Researching Privacy in HIV Care: an Ethnographic Analysis of Methods

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ABSTRACT
Three significant difficulties in the study of privacy are minimising the priming of enhanced privacy sensitive responses; studying privacy sensitive groups and topics; and studying privacy behaviours rather than attitudes. In this article we analyse these challenges ethnographically using two empirical studies on technology development and use in HIV care. In doing so we examine how researchers and participants enact privacy practices in relation to privacy sensitive issues. Drawing on our experiences in relation to qualitative research practices and ethical procedures we focus on four themes: the role of institutional, organisational and personal gatekeepers; identity politics around research topics, researchers and participants; the temporal and spatial contingency of access and disclosure; and micro-negotiations around privacy in interview settings. In conclusion we ask what this analysis can contribute towards tackling methodological problems in privacy research more broadly.

Categories and Subject Descriptors
K.4.1 [**Computing Milieux**]: Computers and Society – Public Policy Issues – *computer-related health issues, privacy;* J.3 [**Computing Applications**]: Life and Medical Sciences – *health, medical information system*; J.4 [**Computing Applications**]: Social and Behavioural Sciences – *sociology;*

General Terms
Measurement, Human Factors.

Keywords
Privacy, HIV, research methods, ethnography.

1. INTRODUCTION
The notion of a 'privacy paradox' is often referenced in the literature on privacy [6][25][32][34]. Although articulated in various forms and across different contexts, discussions on this paradox typically problematise the gap between reported privacy attitudes and actual behaviour. Some explanations for this invoke the role of trust [13], bounded rationality, immediate gratification and hyperbolic discounting [1][2]. This apparent disconnect has, however, been reinforced by a tendency to study privacy using survey methods, which often provide an attitude-centric understanding [36]. Hence, the 'privacy paradox' may be better understood using a combination of different approaches.

Other methodological issues have been identified in privacy research, such as the priming of enhanced privacy sensitive responses [25] and the challenges of studying privacy sensitive groups and topics [34]. To further complicate matters, the difficulty that researchers face in defining privacy consistently is reflected in differences in how it is studied. In this paper privacy is approached as a situated concept governed by different norms and roles across contexts [31]. More specifically, the paper focuses on qualitative methods for studying privacy as a situated practice in relation to practitioners working in HIV clinics and people living with HIV. Instead of attempting to define the best ways to study privacy, the emphasis here is on analysing how privacy is enacted within research practices. The aim is to unpack some assumptions on privacy behaviours by making the practices of research in relation to privacy sensitive groups and topics the object of analysis.

This paper is structured as follows. The following section outlines the approach adopted. Then the two case studies the analysis is based on are documented in more detail, as well as the methods used within them. Next, the key concepts that emerged in terms of gatekeeping and access, perception of researcher identity, temporal and spatial considerations, and micro-negotiations within interview settings, are presented. Finally, we discuss what this approach and analysis can contribute to privacy research more generally.

2. APPROACH
In recognition of the methodological complexity of studying privacy a number of different methods, such as behavioural economics [2], experiments [24], diary methods [5], interviews and grounded theory [3], have been adopted. However, different paradigms and traditions of qualitative research methods have yet to be fully explored.

Work unrelated to privacy has shown that reported plans do not translate directly into action, rather action is highly situated [37]. While the importance of studying action *in situ* has long been central to qualitative research, it has recently gained increasing credence in relation to studying privacy [31]. Moreover, research in natural settings, as well as the use of various information sources, increases the validity and relevance of this work by

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allowing the researcher to examine how concepts are enacted by actors in everyday life [22][8].

Building on empirical material drawn from two qualitative, primarily interview-based, research studies carried out in relation to privacy, technology and HIV, the aim of this paper is to turn the research experience itself into something of analytical and methodological value in the context of privacy. Taking part, or refusing to take part, in research can be part of engaging, or in some cases deciding not to engage with public issues [12]. Therefore, we draw on an understanding of interviews as situations with their own demands and constraints [30][35] and analyse these interactions *ethnographically* as privacy making situations. As such, the tension between research as a public engagement and the need to protect privacy in the context of research interviews in HIV healthcare becomes the focus.

The paper has two levels of analysis. On the first level, we describe the methods used to study privacy in the highly sensitive context of HIV clinics in London. On the second level, we analyse these methods as a means of better understanding how researchers and research participants enact privacy through a range of practices.

