ICT and Vulnerable Older People: Incorporating an Ethical Decision Making Model

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ABSTRACT
As mobile technologies become increasingly affordable and ubiquitous, Human-Computer Interaction (HCI) researchers are becoming increasingly interested in sociotechnical interventions with vulnerable populations. This paper discusses one such project that worked with older people in rural areas with histories of homelessness, social isolation and complex needs. Cellular connected tablets were given to a small number of participants (n=7) and over the course of eight months, researchers provided home based training and support aimed at building I.T. skills, improving links with local support services and building social networks. Many ethical challenges arose during the data collection phase of the project. This paper will discuss three such issues; the blurring of boundaries between researcher and social worker, challenges to maintaining privacy and confidentiality and ethically dealing with participants who are experiencing crises. Drawing on literature from the field of social work, this paper will argue for the incorporation of ethical decision making models into HCI research projects as a way researchers might address issues that exceed those typically considered in formal ethics procedures.

Author Keywords
ICT, Ageing, Substance Abuse, Homelessness, Rural, Ethics

ACM Classification Keywords
H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. H5.2 Information interfaces and presentations (e.g., HCI): Training, help and documentation.

INTRODUCTION
In recent years, HCI researchers have become increasingly interested in studying the impact of mobile technology platforms on vulnerable populations, such as older people and the homeless (Le Dantec, 2010; Waycott et al., 2012). While these projects have exciting implications for those interested in designing technology that better responds to the unique needs of vulnerable users and their communities, there is also an increased likelihood that significant ethical issues will arise in these environments that challenge researchers to make moral and ethical

judgments that cannot be anticipated in traditional formal ethics procedures (Waycott et al., 2015). This paper reports on the ethical challenges faced in one such project and proposes a new dynamic approach to ethical decision making during the course of research that is grounded in similar techniques drawn from the field of social work (Bowles, Collingridge, Curry, & Valentine, 2006; Chenoweth & McAuliffe, 2015). One such model, the *inclusive model* will be described and consideration will be given as to how such a model might assist HCI research with vulnerable people.

RESEARCH BACKGROUND
The Supportive Network research project employed a Participatory Action Research (PAR) methodology and sought to better understand the issues facing rural older people from disadvantaged backgrounds in relation to the use of Information and Communications Technology (ICT). PAR research combines iterations of planning, action and reflection throughout the research project with a particular emphasis on empowering participants and illuminating social problems (Reason & Bradbury, 2008). The project was based in the Assertive Outreach (AO) program at a homelessness support agency in the central Victorian town of Bendigo. The AO programs catchment area extends throughout the Loddon Mallee Region, a vast geographic area spanning over a quarter of the state of Victoria ("Loddon Mallee Region," 2014). AO program social workers provide support services to people over the age of 50 who have histories of homelessness, social isolation and 'complex needs', a catch-all term that covers mental health, physical health and substance abuse issues. Following ethics approval, social workers from the AO team were responsible for circulating information about the research project in the form of a Participant Information Statement (PIS). Social workers were acknowledged as being in the best position to judge potential participants' current circumstances and the researchers relied on their professional judgement as to whose personal circumstances precluded them from being recruited for the project. This reliance on professionals who have ongoing relationships with vulnerable populations to help during the recruitment process has proved effective in similar projects (Le Dantec & Edwards, 2008; Waycott et al., 2015). At the end of this process, eight people were assessed as being interested and eligible to participate in the project. One was subsequently ruled out when they were hospitalised for an extended period, leaving seven participants who then met with the researcher in order to discuss the project in more detail and complete the recruitment process.

Participant Overview

The seven participants chosen for the research project, five men and two women, ranged in age from 58-81. Only two of the participants had ever used a computer of any type before. Both these participants had subsequently suffered an Acquired Brain Injury (ABI). All of the participants had histories of homelessness and social isolation. Complex needs for the participant group included significant physical health issues such as cancer, Chronic Obstructive Pulmonary Disease (COPD) and hepatitis, a range of diagnosed mental health issues and ongoing substance abuse issues. Participants were all living independently in the community in rural and regional locations within an 80 kilometre radius of Bendigo.

