



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

A reflexive analysis of 'context' in privacy research

Citation for published version:

Mazanderani, F, Papoutsi, C & Brown, I 2013, 'A reflexive analysis of 'context' in privacy research: Two case studies in HIV care' International Journal of Human-Computer Studies. DOI: 10.1016/j.ijhcs.2013.06.001

Digital Object Identifier (DOI):

[10.1016/j.ijhcs.2013.06.001](https://doi.org/10.1016/j.ijhcs.2013.06.001)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

International Journal of Human-Computer Studies

Publisher Rights Statement:

© Mazanderani, F., Papoutsi, C., & Brown, I. (2013). A reflexive analysis of 'context' in privacy research: Two case studies in HIV care. International Journal of Human-Computer Studies. 10.1016/j.ijhcs.2013.06.001

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Title: A reflexive analysis of 'context' in privacy research: Two case studies in HIV care

Author 1: Fadhila Mazanderani (corresponding author)^a
fadhila.mazanderani@durham.ac.uk
Tel: +44 (0)191 3344 6843

Author 2: Chrysanthi Papoutsi^b
chrysanthi.papoutsi@oii.ox.ac.uk

Author 3: Ian Brown^b
ian.brown@oii.ox.ac.uk

^a School of Applied Social Sciences, Durham University, 32 Old Elvet, Durham, DH1 3HN, United Kingdom

^b Oxford Internet Institute, University of Oxford, 1 St Giles, Oxford, OX1 3JS, United Kingdom

A reflexive analysis of ‘context’ in privacy research: Two case studies in HIV care

ABSTRACT

Privacy is a much discussed and politically charged topic in contemporary healthcare. Yet, studying the actual privacy practices of healthcare professionals and patients remains extremely challenging. In this paper we reflect on our experiences using qualitative methods in two projects on HIV care, the first researching internet use by a particular group of patients, and the second looking at issues of information technology integration in hospitals. Our aim in doing so is to highlight some of the opportunities and challenges involved in including an explicit focus on ‘context’ in qualitative privacy research in healthcare. We suggest that adopting a more reflexive approach to the way methods are used in relation to ‘context’ in privacy-related HCI research provides opportunities for understanding how different ‘privacy contexts’ are enacted in and through our research practices in different environments.

Keywords: privacy, HIV, methods, context, reflexivity.

1. INTRODUCTION

As is often stated, including by the authors of this paper (Vasalou et al., 2011), privacy is an elusive concept. Along with allied concepts such as confidentiality and security, privacy is socially, culturally and temporally contingent (Altman, 1976; Schoeman, 1992; Dourish and Anderson, 2006; Nissenbaum, 2009); it means different things to different people, and these meanings change across time and space, often extremely rapidly and at very granular levels. In other words, what counts as ‘private’ is highly context dependent, multi-dimensional and dynamic (Marx, 2001; Solove, 2008; Nissenbaum, 2009). Indeed, it has been argued that privacy is ‘defined by its context’ and can only be understood in relation to specific relationships (Gutwirth, 2002, p. 34).

And yet, despite this explicit emphasis on the contextual nature of privacy, what is meant by ‘context’ is rarely defined or analysed by privacy researchers. Instead, context is all too frequently treated as a taken-for-granted placeholder for specific socially defined spaces (the home, a hospital, a school etc.), institutions (the Law, Medicine, Education etc.), activities (buying something online, going to consult a healthcare practitioner) or relationships (doctor and patient, parent and child etc.). Or, in some cases, is left unarticulated or provisionally sketched out through the use of broader social dimensions and variables (e.g. gender, age, ethnicity etc.) deemed to be of relevance. Thus, *context* becomes a convenient mechanism for explaining differences in privacy preference, attitude or practice, but is itself left unexamined.

If context is to play a central role in privacy research, which we believe it should, then it is important for privacy researchers to critically engage with the notion of ‘context’ itself. What do we mean when we refer to context? And, crucially, how do our prior assumptions, methodological choices, and research practices enact different contexts? What are the

implications of this for the development of methods for researching privacy? While we cannot, obviously, answer all these questions here, our aim in this paper is to bring the question of context in privacy research to the fore and, in particular, to examine the relationship between context and method.

Drawing on two qualitative research projects on information communication technologies (ICT) in HIV care in the UK, we problematize the notion of ‘context’ in privacy research through a reflexive analysis of our own research practices and experiences. Our aim in doing so is not to elucidate specific ‘contexts’ of relevance (understood in the traditional social science sense of context as the ‘wider’ background in which the research is ‘embedded’), but rather to explicate how, often seemingly small, decisions, situations and actions, are implicated in the creation of different contexts, which in turn informed our research findings. From this perspective, the methods we use do not simply *reveal* a given context, but play a part in *constituting* it; they do not simply represent reality, they perform it (Law, 2004). An awareness of the performativity of method is, of course, not only of relevance to privacy research. However, insomuch as privacy researchers are explicitly interested in how, why and where people share information, reflecting on our own practices not only helps to develop an increased sensitivity towards the implications of methodological choices, but also enables us to study our research practices as practices of relevance to privacy – privacy practices in their own right.

