., 2016; Rodger et. al., 2016; Taherian et. al., 2015; Talhouk et. al., 2016). Examples such as these can equally be related back to the notion of informed consent, and how informed the participants are about the goals of the research and their role in the research as participants (Rodger et. al., 2015).

These ethical dilemmas mentioned above also relate back to the notion of “therapeutic misconception” (Rodger et. al., 2015). “Individuals do not understand that the defining purpose of clinical research is to produce generalizable knowledge, regardless of whether the subjects enrolled in the trial may potentially benefit from the intervention under study or from other aspects of the clinical trial”

(Henderson et. al., (15) as cited in Rodger et. al., 2015, p. 2). Similar to therapeutic misconception is the aspect of direct benefits, which is typically limited to participants' financial compensation, yet often they hope for longer-term benefits such as having the technology under study (e.g. a helpful assistive device) be given to them at the end of the trial (Munteanu et. al., 2015). Furthermore, the addition of various stakeholders can impose alternative motives for the use or promotion of technology for vulnerable populations create situations that call for a careful reconsideration of informed consent (Busch et. al., 2016; McNaney et. al., 2015; Ramos et. al., 2015) Vines et. al., (2013) note, "Challenges exist for HCI researchers when their research is portrayed by the mass media and commented on by their readership" (p. 1873).

### 3.4.4 Sensitivity

Many developments and HCI technological interventions focus on providing assistive technology (Gerling et. al., 2015; Ramos et. al., 2015; Slegers et. al., 2015; Taherian et. al., 2015; Talhouk et. al., 2016) relate to political settings (Rodger et. al., 2016; Thiel et. al., 2015; Yoo et. al., 2016) or contain illegal content (Gora, 2015; Prichard et. al., 2015; Singh et. al., 2015; Steinberger et. al., 2015). These settings are often deemed sensitive (Dee et. al., 2016; Di Fiore et. al., 2016; Hughes, et. al., 2015; Ramos et. al., 2015; Taherian et. al., 2015; Yoo, 2016).

In an attempt to be sensitive to the needs of participants, researchers have been forced to make alterations to their technological intervention or tool during the study (Taherian et. al., 2015). "The BCI device that we employed in our research was not ergonomically designed to suit our participants' needs. Our participants felt very uncomfortable during most of our interactions" (Taherian et. al., 2015, p. 3). Other researchers were forced to push their participants to their limits and yet were expected to be sensitive to their needs "Challenging players is a core aspect of creating an engaging experience; therefore some of our work needs to explore the boundaries of players and how to push these in a meaningful way" (Gerling et. al., 2015, p. 5).

## 4 Emerging ethical dilemmas

The survey of relevant literature on ethical issues in fieldwork (as summarized in Section 2 (Methodology) has informed our analysis of the ethical dilemmas as presented in the case studies summarized in Section **Error! Reference source not found. (Error! Reference source not found.)**. We now classify these dilemmas along with relevant examples and authors' reflections along the core key points highlighted in this report. We structure this into 4 subsections, one for each such key point (KP 1 to 4). The fifth key point provides an observation on the relative scarcity of Canadian-lead research within the field of ethics as pertaining to techno-centric fieldwork (by way of little bibliographic evidence). Therefore KP 5 is not present in this classification.

### 4.1 Lack of path dependency

Ethical dilemmas	Examples	Source	Reflection / Resolution	Country
<b>Ethically correct but potentially in violation of civil / commercial agreements</b>	Violating twitter's Terms of Services	Bica & Anderson, 2016	Legalities governing social media authorship	United States