Methods

At the beginning of the project, participants were given a cellular network connected tablet computer and were provided with pre-paid SIM cards with a monthly allowance of 1.2 gigabytes for the duration for the data collection period. Once the devices were activated, researchers met with participants regularly over a period of eight months in their homes to provide training and support in the use of the device. In accordance with the PAR methodology chosen for the project, research goals and methods evolved in response to individual participants' needs. Broad goals included using the tablet to improve communication with the participants' social workers, using the tablet to link with local services and supports, strengthening links with existing social connections and building new social networks. Data collection techniques included journaling, semi-structured interviews and collecting a range of digital artefacts such as photographs, audio recordings, e-mail correspondence and instant messages.

ETHICAL CHALLENGES

Given the complex issues being faced by the older people participating in the research project, it was unsurprising that a number of ethical dilemmas arose during the data collection stage that did not easily fit within the confines of the formal ethics agreement. One such issue was the blurring of boundaries that occurred due to the nature of the data collection process. An example occurred mid way through the project when a male participant, during the course of an interview with the researcher, confided that he was depressed due to relationship problems caused by a personal medical issue. When the researcher, who was male, suggested that this was something the participant should pursue with his social worker during their next visit, the participant said that he did not feel confident talking about this issue with a young woman and that he felt embarrassed. He asked if there was any chance that the researcher could take him to the psychologist's appointment instead.

Several ethical challenges arose involving privacy and confidentiality. As the participants were aware that the researcher was based at the homelessness services agency, on many occasions they asked the researcher to relay information back to their social worker. The social workers, who were involved as participants in another phase of the research project, would also ask the researcher about their visits to the participants and prompt the researcher to share information and 'tales' about the older participants. On several occasions, the older participants also confided information about drug use and petty theft to the researcher. This raised ethical challenges in relation to whether it was the researcher's duty to inform the social workers about this behaviour. Additional privacy and confidentiality issues arose due to the blurring of personal and professional profiles on the tablet computers. This issue is becoming increasingly prominent in the field of social work (Chenoweth & McAuliffe, 2015; Reamer, 2013).

A final example of ethical challenges involved occasions in which the researcher was present when the older participant was clearly in crisis. This could involve a range of issues, such as being present when the participant was drug and alcohol affected, being present when a participant was experiencing a decline in their mental health, or simply seeing that the participant was in need of medical assistance. An example of this latter issue arose late in the data collection period when a very elderly participant, whose health had been in decline due to complications with cancer, was visited by the researcher several days after being discharged from hospital. It was clear to the researcher that he was unwell. He did not wish to be taken to the doctor or have an ambulance called; however, he did express a wish to see his social worker. The visit occurred late on a Friday afternoon and the researcher was concerned for the participants wellbeing if he was left alone for the weekend.

RESPONDING TO ETHICAL CHALLENGES IN COMPLEX ENVIRONMENTS

Each of the ethical dilemmas described above presented challenges that could not easily be met by simply referring to the ethics procedures dictated by the universities Human Ethics Committee. How then should researchers working with disadvantaged populations in complex environments respond in ways that are professional and compassionate while still protecting the distinction between research work and social work?

Ethical Decision Making in Social Work

One potential solution to these types of ethical challenges is to employ an ethical decision making model approach drawn from the profession of social work (Bowles et al., 2006; Chenoweth & McAuliffe, 2015). Social work is a profession that has an explicit focus on working with disadvantaged populations and "interven(ing) at the points where people interact with their environments" (Australian Association of Social Workers (AASW), 2010, p. 7). This focus on people and environment places increased burden on social work professionals to respond to ethical dilemmas as they are happening in the field. This characteristic of social work practice, combined with often competing legislative and organisational policy demands of government, social service organisations and professional bodies, has meant that ethical decision making has been extensively covered in the social work literature (Bowles et al., 2006; Chenoweth & McAuliffe, 2015; Reamer, 2013). There has been a strong focus in the literature on a range of models and frameworks that guide the social work professional through a sequence of

