
Ethical Dilemmas in HCI: Small Charities and Politicised Campaigning

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Abstract

We consider the ethical challenges associated with conducting HCI research in collaboration with third-sector organisations, in particular small charities engaged in campaigning on politicised issues. These reflections are based on insights from our research with a UK charity. Ethical dilemmas include participant identification, the capacity and resources of charity partners, issues around researching politically sensitive settings, and the fact that HCI interventions might themselves be ethically challenging. We explore some of the ways in which these issues may manifest in the context of small charities, and pose challenges for HCI researchers that must be considered when engaging with such organisations.

Author Keywords

Ethics; charities; third sector; campaigning; HCI.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous; K.7.4 Professional Ethics; K.4.1 Public Policy Issues.

Introduction

There are a range of ethical challenges associated with conducting HCI research in the context of third-sector organisations. Many of these are amplified when

working with small charities, or investigating politicised issues. Our experience working with a UK charity, on the issue of accessible transport, highlights several areas in which ethical challenges are posed by HCI research in this context. These include: a) the identification of individuals and organisations; b) the linked issues of organisational capacity and the co-ordination of research activities with organisational priorities; c) researching politically sensitive settings; and d) the ethical challenges posed by HCI interventions.

Context: A UK Rare Disease Charity

We worked with Muscular Dystrophy UK (MDUK), a charity covering more than sixty rare and progressive muscle-weakening conditions collectively affecting around 70,000 people in the UK [3]. Their group of young disabled campaigners, the Trailblazers network, were investigating the issue of accessible transport. Our research investigated how the charity conceptualised, captured and presented different forms of evidence to aid in this campaign [6]. Working with the charity highlighted several broad areas where conducting HCI research in such contexts may cause particular ethical concerns. Considering each in turn prompted further reflection on the range of ethical dilemmas which might confront HCI researchers in these settings, beyond those directly noted during our work with MDUK.

Four Ethical Dilemmas

Identification of individuals and organisations

The challenge of anonymisation, in a world of online full-text indexing of research outputs, has previously been highlighted in HCI research [5]. Anonymity in the research process becomes more challenging when the research involves small organisations. This is

particularly true when working with organisations that serve communities with unusual or uncommon shared concerns, such as groups campaigning on behalf of those with rare diseases. In such cases, contextual information about the organisation may identify individuals. Quoting, for example, a 'press officer' may directly identify an individual or small group of people. However, whilst a researcher could instead refer to a 'staff member', emphasising the credentialed knowledge of the aforementioned press officer may be important if it provides particular insight into the topic at hand. This tension may be less pressing when researching large organisations, where one might refer to 'a senior nurse' at a large hospital with less risk of identifying an individual.

It is also important to note that the ethical issues inherent in this situation may not be as clear-cut as we might expect. Even in a highly emotional context, such as the death of a loved one, some research participants are comfortable being identified by their first name [4]. In some charity work, where individuals have actively chosen to campaign publicly on specific issues, participants may be comfortable being identified, or even actively refute anonymity. For example, the Trailblazers' previous report on accessible transport included images of campaigners and testimonies attributed to them by their first name [8]. As researchers, we traditionally seek to preserve participant anonymity and, although there is clearly a distinction between academic research and charity campaigning, there are interesting questions (and challenges) around anonymity which arise when these two worlds meet.

A linked, though distinct, concern is whether or not an organisation wishes to be identified in research. They may wish to do so in order to gain recognition for their work, or for the cause around which they campaign. Yet this desire may also be counteracted by concern for preserving individual anonymity, or by sensitivities around politicised campaigning which are discussed in detail below.

It is therefore clear that anonymity is an innate challenge when conducting research with, and reporting on, small third sector organisations. In particular, there is an inherent tension between generating useful and specific insight into particular contexts, and maintaining the anonymity of participants. One cannot describe only a 'charity' when much of the value of the research is bound up in the specific attributes of that organisation. But in identifying the charity (and/or the specific roles of participants), we increase the likelihood of individual identification.

These issues speak to the difficulty of balancing the desire of many participants to partake in research on issues of great concern to them, with our responsibility as researchers to ensure participant wellbeing. This traditionally includes preserving their anonymity in research outputs. We must ensure that our consent processes are robust enough to ensure, for example, that participants distinguish between activities they undertake *as campaigners* (in which they may wish to be identified) and the research *on campaigning* we undertake in collaboration with them. This is particularly the case when working with groups, such as those with disabilities, who may be considered 'vulnerable' in research contexts.