<b>Issues of contextual ethics that the formal process overlooked</b>	How to handle cessation of studies when participants are asked to use “well being” apps	Buchanan, 2015	Nowhere in the ethical process was the issue of how to handle cessation of the study	United Kingdom
	Signed consent forms create a record of participation in research	Steinberger, Schroeder, & Lindner, 2015	We put in a high-risk application, which dealt with the de-identification of the data	Australia
	Remuneration for refugee women participants’	Talhok, & Thieme, 2016	Considered coercive and place undue influence	United Kingdom United States/ corporate
<b>Don’t have any empirical basis to estimate possible harm</b>	Risks associated when participants interact with each other	Kazemian, Munteanu, & Penn, 2016	Emotional and aggressive exchanges were not anticipated	Canada
	Brain-Computer Interfaces are a novel form of technology	Taherian, Davies, & Owens, 2015	The participant group had never heard of, nor interacted with this technology before	New Zealand
	Unprepared for degenerative changes	Dee & Hanson, 2016	Informed consent from parents with assent from study participants	United Kingdom United States

#### 4.2 Collaboration/ Multi-disciplinarity

<b>Ethical dilemmas</b>	<b>Examples</b>	<b>Source</b>	<b>Reflection / Resolution</b>	<b>Country</b>
Safeguarding participants’ safety and dignity is difficult when outside professional expertise is required for the study (which often comes with conflict of interest).	Clinicians don’t want to impose their therapeutic values onto users beyond face to face interactions by recommending that patients use apps	Estrada, Wadley & Lederman, 2015	Not all users are suitable candidates to use apps based on their level of distress and level of expertise on the use of technology	Australia
	It is important for Internet-based mental health services to be asynchronous	Singh, Kaur, Sajjanhar, & Cross, 2015	It is not cost effective to have a moderator logged in at all times	Australia

	People are unwilling to be identified as clients of mental health services	Wadley, Lederman, Alvarez-Jimenez, & Gleeson, 2015	Stigma attached to mental illness	Australia
Balancing study inclusion criteria with potential participants' privacy	Scanning social media threads for potential suicidal users non disclosure regarding age of participant	Andalibi & Forte, 2016	Unable to recruit enough adult participants -- unable to work with vulnerable populations	United States
Obtaining informed consent directly from a vulnerable participant	Child participation is reliant on informed consent via adult 'gatekeepers'	A child's social location is often viewed as subordinate to adults (Gora, 2015)	It is important to allow teenagers a sense of agency	Australia
	A Person with Dementia (PwD)	Ramos, & van den Hoven, 2015	Individuals might forget being briefed about the research	Australia
	Clinical trials	Rodger, Davidson, & Vines, 2015	Whether a participant in research is truly 'informed' and whether their participation is indeed 'voluntary'	United Kingdom
Scientific merit of the study (risks vs benefits decision) may be tainted by outside competing interests	Problematic if the goals are not aligned with the needs of a Person with Dementia (PwD)	Ramos, & van den Hoven, 2015	May experience decreased personal contact as a result of the introduction of new technologies in the home	Australia
	Initial trials that are reported in the media may provide a false indication of the potential for the technology	McNaney & Vines, 2015		United Kingdom
	Some parents had high expectations about what the technology could enable their	Taherian, Davies, & Owens, 2015	The human research ethics applications that were submitted were in a sense	New Zealand

	children to achieve		“best case scenarios”	
	“Therapeutic misconception”	Rodger, Davidson, & Vines, 2015		United Kingdom
Putting indirect participants at risk of social, personal, or economic loss	Develop an information system in order to support the care activities of a paediatric palliative team --	Di Fiore & D'Andrea, 2016	Research that takes place within a hospital or organizational setting may expose unprofessional behaviours	Italy
Balancing privacy risks with accuracy/relevance of collected data	Understand aspects of the built environment in a care home	Dee & Hanson, 2016	Consider affect on residents' physical activity and social interaction	United Kingdom United States
	Transporting information from a physician to a municipality through a medical information system	Møller & Jensen, 2016		Denmark
	Many hospitals will not support research in the field and researchers are left to investigate error rates in non-clinical settings	Buchanan, 2015	Recruitment of participants of equivalent mathematical ability to the “typical” nurse	United Kingdom

