
Ethical Experiences - Introducing New Technologies for Healthcare Service Improvement

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Abstract

There is an urgent need to apply domain-specific social and collaborative HCI innovations to improve healthcare service delivery. However, the diversity of ethical issues surrounding research with new technologies in such settings is a large and relatively uncharted barrier. Whilst patient orientated issues are relatively well explored, far less is known about the sensitivities surrounding HCI research with respect to the staff themselves, including doctors, nurses, and managers. Nor are the effects well known of the introduction of new technologies upon the public image of hospitals. Ethical issues arising from the use of new technologies in researching and supporting this broad view of users of hospital environments and services forms the basis of this paper. We present three healthcare service delivery research projects that employ new digital technologies and examine a diversity of ethical issues which arise in such settings.

Author Keywords

Healthcare service-delivery; human computer interaction; ethics; secondary care

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ACM Classification Keywords

K.7.4 Professional Ethics: Codes of ethics: Codes of good practice: Ethical dilemmas.

K.4.1 Public Policy Issues: Ethics: Privacy.

H.5.m. Information interfaces and presentation: Miscellaneous.

Introduction

The majority of ethical issues relating to healthcare-based research are typically, and understandably, patient orientated. Indeed, these issues are of growing relevance particularly with the increasing focus on *patient engagement*, which is now seen as a key factor within the clinical and organisational aspects of healthcare [1].

In addition to this, a pervasive desire for new and innovative technologies within healthcare i.e. a *technological imperative* [4], has initiated a rising interest in the diversity of ethical considerations that accompany the use of such technologies; for example, within the emerging area of telehealth [5].

However, in addition to the more acknowledged ethical issues which surround technologically-based, patient orientated healthcare, there is also a wealth of less recognised issues emerging from research into technologically-based, *healthcare service delivery*. The focus of such research being more upon the stakeholders of such services, be they visitors (including patients), doctors, nurses, hospital volunteers, medical students, administrative staff, porters, etc. The use of new technologies in this area is used to understand such users' behaviour and to subsequently support these users to deliver better care within what are clearly sensitive environments.

This paper examines ethical issues arising from technologically-based healthcare service delivery research. The following section presents three research projects as case studies, with each offering its own unique set of ethical dilemmas and challenges. These research projects emerged as part of an on-going collaboration between Horizon Digital Economy Research Institute, University of Nottingham (UK), and Nottingham University Hospitals NHS Trust. Each project was developed in response to a specific healthcare service delivery issue identified through this collaboration, and each correspondingly involved a particular mix of users. These are followed by a discussion of overarching, cross-cutting ethical themes.

Case Studies

The following case studies describe the projects and key ethical issues which arose.

Case study 1 - Navigating in Large Hospitals

Navigating in and around hospitals, which are typically large, complex and evolving spaces, is often a major source of anxiety, frustration and lost time for those visiting and working there, with *getting lost* being a common problem in such environments [6]. The aim of the research has been to understand the navigational behaviors of *users* of such spaces (from full-time doctors through to occasional visitors), to establish the relative benefits of using new adaptive locative technologies in supporting them.

This research revealed various ethical challenges including indirect breeches in privacy; potential infringements of anonymity; and difficulties in gaining 3rd party consent. For example, the research required a diversity of hospital users to describe their recent

experiences of navigating local hospitals. Ideally participants would have been approached directly and *in situ*, to elicit immediate, insightful, and relevant responses. However, University and hospital/NHS ethics required participants to be recruited *indirectly* through their own communication channels (e.g. hospital websites), to avoid breaching the privacies demanded and expected by being in a hospital itself. Such restrictions in turn resulted in increasingly retrospective and generalised descriptions. In addition, the *sensitive setting* has made it prohibitively difficult to capture navigational behaviors as they occur *in the wild*, using still/moving images or audio. This is largely due to the ethical issues involved in recording 3rd parties and the resulting impact upon and infringement of their autonomy, voluntariness, informed consent, confidentiality and anonymity [9].

Case study 2 – Wayward

The Wayward project uses pedestrian indoor navigation systems to look at the task management behavior of doctors working in hospitals at night and over weekends [2]. Task may be inferred through tracking the location of the doctors. The purpose of this research is to measure the number of tasks performed by *out of hours* staff and examine the task management strategies employed by junior and senior doctors. This knowledge will enable us to reduce fatigue and increase efficiency through the intelligent allocation of tasks and data driven rota design.

As this project progresses we are faced with many data security and privacy issues associated with studying workplace performance. The granularity, frequency and metadata associated with staff positioning and tasking data must be carefully considered and justified to staff

and management alike. For example, being able to identify where staff are (and by association what they are doing), how often and for how long may, in some cases, have negative implications. Furthermore, data ownership and transparency are both important and complex issues to tackle. Not only do we have to allow for the wants, needs and rights of patients, staff and management, but we have to do so across multiple hospitals, which are large, complex, and sensitive organisations.

As a relatively underexplored service, the potential exists that this project will initiate changes in staff behaviour due to the knowledge that they are being observed and this in turn could impact patient care. For example, staff may feel more pressure to follow 'procedure', over and above using their own expertise/instinct with respect to individual patient care.

Case study 3 – Sayit.Today

A key area where HCI research can have a large impact for hospital service delivery is in the staff communication systems. The Sayit.Today project aims to simplify the process of reporting minor issues in hospitals (such as broken or missing equipment, and poor sanitary conditions) via introduction of an application that reduces the burden of filing reports and providing crowd-sourcing solutions to issue management. It complements existing clinical incident reporting systems, and makes it fast to report issues in succinct format to those with the power and responsibility to make the requested changes.