decision making steps that combine 'process models' that consider "obligations and duty, and consequences and context", 'reflective models' that call on the social worker to reflect on issues such as power, and the inclusion of clients in decision making processes and 'cultural models' that incorporate "identity issues, worldviews, cultural values or any culturally relevant information" (Chenoweth & McAuliffe, 2015, p. 79). It is our opinion that these types of ethical decision making models have the potential to be of great assistance to HCI researchers working with vulnerable populations. One such model, the *inclusive model* developed by social work academics Lesley Chenoweth and Donna McAuliffe (2015), will now be described. A discussion of how this model might contribute to HCI researchers working with vulnerable people will then be presented.

THE INCLUSIVE MODEL
The inclusive model for ethical decision making is based on a core of four interlinked dimensions that incorporate aspects of process, reflective and cultural ethical decision making models. The four dimensions are: accountability, critical reflection, cultural sensitivity and consultation (Chenoweth & McAuliffe, 2015). *Accountability* prompts the practitioner to ensure that ethical decisions can be clearly articulated and fully justified and that they can be demonstrated to have considered the legal, organisational and professional obligations that guide social work practice. The *critical reflection* dimension calls on the practitioner to make decisions that are open to scrutiny by others so that practice might be improved into the future. The dimension of *cultural sensitivity* reminds the practitioner of the need to make decisions that are culturally appropriate and that take into account differing value positions. The final dimension, *consultation*, calls on practitioners to engage in discussions with others "who may assist accountability, cultural sensitivity and personal reflection" (Chenoweth & McAuliffe, 2015, p. 80). Surrounding this core of interlinked dimensions of ethical practice, Chenoweth and McAuliffe (2015), propose a series of circular decision making steps that prompt the practitioner to consider, and if necessary reconsider, a number of factors as they work towards an ethical decision. These factors are described as: defining the ethical dilemma, mapping legitimacy, gathering information, considering alternative approaches and action and engaging in critical analysis and evaluation (Chenoweth & McAuliffe, 2015). The first step in this circular process, *defining the research problem*, prompts the practitioner to ask a number of questions that frame issues such as who has the ultimate responsibility for the ethical decision, what are the competing ethical principals that are involved in this decision and can the researcher draw on previous experiences to deal with the situation, or do they need to develop new knowledge. Mapping *legitimacy* asks the practitioner to carefully consider who will be affected by the ethical decision and whether the dilemma should be discussed with others in order to involve them in the decision making process. An important step in the model involves practitioners *gathering information* from relevant guidelines and protocols that can assist in the decision making process. The next step, *alternative approaches and*

action prompts the practitioner to weigh up alternatives in order to be sure that the action they take is the one that is most appropriate. Having taken action, the final step calls on the practitioner to engage in *critical analysis and evaluation* so that their decision making and practice can be made stronger in the future (Chenoweth & McAuliffe, 2015). A visual representation of the inclusive model, is included in figure 1.
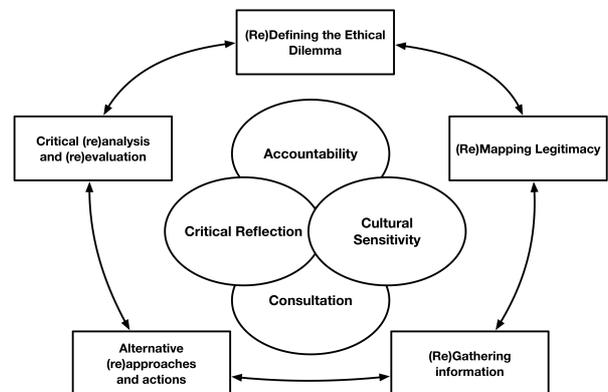