### 4.3 Unpredictable variables

Ethical dilemmas	Examples	Source	Reflection / Resolution	Country
Increasing participants' vulnerability through personal information exposure	Inadvertently reveal more information (in a home setting) about themselves than they would in other settings	Davis & Waycott, 2015	Presence of other family members, too, makes it difficult for researchers to ensure participants' confidentiality	Australia
	Careful exploration of their personal experiences and may bring up negative emotions	Gerling, Lineman, Waddington, Kalyn, & Evans, 2015	Consent procedure included informed consent from parents with assent from study participants that was renewed at each session	United Kingdom

	It can be quite difficult for participants to be confronted with their own limitations, or with other participants living with similar impairments	Slegers, Duysburgh, & Hendriks, 2015	Changes regarding the approach or specific techniques need to be made on the spot, based on the individual participants and context, which is impossible to fully account for in official ethical applications	Belgium
	Expressions can invoke negative connotations, trigger trauma, or contribute to stigma	Yoo, 2016		United States
Deviating from protocol to accommodate and protect participants' needs or well-being when unexpected situations occurred	Changing political climate – need to make individualized, unpredictable changes, to suit the needs of each participant	Yoo, Nathan, & Friedman, 2016	Potential risks involved in reporting and disseminating the research- from choosing a politically legitimated citation to reaching out to appropriate	United States Canada
	Risks were associated with emotional and aggressive exchanges between participants who had cheated each other	Kazemian, Munteanu, & Penn, 2016		Canada
	Many adjustments to the study protocols were made based on our interactions with participants	Taherian, Davies, & Owens, 2015		New Zealand
	Researchers faced with the need to ensure participants' longer-term benefits from the study by giving them the technology	Munteanu et. al., 2015	Even if the technology is not mature it may be beneficial to participants (although long-term software maintenance becomes a concern)	Canada

#### 4.4 Background in Computer Science

Ethical dilemmas	Examples	Source	Reflection / Resolution	Country
Blurring of boundaries between researchers and participants	Privy to a difficult and upsetting conversation and we felt we needed to offer support	Davis & Waycott, 2015	Highlighting the need for great sensitivity when conducting research in people's homes	Australia
	Conflict with managing the relationship between researchers and participants	Andalibi & Forte, 2016	Changed strategy to look at publicly available data	United States
	There is also the emotional impact of working with people living with impairments on researchers and designers themselves	Dee & Hanson, 2016	Researchers have been drawn into the lives and the personal circumstances of the residents and those who interact with them	United Kingdom United States
	Researchers felt emotional conflict while witnessing the dire living conditions of the participants and their health problems that are persisting due to lack of trust between them and the healthcare providers	Talhouk, & Thieme, 2016	The influx of refugees has strained the resources and resulted in tensions among Syrian refugees and their Lebanese host communities	United Kingdom United States/ corporate
Blurring of the boundaries between research and treatment	"Therapeutic misconception"	Rodger, Davidson, & Vines, 2015	For technologies to support participatory consent processes and reduce possible therapeutic misconception, they must demonstrate the potential to improve both comprehension and understanding for potential participants over current models of informed consent (Rodger, Davidson, & Vines, 2015, p. 4).	United Kingdom
	The participants had expectations from the researchers that they possessed medical knowledge	Talhouk, & Thieme, 2016	The participants had expectations from the researchers that they possessed medical knowledge because they were affiliated	United Kingdom United States/ corporate

			with the American University of Beirut Medical Center	
	Conflict with managing the relationship between researchers and participants	Rodger, Davidson, & Vines, 2015	Individuals do not understand that the defining purpose of clinical research is to produce generalizable knowledge, regardless of whether the subjects enrolled in the trial may potentially benefit from the intervention under study or from other aspects of the clinical trial"	United Kingdom

## 5 Policy analysis: TCPS2 and emerging ethical dilemmas

The Canadian Tri-council policy statement (2014) addresses many of the ethical dilemmas that were described by the HCI researchers. Below is a detailed account of each particular dilemma and how it is addressed or connected to specific articles of the TCPS2 (2014) document. As Canadian HCI researchers move forward it is important to consider the following guidelines and examples to help develop their path dependency, to work collaboratively across multi disciplines and to account for unpredictable variables.