Capacity, Resources, and Fitting In

Researchers must be mindful that small charities often have limited resources and organizational capacity. It is imperative for researchers to 'fit in' and be flexible when working with charities, both for pragmatic reasons and in order to build strong relationships and rapport. This is particularly true in participatory research where close collaboration is sought and organisations are co-researchers in the project. Should researchers fail to 'fit in', they risk being unable to conduct their research, as well as potentially undermining the work of their partner organisations.

Working with third sector groups that possess comparatively limited resources can be challenging. Their priorities will likely, and understandably, lie in their primary organisational goals. Even in a participatory research project, working with academic researchers may be one of many competing priorities. Things as mundane as scheduling meetings in a crowded schedule, whether amongst part-time employees or researchers who also have term-time teaching commitments, may impact on the research timeline. In a larger organization, a certain degree of resilience may be built into organisational structures through, for example, overlapping job responsibilities. However, small charities seldom have this luxury. There is an ethical tension here for researchers: how to conduct research as efficiently as possible without imposing an undue burden on collaborators. Although this exists for all collaborative research, the potential impact on a small charity is likely to be more significant than for a large commercial company. In a participatory research project, a charity that feels it may gain something from the collaboration may also feel unable to refuse requests from researchers, even if this goes

against their direct interests (through, for example, the consumption of human or financial resources). Researchers therefore have an ethical responsibility to be particularly sensitive to the needs of charities with whom they work.

A related issue is that of researchers being appropriate in the commitments they make to their collaborators, especially in coordinating activities that are time-sensitive to the charity. The need for clarity on the purposes of a technology deployment, and the importance of setting realistic goals and outcomes in collaborative research, has been highlighted in the context of working with people who have complex communication needs [7]. Where such research is highly exploratory, with a high risk of failure, and/or is being conducted in a sensitive context, it is especially critical that there is trust and clear communication between researchers and participants [4].

In our case, we had planned to deploy a piece of mobile-phone based technology to assist volunteers in documenting issues around accessible transportation. Technical problems meant that the deployment was not successful during the period in which the charity was conducting evidence-gathering. We had taken care to forewarn the charity that the technology may fail to work as anticipated, and this was acceptable to them. However, if this had been a participatory research project in which they were reliant on the successful use of this technology, this delay would have caused difficulties for their campaign, and potentially damaged the relationship between the researchers and the organisation. Even though this was not the case in this instance, the opportunity to deploy a working prototype on a live campaign was lost.

In both cases, the ethical challenges here involve balancing our desire as researchers to undertake timely and efficient research, with being attuned to the needs and expectations of the individuals and organisations with whom we work. We are obliged to minimize any disruption we may unintentionally cause to our partners' work practices and environments.

Researching politically sensitive settings

When conducting research with any organisation that engages with policymakers, there are likely to be several ethical issues relating to the potential sensitivities of this relationship. These include the possibility that one or more actors – either the campaigners or those they are lobbying, such as governments or corporations – may view research into the relationship as threatening. Although not the case with our partner organisation, it is possible that, in other contexts, such a perception would jeopardize both the research project and the relationship between the researcher and partner organisation. From the perspective of those being lobbied, there might be concerns around protecting existing relationships with particular (preferred) groups, while charities that undertake campaigning may fear that publicity might reduce their effectiveness. Some charities are reliant on ongoing goodwill – or even funding – from specific policymakers to undertake their work and so such fears may not be unfounded. In our research with MDUK these issues have not arisen, but we could imagine that, in other contexts, such concerns may undermine research into contentious public policies.

If we, as researchers, seek to bring light to the often highly politicised contexts within which third sector organisations operate, we must be mindful that in

doing so we are potentially disrupting those same processes. Although this effect could be progressive, it is also possible that we might inadvertently undermine what little influence marginalised groups may have on decision makers. This issue of managing disruption also links to our final point on the ethical challenge and role of 'interventions' in HCI research.

The ethical challenges posed by HCI interventions

Research in HCI is often concerned with 'interventions', such as the deployment of new technologies, which are undertaken in order to assess and improve particular processes. In participatory research, there is also a simultaneous aim of empowering co-participants. However, these interventions themselves pose ethical questions around the extent to which researchers align themselves with their participants' interests. If one is seeking, for example, to bring about 'more effective' or useful tools or processes for a charity to undertake political engagement and campaigning, one might also be blurring the boundary between researcher and participants. It might be difficult, if not impossible, to determine the precise extent to which a researcher's involvement contributes to a particular outcome. However, the fact remains that in doing HCI research – and particularly participatory research – we often chose to intervene in order to change an existing system. This is distinct from a more traditional social science approach, which often assumes a researcher who strives for objectivity even if they reject an objective reality or 'truth'.