2. ‘CONTEXTUALISING’ AND ‘CONTEXTING’ IN HCI PRIVACY RESEARCH

Although a number of different, often innovative, methods have been used to study privacy – such as experience sampling (Anthony et al., 2007; Ben Abdesslem et al., 2010) and corpus linguistic approaches (Vasalou et al., 2011) – privacy research has tended to rely on two key

methods: experiments (e.g. Acquisti and Grossklags, 2003; John et al., 2011) and questionnaires and surveys (e.g. Lederer et al., 2003; Buchanan et al., 2007). While this work contributes to our understanding of privacy through trying to isolate and control specific privacy related variables in structured situations, it is rarely able to grapple with the messy, contingent, information practices that people adopt in their everyday lives. In order to address this, a number of researchers have used qualitative methods – such as interviews, shadowing, observation and/or focus groups (Hayes and Abowd, 2006; Kani-Zabihi and Helmhout, 2012; Nardi et al., 1995), grounded theory (Adams and Blandford, 2005; Adams and Sasse, 2001) and videotaped activity scenarios (Little and Briggs, 2006) – to gain insight into privacy-relevant practices. And it is in this latter, more qualitative work, where the importance of context is most frequently invoked.

Simply stating that an awareness of context is important for understanding privacy is, however, not sufficient and a growing number of Human Computer Interaction (HCI) researchers are grappling with how to develop more nuanced understandings of privacy-relevant contexts in their work. For instance, combining insights from the social sciences and psychology with the analysis of video media spaces, Boyle and Greenberg (2005), have highlighted the dialectic and highly contextual nature of privacy. Dourish and Anderson (2006) have situated privacy as one component within the context of wider collective information practices. Building on the concept of privacy as contextual integrity – defined as ensuring that information which flows within and between specific contexts adhere to the norms of those contexts (Nissenbaum, 2009) – Barkhuus (2012) has argued that HCI studies should use a more specific, contextually grounded vocabulary for privacy research.

Similarly, HCI research on system design frequently invokes the importance of context (Mancini et al., 2009; Wixon et al., 1990). Yet, it often treats it as a ‘representational’ problem – trying to pin down what context is and to encode it – rather than treating it as a practice that combines *activity* and *meaning* (Dourish, 2004, p.22). However, treating context as a practice poses a number of methodological challenges. This is aptly illustrated by Nardi (1995) in the article ‘Studying Context’, where she compares activity theory, distributed cognition and situated action, to illustrate how the first two include intentionality in terms of the goal of the user (in the first) or the system (in the second) as *part of* the context being researched. Thus, even when context is treated as a practice, the specific theoretical stance and methods adopted shape what is ‘found’.

In Science and Technology Studies (STS), and particularly in Actor-Network Theory (ANT), taken-for-granted understandings of context have been challenged for some time (Law, 2004). In what is perhaps the most comprehensive explanation of how ANT contests the notion of context as commonly applied in the social sciences (Latour 2005), Latour suggests that we do not need to do away with the notion of context so much as re-think it. Here, he argues that contextualising – framing things within a particular context, such as a historical event or a geographic location – is something we constantly do. But, instead of resorting to ‘social context’ as a taken for granted explanatory resource, we need to analyse the ‘very activity of contextualising’ (Latour, 2005, p.186).

Taking this forward, in a special issue in *Science, Technology & Human Values* that draws heavily on the ANT tradition, Asdal and Moser suggest that context is a troubled and troubling concept, but one that we cannot do without (Asdal and Moser, 2012, p.296). Rather than discussing the concept of context in abstract and philosophical terms, they suggest we

experiment, ‘work on and with’, context, proposing the notion of ‘contexting’ as an alternative to that of ‘contextualising’. According to them, contexting means acknowledging: 1) that context is not something that lies beyond, something ‘out there’, waiting to be ‘discovered’; 2) that contexts are constantly being made alongside the objects or issues being studied; 3) that the ways in which we *do* context matters as it forms part of how different realities and possibilities are enacted (Asdal and Moser, 2012, p. 296).

3. REFLECTING ON ‘CONTEXT’: TWO CASE STUDIES IN HIV CARE

In the field of HCI, it has been argued that research on privacy and security is critical to ensure the safe and productive use of technical systems (Karat et al., 2005). This is particularly relevant in healthcare where sensitive information is often stored and shared. In the UK, the Department of Health has consistently emphasised the need to integrate and facilitate access to information as a key mechanism for improving healthcare (Department of Health, 2012). At the same time, concerns have been raised in relation to the National Health Service (NHS) processes and systems for collecting, storing and anonymising patient information for secondary uses, such as research (Brown et al., 2011).

Due to its status as a stigmatised *and* sexually communicable virus, HIV is an area of healthcare where issues of privacy and disclosure are of central concern (Greene et al, 2003; Parker and Aggleton, 2003). Since the virus entered the medical and popular imagination in the 1980s, HIV research, treatment and care has changed radically. With the emergence and success of Highly Active Antiretroviral Therapy (HAART) as a treatment, but not a cure, the virus has been increasingly normalised as a chronic condition that requires complex, integrated care involving the sharing of information across different medical specialisms and agencies (Clarke, 1994; Rosengarten et al. 2004). Moreover, in keeping with a broader trend

that stresses the central importance of information in healthcare, more and more HIV-information services are being provided on the internet and there has been a concerted effort in the UK for departments of sexual health to integrate their previously stand-alone systems with central hospital databases.

By the end of 2010, approximately 91,500 people were living with HIV in the UK (Health Protection Agency, 2011), the majority of whom receive the bulk of their medical treatment and care in public sector specialist HIV outpatient centres. This paper is based on a comparative analysis of two qualitative studies carried out in three of these centres in London. Each case study dealt with its own substantive area of interest and although the approaches used were similar in some respects, they differed in many others.