### 5.1 Path Dependency

Our first example illustrates ethical dilemmas for a pair of American researchers (Bica et. al., 2016) who used publicly available data on the social media website, Twitter. Ethically, their research was not considered to cause risk in the United States, due to the nature of publicly available data. Additionally, they were required to post all identifiable information according to Twitter’s terms of service agreement, making it impossible to provide any anonymity to conform with the social media authorship regulations. Tensions between an online service’s extensive (and often all-encompassing) terms of services and researchers’ need to access data (about which users may have some reasonable privacy expectations) are expected to become more common within emerging fields such as big data analytics or social media analytics. In Canada, several articles in the Tri-Council policy statement (2014) address this dilemma, with the bulk of the information contained in Chapter Five, Privacy and Confidentiality. In particular, these dilemmas are addressed under the heading Identifiable information, and then further in Articles 5.5, 5.6 and 5.7 that consider consent and secondary use of information. One further section of the TCPS2 (2014) document in Article 10.3 considers observation in virtual settings, “where people have a reasonable or limited expectation of privacy” (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 10.3 - Observation in Virtual settings](#)).

The second example under the heading of path dependency considers researchers that experienced issues of contextual ethics that the formal process overlooked. One particular example provided by a researcher in the United Kingdom (Buchanan, 2015) considered the cessation of studies that used “well-being” apps or provided mental health support. For this particular dilemma the TCPS2 (2014) section eleven considers the topic of Clinical Trials and in particular the area of psychotherapy. In particular the section considers the duration of the trial “The duration of these trials may be longer as a function of

the therapeutic approach and the characteristics of the condition to which it is applied” (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 11.1 - Psychotherapy](#)) and the requirement for trained researchers, “Particular areas of concern are whether the principal investigator or others on the research team are sufficiently trained to provide the investigational therapy and whether there is any risk of a negative impact on participants’ mental health” (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 11.1 - Psychotherapy](#)).

Several researchers in Australia (Prichard et. al., 2015; Steinberger et. al., 2015) considered the potential for harm that existed with the use of signed consent forms, considering these documents to create a record of participation in their research and potentially posing threats to confidentiality. The stipulation that consent shall be documented is referred to in Article 3.12 of the TCPS2 (2014) document, which stipulates is mandatory in some instances, (e.g., Health Canada regulations under the *Food and Drugs Act*, the Civil Code of Québec)” (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 3.12 - Consent shall be documented](#)). However, the section also provides alternative methods of gaining consent that include oral consent, the return of a questionnaire and even a handshake. However, it is noted that if signed consent forms are not to be used the researcher, under Article 10.2 of TCPS2 (2014), must document the procedure to be used.

The notion of providing incentives in the United Kingdom and the United States at a corporate level (Talhouk et. al., 2016) was considered in Chapter Three, The Consent Process, of the Tri Council policy, section one, where Incentives are considered and are neither recommended nor discouraged, however researchers are cautioned that, “The offer of incentives in some contexts may be perceived by prospective participants as a way for them to gain favour or improve their situation. This may amount to undue inducement and thus negate the voluntariness of participants’ consent” (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 3.1 - Incentives](#)).

A concern was raised by several researchers regarding the lack of any empirical basis to estimate possible harm on their ethics protocols and the dilemmas that were incurred when researchers relied on anecdotal evidence or were found to be simply “guessing” the level of potential harm to participants (Busch et. al., 2016). In cases such as group activities where researchers are required to determine risks associated to participants interacting with one another (Kazemian et. al., 2016; Wadley et. al., 2015), or in cases when novel technologies are tested (Taherian et. al., 2015) and finally in cases where participants experience degenerative changes (Dee et. al., 2016). The Canadian Tri-Council Policy (2014) considers this dilemma and offers guidance to researchers in different sections of the statement. In particular, Article 11.1, Medical Device Trials, and Article 11.4, Assessing safety and minimizing risks, however Article 11.3 states, “Clinical trials shall be registered in a publicly accessible registry that is acceptable to the World Health Organization (WHO) or the International Committee of Medical Journal Editors (ICMJE)” (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 11.3 - Clinical Trial registration](#)). Alternatively, researchers in Canada could consider Article 3.3- consent shall be an ongoing process, as a safeguard for both researchers and participants to voluntarily withdraw from a study when the potential for harm was deemed to be too great. Furthermore, Article 10.5, the TCPS2 (2014) allows for qualitative research to involve an emergent design. This allowance affords researchers the ability to make spontaneous changes to their study protocol as deemed necessary.