A number of ethical issues have been highlighted in the work of Sayit.Today, including: the ethics of the *status quo* (such as represented by [8], which noted that

"silent sufferers" choose not to complain "because they believe complaints processes are too complex, involve them having to chase a response and that they fear nothing will change as a result of their complaint."); balancing reporter anonymity and identifiability, with respect to organisational needs and fears of reprisals; revelation of potentially sensitive/embarrassing topics and/or the identities of *second order participants*; the collection and handling of personal data; the duty of managerial response and care; the dangers of negative impacts on existing systems through the introduction of new communications technologies (such as flooding managers with excessive messages); and increased risk and exposure of hospitals owing to rising levels of transparency and, in the UK, the duty of candour as stipulated on the GOV.UK website [3] that "providers must be open and transparent with service users about their care and treatment, including when it goes wrong".

Of these issues two are of particular concern: *balancing anonymity and candour*, and *second order participants*.

The issue of *balancing anonymity and candour* is one which features two competing ethical ideals in opposition to each other. On the one hand undertaking research in sensitive environments is often built upon the assumption that every effort will be made to conceal the identities of participants. Such anonymity is required if we are to facilitate disclosure and participation. On the other hand, in care contexts such as hospitals, there is an often explicit duty of candor, and often information must be disclosed for the public interest. Anonymity is often distrusted by managers of such environments who want guarantees (often owing to legal obligations) that what happens on their

premises, or data networks, can be monitored and responded to. As such anonymity and candour are locked in opposition whereby it is in the public interest to have both, and yet we can only have one at the expense of the other.

The other key issue concerns *second order participants*. These are third parties who can become identified and/or have personal information captured by the main participants or the research method, but have not consented to be part of the research. In Sayit. Today it is possible that by reporting an issue, a participant describes or names a patient or other staff member, and so training is given to the participants to avoid this. In addition, features of the tool involving uploading media (such as images and video) were not developed to minimise the ethical challenge of capturing second order participant data. This problem is comparable to issues identified in wearable camera research, especially in sensitive environments [7].

Discussion

Reviewing the case studies we have identified four cross-cutting themes: *contextual sensitivities; data discovery, ownership, and the public good; the patient-clinician-technology relationship; and conflicts between research needs and care practice*.

Contextual sensitivities

A number of ethical issues related directly to the intrinsically sensitive contexts in which the research was conducted or related to. Indeed, despite the fact that a hospital is theoretically a *public space* and the service-delivery research largely involves no personal, biological or patient-related data, the nature of a hospital's use generates significant ethical implications

and restrictions. Indeed, hospitals operate in reality more like *semi-private spaces*. This is further complicated by the fact that such environments hold different ethical connotations for individual stakeholders e.g. the ethical implications of being a patient being fundamentally different to a porter or in turn a visitor.

Data discovery, ownership, and the public good

Many ethical issues related to introducing new and disruptive technologies into healthcare service delivery and other sensitive environments relate to data ownership, the public's right to such data (such as through the UK's duty of candour [3]), and the potential harm of public disclosure – not just to the principle parties, but also to the public good. Good ethical practice therefore must answer these questions at a minimum: i) When research is conducted using data captured from sensitive equipment or using the environment or network of semi-private spaces (such as recording hospital service information), to whom should such data belong; the researcher and/or their institution; the participant involved in care; the caring organization; or the public (especially in the cases of publicly-funded institutions such as hospitals)? ii) When the public insists that it has a right to data from sensitive environments, and researchers are harvesting information which may reveal such data, to what degree are we under obligation to reveal the data, and what harms to participants, the institutions, and society itself (such as potential unwarranted erosion of trust in the medical practice owing to the misinterpretation of data) may be caused by the revelations?

The patient-clinician-technology relationship

The range of new technologies being introduced across these projects all have the potential to impact upon

patient-clinician relationships. Using SayIt.Today on mobile phones to report breakages could give the impression that a medical professional is disinterested or unprofessional, as mobiles are not widely accepted as an important part of what they do. Similar better in-hospital navigation systems could reduce the number of face-to-face interactions between patients and clinical staff. These possible negative consequences may not be imminently obvious to researchers studying secondary care services or those consenting to take part in their research.

Conflicts between research need and care practice

Conducting research in sensitive environments can introduce conflicts of interest between researchers and the care environment. For instance, research often requires the completion of a method, yet early results may indicate changes that the sensitive environment should make to have immediate benefits to those in care. Furthermore, research may be seen prior to being conducted as a potential harm with respect to the *status quo*, since the *status quo* is not properly measured (the so called *Ostrich algorithm* i.e. ignoring potential problems). Good ethical practice therefore requires appropriate consideration and risk management prior to conduct in order to determine, ideally *a priori*, how to act to resolve potential conflicts.

Conclusion

The ethical issues involved in employing new technologies within healthcare service delivery are however diverse, complex and emergent. Some of the themes appear common to more clinical, patient-orientated research (e.g. data ownership, the patient-clinician-technology relationship), whereas others (such as negative connotations of healthcare professionals

using phones as a workplace tools-arising from research practice), appear more unique to healthcare service delivery research.

Despite their complexities, conflicts and conundrums, an understanding of the ethical issues surrounding the use of new technologies within healthcare service deliver is crucial, in order that studies in this area afford an appropriate degree of legitimacy, value and recognition.

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