Study one, conducted by the first author, with fieldwork carried out during 2009, focused on how women originally from sub-Saharan Africa, but living in the UK at the time, used the internet in relation to their health. The primary method used for this study was qualitative interviews, and 41 women from 13 different African countries were interviewed. These women were recruited from three HIV specialist outpatient centres in east London. The interviews were supplemented by two focus groups at different community organisations, six interviews with people working on the provision of patient-centred HIV information and services, and informal discussions with community workers and healthcare practitioners. Although participants were never asked explicitly about privacy, issues of privacy, stigma, and disclosure emerged as topics of central concern in the interviews. This is unsurprising as existing research has already highlighted the importance of information management (Doyal and Anderson, 2005). So while privacy was not the primary research question, it was a key

topic of interest and privacy-related data in interviews and field notes were a crucial part of the overall analysis of health-related internet use.

Study two, carried out by the second author, looked at the integration of stand-alone HIV patient records from two specialist HIV outpatient centres with the centralised Electronic Patient Records (EPR) used in their respective NHS Hospital Trusts. These cases were of particular interest as conflicting privacy perceptions between HIV professionals and EPR staff had for many years hindered the integration. As a result participants were concerned about privacy on multiple levels: patient privacy as a political and organisational issue in the NHS; research confidentiality to avoid professional and personal repercussions; and privacy as a sensitive matter in the history of technological integration.

This research used ethnographically informed methods and took place between October 2009 and October 2010 (including a pilot project in a third hospital). Research methods included 46 in-depth interviews with clinical and administrative staff in the HIV clinics and other hospital departments, as well as with IT and EPR professionals, external 'experts', senior managers from IT agency *Connecting for Health*¹ and community organisations. Each interview lasted on average for an hour. Participant recruitment was based on purposive and snowballing sampling, aiming at the widest range of understanding across occupational groups. Interviews were supplemented by six months of participant observation in the HIV outpatient clinics and document analysis.

Study one was carried out with ethical approval from the Outer North East London Research Ethics Committee (Ref. No. 08/H0701/75) and study two from the UCLH Research Ethics Committee Alpha (Ref. No. 09/H0715/78). In both studies, where possible and with the

consent of the interviewee, interviews were recorded and transcribed fully. If participants did not want the interviews to be recorded simultaneous notes were taken. Field notes were kept during observation, interviews and after all interaction, to further understand and contribute to the findings.

During the course of the research projects, the authors discussed and compared their different methods and experiences. In both cases the projects were strongly informed by an interpretivist research tradition that highlights the importance of embedding research within specific contexts and cases. But once the projects started, questions around what were the actual ‘contexts’ being studied often arose. Was the ‘context’ the specific clinics? Healthcare or HIV care? Specific technologies and platforms: the internet (study one) and EPR (study two)? Particular professional (study two) or patient (study one) groups? This article emerged out of a collaborative analysis in which we tried to untangle these questions, combining the notion of ‘contexting’ with an emphasis on context as emerging dialectically through the interaction between representation and practice (Dourish, 2004).

4. RESEARCH PRACTICES AS PRIVACY PRACTICES

4.1 ‘Getting into place’: Gatekeepers and gatekeeping

The importance of gaining access to particular research sites and people, what Goffman referred to as ‘getting into place’ (Goffman, 1989), has long been emphasised in qualitative research. Obviously, what ‘getting into place’ means differs between projects. Here, we focus on one dimension of accessing research sites and participants: the role of ‘gatekeepers’ and practices of ‘gatekeeping’. We show how different levels of gatekeeping are implicated in constructing and sustaining different contexts for privacy research, raising ‘contexting’ challenges that researchers need to ‘work on and with’.

‘Gatekeepers’ is a term used to describe actors with ‘control over sources and avenues of opportunity’ (Hammersley and Atkinson, 2007). Although the role of gatekeepers and gatekeeping discussed here is of relevance to a wide array of research on different topics, it is particularly pertinent when participant recruitment takes place in medical contexts, for example hospitals or GP practices. Because patient confidentiality and privacy are of central concern in medicine, there are specific gatekeeping institutions, rules and practices, such as formal Ethics Committees, that oversee and govern research practices under their remit.

In the UK, researchers hoping to conduct research in the NHS are required to have a ‘sponsor’. These sponsors are individuals from within the NHS who agree to mentor and take responsibility for the research project. Before gaining access to our research sites a period of time was required for negotiating and building relations of trust with potential sponsors and other stakeholders. This was necessary in order to gain formal approval for the research, but how this was carried out and with whom continued to shape our research post receiving ethics approval.

In both studies, the key research sponsors were senior consultants. While it was necessary to negotiate the scope of the research with them in order to get to the point where data collection could commence, once started, the sponsor still played an important role, often in unexpected ways. For example, in the clinics participating in study two, it was widely known to staff that particular consultants generally sponsored most of the research projects. Thus, even without drawing attention to sponsorship, most health professionals from these clinics were aware of who was involved in the research. Many of them readily agreed to be interviewed due, in

part, to their occupational or other commitments towards the research sponsors, within relationships where traditionally hierarchical structures have been important.

When the researcher attempted to interview EPR staff working outside these teams, however, she faced significant access difficulties, mainly because the primary gatekeepers for the research came from the HIV team. Although an explicit effort was made *not* to become associated with organisational politics, some EPR staff interpreted the research as an enquiry into the delays with implementing the integration of HIV patient notes to the main EPR system and, subsequently, their conflict with HIV clinicians. Being associated with specific gatekeepers, either explicitly or implicitly, created both opportunities and challenges for researching privacy in this and other environments. On the one hand it was only through specific gatekeepers that access to research sites (forming particular ‘contexts’) was gained, on the other the association with these gatekeepers shaped how the ‘context’ of the research was perceived by participants, resulting in different practices, which in turn shaped that context. In many instances this meant that the researcher had to actively work at re-contextualising the research project for potential participants.