One final Australian researcher (Gora, 2015) considered the challenges of researching teens aged 12-17 who are considered a potentially vulnerable population and attempted to determine appropriate levels of confidence and privacy for each participant as they became Facebook “friends”. This research is

covered under two sections of the TCPS2 (2014) document. Chapter ten, observation in virtual settings where participants have a reasonable or limited expectation of privacy and under the section of psychotherapy in Chapter eleven, if the researcher attempts to offer advice or guidance to participants in an online format based on their observations. Whether or not a researcher intended to take on the role of guidance or counsellor, their observational presence online or in a network of friends may inadvertently suggest to a vulnerable participant that they, the researcher, are looking out for their, the participant, best interest, or that the researcher would advise them of wrong doings or the potential for negative consequences.

## 5.2 Collaboration/ Multi-disciplinarity

In applied disciplines Friesen (2010) argues, such as in HCI and educational technology, there are conflicting roles. Technology, "first operates heuristically to explain complex mental phenomena; it is then designed and developed explicitly as a tool for facilitating and developing these same complex mental processes" as Friesen (2010) continues, "this dual role represents an ethical dilemma—a kind of epistemological and practical "conflict of interest" (p. 83).

One emerging technology that is currently considered to be in an "ethical vacuum" (Buchanan, 2015) is that of "well-being" apps and/or mental health services made available online. In our discussion, our example considers the dilemmas researchers face when collaborating with mental health professionals, as well as a researcher's reliance on Clinicians' support to advocate the use of the app and to recommend users. Various Australian researchers provided examples of dilemmas that relate to this concept. Estrada et. al., (2015) found dissonance between clinicians in their support of mental health apps based on an understanding of duty of care, Singh et. al., (2015) experienced the same concern regarding the applications ability to provide online support at all times. The TCPS2 (2014) document considers duty of care in Chapter eleven, along with considerations for clinical trials that involve psychotherapy in Article 11.1.

One further consideration was noted by Wadley et. al., (2015) who had dilemmas regarding access to potential participants based on perceived stigmas surrounding mental health and concerns about confidentiality. Canadian researchers may also wish to review Chapter five regarding the use of identifiable information and then further in Article 5.3 of the same chapter guidance regarding the safeguarding of information. Finally, reviewing alternatives provided in Article 3.12, consent shall be documented, might also help to relieve Canadian researchers concerns and/or dilemmas.

When researchers are attempting to gain consent from a vulnerable participant, Chapter three, section 7A and 7B consider alterations to consent requirements, and debriefing in the context of alterations to consent requirements, when vulnerable participants are considered to be children or young adults. Participants with diminished capacity have considerations and guidance for consent forms available to researchers in Article 3.9- Decision Making capacity. The TCPS2 (2014) document considers participants who have both a permanent and a temporary diminished capacity and provides minimum conditions that must be met by researchers to assure that every attempt is made to involve the participant in the decision making process.

In particular, the TCPS2 (2014) document grants researchers the ability to place the participants wants and needs ahead of the caregiver or proxy as outlined in Article 3.10, "Where an authorized third party has consented on behalf of an individual who lacks legal capacity, but that person has some ability to

understand the significance of the research, the researcher shall ascertain the wishes of that individual with respect to participation. Prospective participants' dissent will preclude their participation" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 3.10](#)).

Vulnerable participants are considered capable of assent or dissent include those whose decision-making capacity is in the process of development, such as children whose capacity for judgment and self-direction is maturing" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 3.10](#)).