3. CASES

According to the latest 'HIV in the United Kingdom' Health Protection Agency (HPA) report, there are an estimated 83,000 people living with HIV in the UK [23]. People diagnosed with HIV in the UK are diverse, but people of African origin and men who have sex with men (MSM) are disproportionately affected. Over half of those diagnosed in 2008 had a CD4 count below 350[1] within three months of their diagnosis. This means that, according to UK clinical recommendations, treatment should start immediately, and in the UK the majority of this treatment and related care is carried out in public sector specialist HIV outpatient centres [18].

This paper is based on a comparative analysis of two qualitative studies carried out in these specialist HIV outpatient centres in London. Both of these studies, in different ways, focus on the relationship between technology, privacy and healthcare service provision.

Study one, carried out by the first author, focuses on processes of organisational change in information privacy conditions, in the context of the integration of Electronic Patient Records (EPR) from a specialist HIV outpatient centre into a central university hospital information system. Following the completion of a pilot at a teaching hospital, carried out between November 2009 and January 2010, research in London has been ongoing since April 2010 and will continue until the end of September 2010. The analysis presented here is based on 26 semi-structured, in-depth interviews. Participants included HIV consultants, registrars, nurses, health advisors, pharmacists, administrative employees, IT staff in the HIV unit and EPR staff from the corresponding department of the hospital, as well as people in senior management positions in specialties such as Intensive Care and A&E, where patients are often diagnosed with HIV. Sampling and participant recruitment were based on quota and snowballing methods, and each interview lasted on average for an hour. In addition, the researcher did non-participant observation in the HIV outpatient centre for an average of two days a week over a period of three months and participated in four staff meetings. Other sources of data include documentation material, email communication and minutes of meetings from 2005 to 2010.

This case is of particular interest as conflicting privacy perceptions have for many years hindered the effort to integrate the stand-alone HIV information system with the EPR used in the main hospital. As a result patient privacy in relation to the design and usability of information technology has become an object of organisational politics. Therefore, the participants who took part in this research were concerned about privacy on multiple levels. Firstly, they were concerned about disclosing information to the researcher that could have negative repercussions for them professionally and personally. Secondly, in dealing with issues around patient privacy on a daily basis, they were highly aware of privacy as a political and organisational issue in the NHS. Thirdly, due to this history, the issue of technological integration has in itself become, in this context, a topic with high privacy-sensitivity.

Existing empirical research has focused more on privacy attitudes and practices of data subjects rather than practices of organisational data users, with some exceptions [4][7][10]. The reasons for this lie partly in the methodological difficulties such research entails. Organisational actors are difficult to approach with research questions on privacy practices and when access is granted, rhetoric and politics tend to obscure actual meaning. Relevant work on information security [38] does not document research practices and methodological issues thoroughly, making it difficult to understand how simple assurances of anonymity and confidentiality suffice to allow the researcher access to organisational reality. In addition, research in healthcare reports organisationally desirable findings on privacy understandings and behaviour through interviewing, but provides a richer picture after observation of practices [9].

Study two, carried out by the second author, focuses on health-related internet use by African women living with HIV in London, and was carried out between June 2009 and December 2009. The primary method used for this study was qualitative interviews and 41 women from 13 different African countries were recruited from three HIV specialist outpatient centres in east London. The majority of participants were interviewed once, but in some cases, depending on their willingness to take part in follow up interviews, participants were further interviewed once or twice, either in a private room in the clinic or else at their homes. The interviews lasted between 30 minutes and 3 hours. These interviews were supplemented by non-participant observation for two to three days a week in the same HIV centres over a period of six months, two focus groups at different community organisations, and six interviews with people working on the provision of patient-centred HIV information and services, and informal discussions with community workers and healthcare practitioners working in the HIV centres. Although participants were never asked explicitly about privacy or secrecy, unsurprisingly, issues of privacy, stigma, and disclosure emerged as being of central concern.

[1] In the UK the guidelines are that once a patient's CD4 count drops below 350 per cubic millimeter of blood they are eligible for ART treatment. A normal CD4 cell count in an HIV-negative person is between 400 and 1600. Taken from NAMlife website: http://www.namlife.org, last accessed 13 March 2010.

In terms of methods for researching privacy, this study is of interest because of its focus on use of the internet by a highly privacy sensitive group of individuals [16]. Moreover, not only do African women living with HIV have to deal with continuing high levels of stigma around the condition, they also often have to cope with socio-economic hardship, past traumatic events and difficulties around immigration [16][19]. In the last UK census, conducted in 2001, there were over 480,000[2] people living in England who self-identified as 'black African',[3] accounting for 0.97% of the population. Over three-quarters of whom lived in Greater London, and made up 8.3% of the population in the Inner boroughs[4] and 3.4% of the Outer boroughs [14]. Considering the regional discrepancies in the demographics of the African population in the UK, it is unsurprising that 53% of all African HIV infections have been reported in London [19]. Clinics in east London, where this research was carried out, treat a large proportion of the female African HIV positive patients in public sector HIV specialist centres [17].