While this often posed a challenge, it also provided opportunities for exploring how privacy and medical confidentiality were understood and practised by different organisations and actors. Although this is frequently discussed in methodological literature, it has not been equally acknowledged in privacy research, where issues like confidentiality are often treated as the contextualised version of privacy in environments where disclosure and sharing of what might be regarded sensitive information takes place. Thus, an active awareness of in the creation and interaction of different contexts not only has methodological value, but can also contribute to a better understanding of analytical and conceptual dimensions.

In study one the sponsors similarly played a key role, introducing the researcher to other healthcare practitioners and to potential participants. Here, having the support of clinical staff members was a major asset in terms of recruiting participants. This was sometimes articulated in interviews when a patient would express the appreciation they felt for the practitioner who had made the introduction, making it clear that at least part of the reason they had agreed to take part in the research was because of the person who had introduced them. However, while some patients were introduced to the researcher by healthcare practitioners whom they trusted, others who might have been less happy with their care were less likely to take part in the research and therefore their views were excluded. Consequently, formal and informal gatekeepers had a significant effect in shaping the research context in terms of the environment in which the research was conducted, but also the type of participants recruited.

Apart from recruitment, when the actual interviews took place what participants were willing to say was shaped by their pre-existing commitments and relationships. On a more granular level, who introduced the study and how they did so mattered. Different informal gatekeepers played a significant role in framing the study as they introduced it to participants according to their own understandings and assumptions ('contexting' it in specific ways). This meant that the research was often presented in different ways, influencing the type and amount of information participants were willing to share. For example, in study two, the research was introduced by the gatekeeper to one of the interviewees as looking at the clinic as a role model. In this case, the interview that ensued resembled a job interview, where the participant tried to emphasise their contribution to the clinic and the advantages of the environment, rather than discussing lived experience and meaning, despite the researcher's effort to redirect the discussion.

We have only mentioned a few examples here, but throughout the duration of the research different gatekeepers and forms of gatekeeping continued to appear as access was required to different organisational groups, types of meetings, documentation and technological systems.

While it was not always possible to control who we were associated with in the research environment, as we became increasingly sensitised to various dynamics we were able to experiment with different associations and forms of introduction, connecting with a mix of different people in different ways. While managing who you are associated with is a well-known feature of qualitative research, when conducting research on privacy practices, how and why we manage these associations needs to be included as an integral part of how we analyse our data. For not only does it affect what is said and by whom, it also provides insight into practices and norms of direct relevance to privacy. In the cases discussed above this related to how the sharing of information is influenced by medical hierarchies and the relationships between different inter-professional groups, patients and healthcare practitioners.

4.2 ‘Staying in place’: the role of space and time in enacting research contexts

Traditionally the ‘field site’ denoted a geographically bounded space where ethnographic research was carried out. Under the auspices of multi-sited ethnography, however, the centrality of the notion of a static, geographically demarcated, culturally specific, site has been challenged (Marcus, 1995; Gupta and Ferguson, 1997). The requirement of spending long periods of time ‘in the field’, regardless of how that field is defined, remains one of the hallmarks of ethnographic practice.

In privacy related research where people may be particularly concerned about information disclosure or dissemination, such as in an HIV clinic, spending extended periods of time in a specific place, observing interactions and speaking to potential participants informally can be especially beneficial. In study one, for instance, as HIV patients come into the clinic relatively regularly for blood tests and consultations, this meant they often saw the researcher more than once. Participants who initially expressed no interest, or concern, about taking part in the study, after having seen the researcher in the clinic a few times sometimes volunteered. These were often good interviews in terms of richness of content and length as participants had actively decided to take part over a period of interaction with the researcher. Not only did the decision to start recruitment in a healthcare environment shape the context of the research, but in doing so, albeit for a brief period, the researcher became part of that healthcare context. Indeed, even though the researcher tried to distance herself from the day to day running of the clinical environment, interviewees often assumed that she was part of the clinical team (i.e. a trainee nurse). This was despite the fact that every attempt was made to clarify that the researcher was not part of the clinical team. In study two, however, not being part of the context in terms of being perceived as *not* having a clinical background or experience in the NHS, influenced the type and depth of information shared when, for example, discussing the duty of medical care over confidentiality and other priorities.

In both studies, what often seemed like relatively small spatial or temporal differences, such as moving from one room to the next, made a difference to the research contexts. In study one, differences were noted in what interviewees were willing to disclose prior to an interview between clinics that had waiting rooms for HIV patients only versus those combined with other sexual health services. In HIV-only waiting rooms patients usually avoided eye contact with the other people in the waiting room. Yet, when the research was

discussed with one patient, others often became animated and started discussions for, or against, the merits of using the internet for their health. This served, in some instances, to relax patients both in relation to the researcher and the study and after those kinds of discussions one or more patients often agreed to take part in the research. In one of the hospitals where participants were recruited, the waiting room in the department of sexual health was more mixed. Although the people in the waiting room were primarily HIV positive, this was not always the case and so patients could not openly ask the researcher questions due to privacy concerns, nor could informal group discussions take place. In these cases, the research site became narrowed in a way that had negative implications for the recruitment of participants, but drew attention to the way in which apparently small differences can shift the boundaries of what counts as a private versus a public space in relation to a particular research topic.