One issue that was raised with the use of research that benefits policy-makers, organizations and caregivers (such as increased efficiency through the introduction of technology -based solutions). Ramos et. al., (2015) iterate that this becomes problematic if the goals are not aligned with the needs of particular vulnerable participants, or when parents and/or caregivers have unrealistic expectations about the potential for the technology with their child. Therapeutic misconception, dual roles and medical device trials are addressed in the TCPS2 (2014) document in Chapter 11, which advises "Research has shown that clinician- researchers may conflate their clinical practice with their clinical trial research. Some may be overly optimistic about the prospects of an experimental intervention and overstate potential benefits or understate foreseeable risks to prospective participants" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 11](#)).

Finally, one further consideration that involves conflicts of interest concern researchers whose work within a hospital or organizational setting may potentially expose unprofessional behaviours. Researchers, in an attempt to develop assistive technology, often express a need to test technology in the field and rely upon medical staff and caregivers to grant entry and to support their research efforts by allowing them access to participants or employees. This collaborating relationship become problematic in cases where researchers are privy to questionable moments of professionalism (Dee et. al., 2016), to questionable moments of ability (Buchanan, 2015), to perceptions of insensitivity (Di Fiore et. al., 2016) and to the release of information (Møller et. al., 2016). The Canadian Tri- Council Policy (2014) addresses each of these concerns in multiple sections. In Article 10.3, the policy statement considers obligations for Canadian researchers as they engage in qualitative research and their observations in natural settings, "REBs and researchers need to consider the methodological requirements of the proposed research project and the ethical implications associated with observational approaches, such as the possible infringement of privacy. They should pay close attention to the ethical implications of such factors as the nature of the activities to be observed, the environment in which the activities are to be observed, whether the activities are staged for the purpose of the research, the expectations of privacy that prospective participants might have, the means of recording the observations, whether the research records or published reports involve identification of the participants, and any means by which those participants may give permission to be identified. REBs shall ensure that the proposal contains measures to protect the privacy of the individual in accordance with the law" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 10.3](#)). Furthermore, Articles 5.1 and 5.2 offer guidance to Canadian researchers on the ethical duty of confidentiality and the ethical duty to disclose information to third parties. Additionally, Article 3.3 - Incidental findings may also offer insight to Canadian researchers as they plan their study.

### 5.3 Unpredictable Variables

HCI researchers are often struck by the unpredictable variables that occur during fieldwork that were non-existent in lab settings. Our report highlighted that participants have a tendency to share more

personal information when they are in natural settings (Davis et. al., 2015) and therefore when researchers make enquiries that relate to participants' personal situations, they potentially expose vulnerability. The TCPS2 (2014) document considers the unpredictable nature of participants' reactions to various research questions or situations that bring up negative emotions (Gerling et. al., 2015), trigger trauma, (Yoo, 2016) or reveal private information to family members or care workers who are present as a condition of the informed consent process for vulnerable populations or studies that consider group activity. The simple acknowledgement by vulnerable participants that they are vulnerable can be a difficult revelation (Slegers et. al., 2015). For these reasons, Canadian HCI researchers would be wise to consider the guidance in Chapter 11, related to duty of care and psychotherapy when designing ethics protocols and calculating risks for potential harm. The revelation of personal information may also cause many researchers to consider Article 5.1, Ethical Duty of confidentiality and Article 5.2 - requirement to disclose information to third parties. In some instances, Article 3.3, incidental findings may offer further direction on material findings or unexpected discoveries that occur in the process of a research study. "Incidental findings are considered to be material incidental findings if they have been interpreted as having significant welfare implications for the participant" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 3.3](#)).