Furthermore, in the dominant neoliberal economic system, whenever we chose to intervene alongside or on behalf of a specific actor there will likely be others who lose out. These include other causes, or charities

with whom we chose not to work for whatever reason. It might also include 'competing' organisations or causes who are directly disadvantaged should our 'chosen' collaborator benefit from our intervention. This might be through the practical tools or technologies that we build and deploy as part of our research, through the insight our research generates, or through the unquantifiable 'participation' of a researcher working towards the goals of the partner organisation.

These issues raise a range interesting ethical questions in the year of *#Chi4Good*. How do we articulate our rationale for working with specific groups and not others, in the knowledge that we might be providing the former with some kind of advantage? If these decisions are purely pragmatic, to what extent are we still subconsciously influenced by our implicit understandings and beliefs around social justice? If we explicitly reject working with, for example, a tobacco company, we might also reject working with Forest, a nominally independent pro-smoking organisation that is in fact largely funded by the tobacco industry [2]. Yet the boundaries between what we might regard as 'acceptable' and 'unacceptable' partners are not always so clear-cut. Given the potential impact of our work, should we, as HCI researchers, have an explicit ethical commitment to social justice – and to *whose* vision of social justice? If our participation helps a partner charity to gain grant funding at the expense of another (equally or more deserving) cause, how do we reconcile these ethical issues? Moreover, if we step back and attempt to preserve researcher objectivity, will our interventions inherently be in some way substandard or 'lacking' in comparison? All of these issues speak to our role and values as researchers, and how they interface

with the needs, concerns and values of those with whom we work in sensitive, politicized settings [1].

Conclusion

Working with a small third sector charity on a campaign around the politicised topic of accessible transport has given us a lens through which to begin to consider some of ethical challenges posed by these issues. Reflecting on these has prompted broader consideration of the diverse range of issues faced by HCI researchers working in these environments. Many of these go beyond specific issues we encountered, and are general concerns which we contend it is imperative that researchers consider. We should be mindful of these both prior to and during politicised work with organisations such as small charities, for whom the consequences of our failure to do so may be significant.

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References

1. Abigail C. Durrant, David S. Kirk, and Stuart Reeves. 2014. Human values in curating a human rights media archive. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '14)*. ACM, New York, NY, USA, 2685-2694. <http://dx.doi.org/10.1145/2556288.2557196>
2. Forest. 2016. Forest Website. Retrieved 12th January 2016 from <http://forestonline.org>
3. MDUK. 2015. MDUK Website: About Us. Retrieved 19th August 2015 from <http://www.musculardystrophyuk.org/about-us/>
4. Wendy Moncur, Elise van den Hoven, Miriam Julius, and David Kirk. 2015. Story Shell: The Participatory Design of a Bespoke Digital Memorial. In *Proceedings of the Participatory Innovation Conference 2015 (PIN-C 2015)*. 470-477. <http://repository.tue.nl/837676>
5. Irina Shklovski and Janet Vertesi. 2013. "Un-googling" publications: the ethics and problems of anonymization. In *CHI '13 Extended Abstracts on Human Factors in Computing Systems (CHI EA '13)*. ACM, New York, NY, USA, 2169-2178. <http://dx.doi.org/10.1145/2468356.2468737>
6. Sunil Rodger, John Vines and Janice McLaughlin. 2016. Technology and the Politics of Mobility: Evidence Generation in Accessible Transport Activism. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI '16)*. ACM, New York, NY, USA. <http://dx.doi.org/10.1145/2858036.2858146>
7. Sarvnaz Taherian, T. Claire Davies, and R. Glynn Owens. 2015. The Ethical and Practical Issues Surrounding the Design of Assistive Technology for Individuals with Severe Physical Disability and Complex Communication Needs. In *OzCHI '15: Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction*.
8. Trailblazers. 2009. End of the Line: The Trailblazers' Transport Report – Report 1 of the Inclusion Now series (May 2009). Retrieved 19th August 2015 from http://www.mdctrailblazers.org/assets/0000/1411/_End_of_the_line__Report_FINAL.pdf