That information practices are not always easily visible or located in one time or place is a key methodological challenge for privacy research and was a topic of interest in both studies. For example, although study one was about internet use, it was not possible (due to pragmatic and ethical constraints) to observe people using the internet in the usual environment where they did so (at home, internet cafes, libraries etc.). As HIV outpatient centres were not where potential interview participants actually used the internet, it was nonetheless decided to use them as the primary recruitment site in order to situate (and hence implicitly ‘contextualise’) the research in relation to contemporary HIV medical practice. An alternative choice, such as recruiting through online support groups or public advertisements, would not only have resulted in the recruitment of different people, it would have resulted in the emergence of a different research context, bringing different privacy issues to the fore. Instead of physically observing how people used the internet, interviewees were asked to describe the last time

they had done so in relation to their health. The websites and online services mentioned were then followed up by the researcher and analysed in conjunction with the interviews (e.g. popular health information websites, data websites etc). So even though the researcher could not be co-located with interviewees while they used the internet, an emphasis was placed on developing a sense of 'co-presence' through regularly visiting the same online environments as them (Beaulieu, 2010).

As already mentioned, the explicit research focus of study two was privacy. This was stated from the beginning of the project and included in information sheets, formal and informal communication with participants. However, by the time the study commenced HIV staff in the clinics had already undergone a long period of negotiations with the EPR team in relation to what confidentiality practices would be adopted for HIV patient information in the main hospital system. These on-going tensions meant that the researcher entered a 'context' in which privacy was already a topic of key concern, providing exposure to valuable information as people were already talking about it. At the same time, as it was a sensitive and political issue and approaching potential participants and getting them to talk openly was challenging. As there was very little the researcher could do to minimise the political nature of the research topic, managing how she was perceived became critical. Spatial constraints in the environment, where staff worked in offices and consultation rooms behind locked doors, created the need for the researcher to explore different ways to establish rapport in the organisation.

Being mostly based in a room with two or three more people, the researcher had to manage her time and participation outside that place so as not to be perceived as a stranger and become trusted by the rest of the staff. She was fortunate in that during her research some of

the offices were being re-decorated and the distribution of staff restructured in one of the clinics. This gave her the opportunity to engage more people and participate in situations with higher mobility and interaction than normal. Natural situations such as staff meetings or cases where, for example, people in the office discussed how to put research files in locked cabinets, provided more information on the daily practices of privacy management. It was, however, challenging to draw boundaries between doing research on privacy and protecting the confidentiality of participants. When sitting in an office with people for several weeks, to build trust, the researcher had to be explicit about whether every casual conversation counted as research data. The decision to use such observations only to inform understanding made a difference in relation to how one draws contexts together, when privacy is both a subject of study and part of research practices.

We have emphasised how our methods and associated actions play a key role in how our research is contextualised by us and others. In many cases, however, how other people contextualised the project was out of our control, unexpected and unplanned for. The researcher in study one wears a scarf and while this might seem like a relatively minor consideration, in some cases it influenced the way in which interviews unfolded as it was seen as an indicator to participants that she belonged to a religious group. This was often raised in interviews, and while it was usually assumed that the researcher was Muslim sometimes she was asked if she was Jewish. This resulted in discussions on religion and belief and it was common for participants to say something along the lines of ‘As a Muslim woman you will understand...’ or ‘You know what it is like in the Muslim community...’ This highlights how details in a researcher’s appearance can influence the nature and type of information shared in interviews (despite the same or similar questions being asked). While some participants were Muslim, many were not, but many interviewees expressed a strong

religious ethos, which was not prompted by direct questions but simply by the presence of a scarf. The representation of a particular religion (a scarf), unintentionally prompted particular actions (information disclosure about religious beliefs) and, therefore, became a 'context' of relevance in these interviews.

4.3 Interview contexts: situated negotiations and the ethics of sharing

In the previous sections we focused on some of the ways in which context was shaped through our research practices, associations, perceptions and decisions. In this section we draw attention to the ways in which researchers are constantly negotiating privacy and information disclosure in interview settings: taking informed consent, recording observations and interviews, and protecting participant anonymity. The tension between collecting and analysing data while protecting participant privacy is a much discussed part of standard ethics protocols; however, in relation to privacy research such tensions are valuable not only methodologically, but also analytically. Once participants agreed to take part in research the management of privacy concerns did not come to a halt. Rather, a multitude of micro-negotiations around privacy ensued. Many of these fell within the repertoire of ethically accepted standard research practices with human subjects. However, these accepted procedures (such as gaining informed consent) often enacted more complicated privacy contexts than anticipated.

For example, in study one, sometimes patients who were interested in taking part in the research felt uncomfortable signing informed consent forms. Although informed consent procedures are designed to protect participants, in cases such as this, where participants were highly concerned about confidentiality and the content of their disclosure, signing their name to a sheet of paper that would be kept by a researcher before being destroyed was considered

a risk and sometimes even a deterrent to taking part in the research. When the researcher investigated whether another option would be possible, such as getting a witness in the hospital to sign, she was informed that this was only considered in cases where research participants were deemed incapable of signing the informed consent form themselves. This raises questions about the tension between accepted research practices designed to protect participants and participants' desire to protect their privacy in relation to their participation in research. It also shows that what we would regard as context is not only the context(s) within which HIV patients use the internet – which are again multiple and influenced by several factors – but also the context of the interview in an HIV outpatient clinic, where that patient is embedded in relationships with people, within and outside. The negotiation of privacy concerns in relation to the research itself interferes here with how privacy becomes contextualised as a research subject.