The reality of unpredictable variables in fieldwork forces many HCI researchers to make individualized, unpredictable changes, to suit the needs of each of their participants. Changes to protocols can occur due to a changing political climate (Yoo et. al., 2016), can be based on emotional and aggressive exchanges between participants (Kazemian et. al., 2016) or simply when a researcher deems it is in the best interest of the study and the welfare of the participants based on their interactions (Taherian et. al., 2015). The Canadian Tri-Council Policy (2014) affords qualitative researchers the ability, under Article 10.5 to apply for ethics with a research involving emergent design. "Although initial research questions may be outlined in the formalized research proposal, REBs should be aware that it is quite common for specific questions (as well as shifts in data sources or discovery of data sources) to emerge only during the research project" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 10.5](#)). However, if the changes in the ethics protocol are not an attempt to lower the risk of harm to participants, but rather potentially increase the risk, TCPS2 (2014) states the following warning for researchers, "Consistent with [Article 6.15](#), where changes of data collection procedures would represent a change in the level of the risk that may affect the welfare of the participants, researchers shall seek approval from the REB prior to implementing such changes" (Retrieved on Oct 24<sup>th</sup>, 2016 from [Chapter 10.5](#)).

#### 5.4 Background in Computer Science or Related Fields

A few ethical dilemmas were related to blurring of boundaries for HCI researchers that can be attributed to a common background in computer science compared to other disciplines and a general lack of experience with qualitative studies. Many researchers, in sensitive settings, felt the need to comfort their participants when privy to upsetting conversations (Davis et. al., 2015) and in some cases to manage conflicting relationships (Kazemian et. al., 2016). 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 et. al., 2016). The intervention of HCI researchers into the private lives and or conflicts of their participants could be viewed through the lens of Article 7.4 Researcher conflict of interest.

HCI researchers also commented that blurring of boundaries between research and treatment occurred in the field, when some participants assumed they held medical knowledge, or the researchers were trusted more than the medical professionals (Talhouk et. al., 2016). Chapter 11 considers Therapeutic Misconception, Clinical Trials as well as Dual roles and as such is applicable as guidance for these cases.

## 6 Conclusions and moving forward

Fields such as Human-Computer Interaction (HCI) are traditionally dedicated to studying how humans interact with novel technologies. Recent years have witnessed a significant increase in the development of such emerging technologies. This raises unseen challenges with respect to the ethical conduct of techno-centric fieldwork or studies with human participants.

In this synthesis report we have reviewed recent examples of such studies and analyzed these from a policy perspective (namely the Tri-Council Policy Statement for the Ethical Conduct of Research with Human Participants – TCPS2). The case studies were collected from recent workshops held in conjunction with ACM CHI – the largest academic conference within the field of HCI (a conference with a very large presence by Canadian researchers). The analysis was conducted under a thematic framework developed by synthesizing recent scholarly articles at the intersection of ethics, fieldwork, qualitative and quantitative studies, and HCI. While not all studies were conducted in Canada, these captured the same breadth of research that most Canadian HCI researchers are currently engaging in.

The overarching goal of this synthesis was to analyze how existing ethics policies such as the TCPS2 can provide guidance that is relevant to the particularities of new field-based techno-centric evaluations, qualitative studies, challenging lab-based evaluations, and ethnographic observations of emerging digital technologies as used by vulnerable or under-assessed user groups. Based on the thematic and policy analysis we have conducted over the repository of relevant case studies we conclude that, although TCPS2 was not originally drafted to cover such new cases, with careful interpretation it can be used to inform the ethical design of fieldwork studies with emerging technologies. Many other fields have been exposed to similar ethical dilemmas that are now emerging in techno-centric domains; however, HCI researchers often do not have the resources to solve such dilemmas. This is particularly evident in cases where the technology that is under study is, in itself, the cause of unexpected ethical situations. Succinctly, we have found evidence that:

1. HCI researchers are venturing into unknown 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
2. 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
3. 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
4. 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

5. Very little evidence exists of Canadian HCI researchers studying the ethical challenges of techno-centric fieldwork, especially outside lab settings or with vulnerable users

In light of the synthesis presented here, we make the following preliminary recommendations and suggestions for increasing the ability of Canadian research to anticipate and solve ethical dilemmas in techno-centric fieldwork with emerging technologies:

1. Increase efforts to improve the training of HCI researchers with respect to ethics. This includes increasing the availability of lectures (such as webinars), incorporating ethics training within the graduate HCI curricula, or the development of repositories of relevant case studies
2. Shift the nature of the dialogue between Canadian techno-centric researchers and their institutional REBs. In particular, emphasizing the consultative and mentorship role of REBs instead of administrative guardians and policy enforcers, as well as transforming the ethics application process from a static one to a more dynamic dialogue that can help researchers better (and efficiently) manage unexpected ethical situations arising from fieldwork.
3. Update of TCPS2 guidelines to more explicitly address the ethical situations encountered in fieldwork with emerging interactive technologies.