Study one was carried out with ethical approval from the UCLH Research Ethics Committee Alpha (Ref. No. 09/H0715/78) and study two from the Outer North East London Research Ethics Committee (Ref. No. 08/H0701/75). In both of the case studies, where possible, interviews were recorded with the consent of the interviewee 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 understanding and contribute to the findings.

4. DISCUSSION

Our primary aim in this article is to use empirical experiences to discuss some of the methodological difficulties of studying privacy. Therefore, our focus is not the content of the above-mentioned studies, but rather an examination of how they were carried out. We approach this in two ways: firstly, through a discussion on ethical and pragmatic issues around researching privacy, both amongst sensitive groups and in situations where privacy is in itself a sensitive topic; secondly, through a reflexive analysis of how researchers and participants in these contexts try to enhance privacy through various practices.

Although we present themes emerging from an ethnographic analysis of our research interactions using chronological and spatial distinctions, the actual research process consisted of iterative cycles, where the topics analysed below converged into multi-faceted problems. However, for the sake of clarity and brevity this has been deconstructed and simplified here.

4.1 Gatekeeping and Access

Medical environments are places where confidentiality and privacy are of central concern. Unlike a lot of contexts where privacy is present but invisible, in hospitals and other settings of contemporary medical care the relevance of privacy is made explicit. This can be seen in processes of gaining ethical approval to access such settings for research, which in the UK involves going through an NHS ethics review process. With a view to protecting human subjects taking part in medical research institutional gatekeepers such as the NHS Research Ethics Committees can present a significant barrier to entry. As these committees are primarily centred on reviewing medical and pharmaceutical studies, they are not always flexible with regards to the emergent nature of more qualitative studies. Previous work discusses benefits and points of criticism to regulation and governance of research in healthcare [15], but also explains how threats to the legitimacy of RECs can be reinforced by the way they 'produce' accountability in decision letters [33].

As Gellner and Hirsch [18] observe, issues such as access reveal how organisations place boundaries to its environment. In our studies, gaining access, what Goffman referred to as 'getting into place' [20], initially involved receiving institutional legitimacy through formal processes of ethics approval in which research methods had to be articulated in detail and practices around informed consent, data retention and protection made explicit. At this stage, the formal involvement and commitment of one or more local gatekeepers was already required.

'Gatekeepers' is a term used to describe actors with 'control over sources and avenues of opportunity' [22]. In a hospital setting finding the appropriate gatekeepers is crucial not only because you are required to have a 'sponsor' for the formal requirements of ethics approval, but also in order to recruit participants. To negotiate the terms of access, their role in the setting and to gain legitimacy with key gatekeepers in the actual clinics, the researchers had a series of informal discussions and meetings with people at different stages, starting almost a year before the actual studies. What this highlights is that before even gaining access to the 'site', researching in some privacy sensitive contexts requires a great deal of forward planning and trust building.

Study one was introduced to the organisation by a senior consultant. However, informal and personal gatekeepers continued to appear at a lower level throughout the research, as access was required to different organisational groups, different types of meetings, documentation and technological systems. Study two was aided by a senior consultant who acted as sponsor for the project, introducing the researcher to other staff members, legitimising her presence at the site. Once again, while this acted as the first tier of organisational gatekeeping on a day to day level this was supplemented by the physicians on duty, the nurses and related staff (primarily secretarial and nurse assistant staff) who introduced the researcher to potential participants. Therefore, researchers needed to constantly re-negotiate access and legitimacy under different conditions in different settings. This experience reinforces how it is often necessary to adopt different roles to access different kinds of data [22].

On a more granular level it was not just gaining access to the research 'site' that was important. How research participants were introduced to the study influenced the type and amount of information they were willing to disclose. Different gatekeepers

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[2] Taken from latest UK Census data, http://www.ons.gov.uk/census/index.html, last accessed 12 March 2010.

[3] For the sake of brevity we use African rather than black African.

[4] The Inner boroughs are Camden, Greenwich, Hackney, Hammersmith and Fulham, Islington, Kensington and Chelsea, Lambeth, Lewisham, Southwark, Tower Hamlets, Wandsworth and Westminster; taken from http://www.londoncouncils.gov.uk/londonlocalgovernment/londonboroughs.htm, last accessed 16 March 2010.

played a significant role in framing the study as they introduced it to participants according to their own cognitive schemas. This meant that the research was often presented in different ways – for example, as a study looking at the clinic as a role model. In one specific case, the interview that followed such a characterisation resembled a job interview, where the participant tried to emphasise their contribution to the clinic and the advantages of the environment, rather than actually discussing lived experience and meaning.