Similarly, representations and activities centred on capturing research interactions can be considered as particular contexts of relevance to privacy. For example, the audio recording of interviews posed problems for some privacy sensitive research participants. In study one, the patients most concerned with being audio recorded were also those that were hesitant about signing their names, and they also tended to be people who had not taken part in previous research and did not attend community groups. Often concerns about privacy were explicitly raised once the interview had already started, as in the case shown below:

Participant: Are you not going to take the recording and put it somewhere on the internet?

Researcher: No. Of course not!

Participant: [laughs] it's just for your personal use?

Researcher: What I will do with the recording after I interview you is I will take it and I will write it up because otherwise it is very hard for me in the interview to keep notes.

Participant: Without quoting my name?

Researcher: Of course without quoting your name. I will take it, write it up, I will give you another name, and then at the end of the study I will delete the file. The form you signed is locked away and at the end of the research I will then destroy it.

Participant: OK [pause].

Researcher: And even the things you tell me I won't tell the doctors and nurses here either. So when I write up the research it will be someone else's name, so they won't know who said what. I might take some quotes from what you say but it will be with what other women said, so like these are the kinds of things that were said and here are examples.

Rather than simply being a means of facilitating information sharing, these negotiations provide valuable insights into people's privacy concerns and preferences. In the example above, uploading the interview on the internet, the potential audience for the interview ('for your personal use'), and the protection of participant identity, are all raised as areas of concern (also see Mazanderani and Brown (2010)).

In study two, an interviewee who refused to be audio recorded, initially also refused to disclose their position in the organisation, stating it was irrelevant to the research. In such interviews, we were flexible and took notes, enabling the interviewee to define what information was recorded. However, in both case studies, the majority of interviewees seemed comfortable with the methods employed and the privacy practices enacted during the interaction and did not request further proof or protection.

A frequent topic in the privacy literature is the question of whether people are willing to make privacy trade-offs in relation to perceived gain (Adams and Sasse, 2001). The motivation for taking part in research is an important issue to take into consideration when researching privacy sensitive groups, and in health research it has been shown that people are often willing to discuss extremely sensitive topics and give a considerable amount of time if they perceive the research as having value. In study one, this took the form of participants asking what the information would be used for and what the benefits would be. A desire to help other people living with HIV was often expressed by participants as a major motivation for taking part in the research. In addition to this, participants said they wanted to take part because they felt strongly about the topic, either negatively or positively. This situates privacy responses in a context of helping others and adding value to something perceived as important.

5. CONCLUSION

Despite the explicit emphasis on the contextual dynamics of privacy in HCI, context is still typically treated as something within which privacy discourse and practices are *embedded* – something that we should be able to ‘discover’ by our research methods, rather than, at least in part, something that is enacted through our methodological choices and research practices. Even when a focus is placed on how and what ‘contextual factors’ should be brought to the fore and included in an analysis of privacy, the underlying assumption that context is something ‘out there’ is rarely questioned.

In this article, we documented two studies on privacy and technology use in HIV care. More specifically, we focused on some of the methodological opportunities and complexities in working with ‘context’ in privacy-related healthcare research. The way in which privacy can

and is 'contextualised' does not solely depend on the environment within which it is studied or the variables we choose to isolate and measure. Context is constituted through the intersection of many different decisions, factors, methods, relationships and practices, intentional and unintentional, that we employ when researching privacy or any other phenomenon. To illustrate how we worked 'on and with' context (Asdal and Moser, 2012), we sketched out our experiences in relation to three aspects of our field work: accessing research sites and participants; how different spatial and temporal dynamics contextualised our research; and negotiations about information sharing and protection in interview settings.

Gatekeepers and gatekeeping is a reality of doing research in healthcare and many other environments. Beyond providing access to research sites, the choice of gatekeepers and their involvement in a project can actively shape the way the research is understood and interpreted by other stakeholders. In the cases discussed here, this meant privacy was not just situated in the context of healthcare, as was our intention, but in pre-existing organisational dynamics, power structures and relationships. By taking these pragmatic research considerations into account as part of what we refer to when analysing the contextual dynamics of privacy, we incorporate new possibilities and nuances.

Although frequently discussed in ethnographic research, the relevance of different spatial, temporal contingencies and constraints are rarely explicitly discussed in privacy research. Here, we have drawn attention to how spending time in research environments and with research participants, increasing our sensitivity to how we as researchers are perceived, creates different privacy contexts. This has implications for how challenges in the wider privacy literature, such as the 'privacy paradox' – the disconnect between reported privacy attitudes and actual behaviour (Awad and Krishnan, 2006; Norberg et al., 2007; Paine et al., 2007) – are understood. Indeed, in our analysis the fact that there are differences between

stated attitudes and actual practices ceases to be paradoxical and becomes a ‘normal’ part of how people’s privacy attitudes and practices change in different contexts.

Throughout the article we have advocated adopting a reflexive approach to tackling the notion of context in privacy research. Privacy practices – information disclosure and withholding, protection and refusal – do not simply happen ‘outside’ of our research activities, but are intrinsic to them. Privacy is contextual, not only as a subject of study, but also in relation to how it is situated within our research practices, requiring a more nuanced appreciation for how context matters in privacy research, both methodologically and analytically. This echoes Dourish and Anderson (2006) who suggest that privacy is not an abstract trade-off, a technical property or a set of preferences, but an inherent part of interrelated and performative social and cultural practices. It follows that there are many contexts of relevance in which privacy takes different forms and shapes and we need to engage in an on-going process of negotiating what it means and how it is done – working ‘on and with’ context(s). This is of particular relevance to systems design and usability studies in HCI, because it highlights the need to take a more reflexive view of what context(s) count for privacy, how they can be co-constructed, consolidated and interfered with, to draw on those that are important and meaningful.