This report serves as a preliminary, bibliography-based analysis of the ethical challenges faced by researchers when conducting fieldwork investigations of emerging interactive technologies. Based on this analysis we recommend further formal study of the ethical dilemmas encountered in particular by Canadian researchers and directly understanding how or if TCPS2 and their institutional policies and processes provided guidance in addressing these dilemmas. Motivated by this synthesis report and to further explain why we have not seen evidence of scholastic interest in the ethical aspects of techno-centric fieldwork (key message KP 5), we have already initiated a set of interviews with more than 20 Canadian HCI researchers which we plan to analyze. Following this, we plan to increase the awareness of these challenges among Canadian techno-centric researchers through several knowledge mobilization activities: wide distribution of the current synthesis report, academic publication and dissemination of findings from the on-going interviews, and establishment of an online living repository of relevant case studies (all available through the principal investigator's university website at: <http://cosmin.taglab.ca/share/sshrc-ethics> )

## Appendices

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### Top-tier Publications for Human Computer Interaction

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	Publication	h5-index	h5-median
1.	Computer Human Interaction (CHI)	83	122
2.	ACM Conference on Computer-Supported Cooperative Work & Social Computing	49	74
3.	ACM Symposium on User Interface Software and Technology	44	66
4.	ACM Conference on Pervasive and Ubiquitous Computing (UbiComp)	41	73
5.	IEEE Transactions on Affective Computing	34	65
6.	ACM/IEEE International Conference on Human Robot Interaction	33	50
7.	International Journal of Human-Computer Studies	32	42
8.	Mobile HCI	30	47
9.	ACM Transactions on Computer-Human Interaction (TOCHI)	30	43
10.	Behaviour & Information Technology	30	42

11.	Interacting with Computers	28	41
12.	International Conference on Affective Computing and Intelligent Interaction and Workshops	27	48
13.	International Conference on Multimodal Interfaces (ICMI)	26	42
14.	IEEE International Symposium on Mixed and Augmented Reality	26	36
15.	International Journal of Human-Computer Interaction	26	34
16.	International Conference on Intelligent User Interfaces (IUI)	26	33
17.	IFIP Conference on Human-Computer Interaction (INTERACT)	25	35
18.	International Conference on Tangible, Embedded and Embodied Interaction	24	39
19.	Conference on Designing interactive systems	24	31
20.	IEEE Transactions on Haptics	23	36

### Top-tier Publications for Ethics

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	Publication	h5-index	h5-median
1.	Journal of Business Ethics	78	104
2.	Corporate Social Responsibility and Environmental Management	33	50
3.	Business Ethics Quarterly	31	55
4.	Business & Society	26	47
5.	Science and Engineering Ethics	26	36
6.	The Journal of Law, Medicine & Ethics	26	34
7.	Social Responsibility Journal	20	38
8.	Ethics	20	35
9.	Business Ethics: A European Review	20	30
10.	Ethics & International Affairs	18	33
11.	Environmental Values	16	27
12.	Global Responsibility to Protect	15	18
13.	Ethics & Behavior	14	19
14.	Ethics, Policy & Environment	12	21
15.	Journal of Moral Education	12	19
16.	Ethical Theory and Moral Practice	12	18
17.	Journal of Academic Ethics	12	18

<b>18.</b>	Journal of Moral Philosophy	12	18
<b>19.</b>	Business and Society Review	11	21
<b>20.</b>	American Philosophical Quarterly	11	20