Figure 1. The inclusive ethical decision making model

The 'Inclusive Model' and Research with Vulnerable Participants
The inclusive model of ethical decision making includes a number of valuable new dimensions that can help HCI researchers take ethical action that, in addition to complying with formal ethical procedures, respects vulnerable participants and helps to inform better research practice in the future. These approaches to ethical decision making take the researcher beyond simple compliance and prompt the researcher to be able to justify their actions and engage fully in the process of ethical decision making. The adoption of models such as the inclusive model also call on researchers to seek new forms of support, such as ethical mentors and the participants themselves, so as to ensure that alternate views are considered and new processes can be incorporated into future research. The inclusive model is particularly appropriate in participatory forms of research as it can be incorporated into the traditional stages of planning, action and reflection that are typical of such methodologies (Reason & Bradbury, 2008). This made the inclusive model perfect for this research project, ultimately improving outcomes not just for the research project, but for the participants who were often those most impacted by ethical decisions. An example of how the model was applied to one of the ethical issues raised earlier in this paper is illustrative. Having been asked by a participant to accompany him to his psychologist appointment, stepping through the inclusive model proved valuable in meeting the ethical challenges involved. During the first step, *defining the ethical dilemma*, a number of potential ethical issues were identified that simultaneously clarified issues relating to the second step of the model *mapping legitimacy*. Firstly, agreeing to take the participant to his psychologist was clearly beyond the bounds of my role as a researcher, but was it unethical, particularly given the participatory nature of the research design? Secondly, how might agreeing to

take the participant to his appointment reflect on my role in the eyes of his social worker? There seemed to be a clear risk that the social worker might feel that I was encroaching on her role and jeopardising her trust in me as a researcher. Finally, there was the risk to the participant himself as it might create an expectation that I would continue to provide support into the future. From the point of view of *mapping legitimacy,* it seemed clear that I would need to consult with other people to decide the best course of action. Next, came the step of *gathering information*. Neither my agreement with the homelessness organisation, nor my formal ethics documents, precluded me from transporting one of their clients to an appointment. However, I had informally discussed the potential for the blurring of roles with the social workers and had committed myself to research only activities to avoid any conflicts. My decision at this stage of the process was to discuss the issue with the participant and inform him that I would need to discuss the matter with his social worker before making a decision. Importantly, I committed to not discuss the personal medical issue with his worker. The decision to discuss the matter with the participant's social worker proved valuable as she was able to suggest a possible *alternative approach and action* whereby a male social work student, who was currently on placement at the agency, would take the participant to his appointment. This arrangement was ultimately chosen as being the most appropriate for the situation. However, was it the best approach? This question is considered during the final step of the inclusive model, *critical analysis and reflection*. The outcome was good from the point of view of myself, as my role as a researcher was kept separate from a support/social worker role and it was also good for the social worker as her control of the case was maintained. Was it, however, the ideal result for the participant, who had chosen me to confide in about his sensitive medical issue? He did get his wish to be accompanied by a male to his appointment, however, it was a stranger with whom he had no rapport. The participant was already in a very vulnerable position and had little power. Was this the most ethical result for him? This reflection will certainly be top of mind should situations such as this occur in the future. Ultimately, while making ethical decisions in the field will never be easy, the inclusive model ensures that they can at least be made in reference to a sound framework that assists the researcher to take into account a range of relevant perspectives.

CONCLUSION
As technology, particularly mobile technology, becomes ever more affordable and ubiquitous, HCI researchers are beginning to work with participants from vulnerable or marginalised populations. In complex environments such as this, researchers increasingly find themselves facing ethical dilemmas that are beyond the scope of traditional formal ethics procedures. The Supportive Network research project demonstrates several such ethical dilemmas including the blurring of lines between research work and social work, challenges to maintaining privacy and confidentiality and ethically responding to participants who are experiencing crises. Drawing on the ethical decision making models that are prevalent in the profession of social work, a profession with a long history of working with vulnerable populations in challenging regulatory environments, this discussion paper argues that HCI researchers should begin to incorporate such ethical decision making models into their research designs. One such model, Chenoweth and McAuliffe's inclusive model is proposed as having particular relevance. Consideration is then given to how the inclusive model might make a positive contribution to HCI researchers working in the field with vulnerable people.

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