6. NOTES

¹ NHS Connecting for Health is part of the Department of Health in the UK and manages the NHS IT health infrastructure (<http://www.connectingforhealth.nhs.uk>).

7. ACKNOWLEDGEMENTS

The authors would like to thank all the research participants. Without your support and involvement this research would not have been possible. We also gratefully acknowledge support from the Engineering and Physical Sciences Research Council (grant EP/G002606/1)

and the Foundation for Education and European Culture in Greece. Two anonymous reviewers provided very useful feedback that improved the paper – thank you.

8. REFERENCES

- Acquisti, A., Gross, R., 2006. Imagined communities: awareness, information sharing, and privacy on the Facebook. *Privacy Enhancing Technologies*. Springer, Berlin / Heidelberg, pp. 36-58.
- Acquisti, A., Grossklags, J., 2003. Losses, gains, and hyperbolic discounting: an experimental approach to information security attitudes and behavior. Paper presented at the 2nd Annual Workshop on Economics and Information Security.
- Adams, A., Lunt, P., Cairns, P., 2008. A qualitative approach to HCI research, in: Cairns, P. and Cox, A. eds. *Research Methods for Human-Computer Interaction*. Cambridge, UK: Cambridge University Press, pp. 138–157.
- Adams, A., Blandford, A., 2005. Bridging the gap between organizational and user perspectives of security in the clinical domain. *International Journal of Human-Computer Studies*, 63, 175-202.
- Adams, A., Sasse, M.A., 2001. Privacy in multimedia communications: protecting users, not just data, in: *People and Computers XV - Interaction Without Frontiers*. Springer, Lille, pp. 49-64.
- Altman, I., 1976. *The environment and social behaviour*. Brooks/Cole Publishing Co, Monterey, California.
- Anthony, D., Henderson, T., Kotz, D., 2007. Privacy in location aware computing environments (PLACE): how users' social context influences willingness to share location information. *IEEE Pervasive Computing*, 6, 4, 64-72.
- Awad, N. F., Krishnan, M. S., 2006. The personalization privacy paradox: an empirical evaluation of information transparency and the willingness to be profiled online for personalization. *MIS Quarterly*, 30, 13-28.
- Barkhuus, L., 2012. The mismeasurement of privacy: using contextual integrity to reconsider privacy in HCI. Paper presented at the Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems.
- Beaulieu, A., 2010. Research Note: From co-location to co-presence: shifts in the use of ethnography for the study of knowledge. *Social Studies of Science*, 40, 453-470.
- Ben Abdesslem, F., Parris, I., Henderson, T., 2010. Mobile experience sampling: reaching the parts of Facebook other methods cannot reach. Paper presented at the Privacy and Usability Methods Workshop, British Human-Computer Interaction Conference, Dundee, Scotland.
- Boyle, M., Greenberg, S., 2005. The language of privacy: Learning from video media space analysis and design. *ACM Trans. Comput.-Hum. Interact.*, 12, 328-370.
- Brown, I., Brown, L., Korff, D., 2011. Limits of anonymisation in NHS data systems. *BMJ*, 342, d973-d973.

- Buchanan, T., Paine, C., Joinson, A.N., Reips, U.-D., 2007. Development of measures of online privacy concern and protection for use on the Internet. *Journal of the American Society for Information Science and Technology*, 58, 157-165.
- Clarke, A. 1994. What is a chronic disease? The effects of a re-definition in HIV and AIDS. *Social Science & Medicine*, 39, 4, 591-597.
- Cranor, L., Garfinkel, S.L., 2005. *Designing secure systems that people can use*. O'Reilly & Associates, Cambridge.
- Department of Health, 2012. *The power of information: putting all of us in control of the health and care information we need*. London: Department of Health, London.
- Dixon-Woods, M., Ashcroft, R.E., 2008. Regulation and the social licence for medical research. *Med Health Care Philos.* 11, 381-391.
- Dourish, P. (2004). What we talk about when we talk about context. *Personal Ubiquitous Comput.* 8, 19-30.
- Dourish, P., Anderson, K., 2006. Collective information practice: exploring privacy and security as social and cultural phenomena. *Hum.-Comput. Interact.* 21, 319-342.
- Doyal, L., Anderson, J., 2005. 'My fear is to fall in love again' How HIV-positive African women survive in London. *Social Science & Medicine*, 60, 1729-1738.
- Goffman, E., 1989. On fieldwork. *Journal of Contemporary Ethnography*, 18, 123-232.
- Greene, K., Derlega, V. J., Yep, G.A., Petronio, S. 2003. *Privacy and Disclosure of HIV in Interpersonal Relationships: A Sourcebook for Researchers and Practitioners*. Routledge, London.
- Gupta, A., Ferguson, J., 1997. *Culture, power, place: explorations in critical anthropology*. Duke University Press, Durham.
- Gutwirth, S. (2002). *Privacy and the information age*. Rowman & Littlefield Publishers, Oxford.
- Hammersley, M., Atkinson, P., 2007. *Ethnography: principles in practice*. Taylor & Francis, Abingdon.
- Hayes, G.R., Abowd, G.D., 2006. Tensions in designing capture technologies for an evidence-based care community. Paper presented at the Proceedings of the SIGCHI conference on Human Factors in computing systems.
- Health Protection Agency, 2011. *HIV in the United Kingdom: 2011 Report*. Health Protection Services, London.
- Jensen, C., Potts, C., Jensen, C., 2005. Privacy practices of Internet users: self-reports versus observed behavior. *International Journal of Human-Computer Studies*, 63, 203-227.
- John, L.K., Acquisti, A., Loewenstein, G., 2011. Strangers on a plane: context-dependent willingness to divulge sensitive information. *Journal of Consumer Research*, 37, 858-873.
- Joinson, A. N., Paine, C., Buchanan, T., Reips, U. D., 2008. Measuring self-disclosure online: Blurring and non-response to sensitive items in web-based surveys. *Computers in Human Behavior*, 24, 2158-2171.

- Kani-Zabihi, E., Helmhout, M., 2012. Increasing service users' privacy awareness by introducing on-line interactive privacy features. Paper presented at the Proceedings of the 16th Nordic conference on Information Security Technology for Applications.
- Karat, C.-M., Karat, J., Brodie, C., 2005. Why HCI research in privacy and security is critical now. *International Journal of Human-Computer Studies* , 63, 1-4.
- Langheinrich, M., 2001. Privacy by Design – Principles of Privacy-Aware Ubiquitous Systems, *UbiComp 2001, Ubiquitous Computing*. In G. Abowd, B. Brumitt S. Shafer (Eds.), Springer, Berlin / Heidelberg, pp. 273-291
- Law, J., 2004. *After method: mess in social science research*. Routledge, London.
- Latour, B., 2005. *Reassembling the social: an introduction to Actor-Network Theory*. Oxford University Press, Oxford.
- Lederer, S., Hong, J.I., Dey, A.K., Landay, J.A. 2004. Personal privacy through understanding and action: five pitfalls for designers. *Personal and Ubiquitous Computing*, 8, 440-454.
- Little, L., Briggs, P., 2006. Investigating privacy in an ambient world. Paper presented at the CHI 2006 Workshop.
- Lynch, M., 2000. Against reflexivity as an academic virtue and source of privileged knowledge. *Theory, Culture & Society*, 17, 26-54.
- Mancini, C., Thomas, K., Rogers, Y., Price, B.A., Jedrzejczyk, L., Bandara, A.K., Joinson, A.N., Nuseibeh, B., 2009. From spaces to places: emerging contexts in mobile privacy. Paper presented at the Proceedings of the 11th international conference on Ubiquitous computing.
- Marcus, G.E., 1995. Ethnography in/of the world system: the emergence of multi-sited ethnography. *Annual Review of Anthropology*, 24, 95-117.
- Marshall, C., Rossman, G.B., 2010. *Designing qualitative research*, Fifth ed. Sage Publications, Inc, London.
- Marx, G.T., 2001. Murky conceptual waters: the public and the private. *Ethics & Information Technology*, 3, 157-169.
- Mazanderani, F., Brown, I., 2010. Privacy as practice: exploring the relational and spatial dynamics of HIV-related information seeking', in: Gutwirth, S., Poulet, Y., De Hert, P. Leenes (Eds.), *Computers, Privacy and Data Protection: An Element of Choice*. Springer, Dordrecht, pp. 251-268.
- Nardi, B.A., 1995. Studying context: a comparison of activity theory, situated action models, and distributed cognition, in: *Context and Consciousness: Activity Theory and Human-computer Interaction*. Massachusetts Institute of Technology, pp. 69-102.
- Nardi, B.A., Kuchinsky, A., Whittaker, S., Leichner, R., Schwarz, H., 1995. Video-as-data: technical and social aspects of a collaborative multimedia application. *Computer Supported Cooperative Work (CSCW)*, 4, 73-100.
- Nissenbaum, H.F., 2009. *Privacy in Context: Technology, Policy, and the Integrity of Social Life*. Stanford University Press, Stanford.

- Norberg, P.A., Horne, D.R., Horne, D.A., 2007. The privacy paradox: personal information disclosure intentions versus behaviors. *Journal of Consumer Affairs*, 41, 100-126.
- Paine, C., Reips, U.-D., Stieger, S., Joinson, A., Buchanan, T., 2007. Internet users' perceptions of 'privacy concerns' and 'privacy actions'. *International Journal of Human-Computer Studies*, 65, 526-536.
- Parker, R., Aggleton, P. 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science & Medicine*, 57, 1, 13-24.
- Rosengarten, M., Imrie, J., Flowers, P., Davis, M., Hart, G. 2004. After the euphoria: HIV medical technologies from the perspective of their prescribers. *Sociology of Health & Illness*, 26, 5, 575-596.
- Schoeman, F.D., 1992. *Privacy and social freedom*, 1st ed. Cambridge University Press, Cambridge.
- Solove, D.J., 2008. *Understanding Privacy*. Harvard University Press, Boston.
- Vasalou, A., Gill, A.J., Mazanderani, F., Papoutsis, C., Joinson, A., 2011. Privacy dictionary: A new resource for the automated content analysis of privacy. *Journal of the American Society for Information Science and Technology*, 62, 2095-2105.
- Wixon, D., Holtzblatt, K., Knox, S., 1990. Contextual design: an emergent view of system design. Paper presented at the Proceedings of the SIGCHI conference on Human factors in computing systems: Empowering people.