In the same way that interviewees sometimes express opinions to please interviewers, participants may perceive it appropriate to align their position with the gatekeeper's view or perceived interests. Study one took place in an organisation with a culture of social science research (unusual in such medical settings) where one gatekeeper in a senior position organises most research. Although potential participants received detailed information sheets providing confidentiality and anonymity assurances, the reason why none of the staff members within the HIV clinic denied an interview invitation lay elsewhere. Compliance, in this sense, may have arisen due to occupational commitments or commitments towards gatekeepers. In such cases, privacy practices were enacted prior and during the interview process, manifesting variously in the location chosen, consent to recording and disclosure. Understanding of such privacy dynamics can contribute to effectively situating research practices and their content. Moreover, the limits of the main gatekeeper's power to provide access became evident when seeking interviews with EPR staff outside the HIV clinic, where the researcher faced difficulties in recruiting on her own. Hence, in this situation, the type of disclosure followed a different pattern, shedding light on different information. In both cases, however, in addition to gatekeeper factors the researchers constantly had to manage the identity of the project and themselves in relation to it, as discussed in the following section.

4.2 Perception of Researcher Identity

Reflexivity is often suggested as a means of appreciating the effects of the researcher on research processes, which may provide valuable insights on the object of study [24]. While there are many versions of what reflexivity is, we adopt an understanding of it as 'an unavoidable feature of the way actions are performed, made sense of and incorporated into social settings' [26]. Beyond any methodological choice, the researcher is an inherent part of the social world under study [22] and has an impact on the situation according to participants' perception of her identity. While we cannot go into the details of how this played out across both case studies, a few examples are shown in this section to provide a feel for how perceptions and management of identity influence disclosure in research settings.

The researcher in study two wears a scarf and this was a clear indicator to participants that she belonged to a religious group. Often in interviews this was raised, and while it was usually assumed that the researcher was Muslim sometimes she was asked if she was Jewish. This opened up avenues of discussion 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 highlighted how details in researcher appearances influenced the nature and type of disclosure that took place. While some participants were Muslim, many were not. However a strong religious ethos voiced by participants was often prompted, not by direct questions but simply by the presence of a scarf.

Moreover, coming from a well-known university was often seen as a mark of academic legitimacy, and participants in study two would reference this by saying things such as 'You must be very clever then'. This required a balance between appearing knowledgeable versus naive. To organisational actors in study one this contributed to study acceptance, but did not explicitly impact on disclosure. However, the fact that the researcher had no clinical background influenced the type and tone of information shared when discussing the duty of medical care over other priorities.

In addition, with gatekeeper sponsorship playing such an important role in the context of healthcare it is often difficult to control one's associations within the research environment. Although participants were recruited with considerable assistance from the gatekeeper, the researchers also chose to be introduced to potential interviewees on their own or with the help of other individuals, attempting to connect with a mix of people and emphasise different associations according to the situation. Presenting different parts of one's identity – as in every social interaction – and adjusting that to the requirements of the context becomes an important strategy as 'qualitative researchers identify and present aspects of themselves that will be useful' [28].

As NHS ethics approval requires explicit information on the participant information sheet, in study one the research focus on privacy had to be stated from the very beginning. In order to minimise priming, the topic was reframed before the interviews. An important tool for doing so was the use of a specific problem in the organisational reality – integration of HIV patient records – around which participants formulated their perceptions and understandings, instead of focusing on privacy specific questions and priming responses. This strategy was problematic when approaching the EPR team, as the integration of records turned out to be a politically loaded project in the organisation. At that stage managing perceptions of researcher identity became critical. A highly political topic raises specific connotations and research may be easily perceived as enrolled in an effort to put pressure on one of the conflicting parties in the organisation. In these cases, privacy practices of participants became apparent as they attempted to understand to whom in the organisation the research was attached and decide on their participation and disclosure accordingly.

EPR staff perceived the researcher to be an HIV student coming from the relevant hospital department, not a privacy researcher coming from the university. Therefore, they considered the research as an enquiry into their work. Although an explicit effort was made not to become part of the systems integration politics, the fact that this research was related to the HIV department was enough to be associated as such. One of the interviewees reported, after the interview, to have completely shut off the fact that this research was about information privacy, despite this being stated in every communication and on the participant information sheet. Instead the participant perceived it to be about the challenges and conflicts in the process of integration as that was an ongoing issue at the time.

Therefore, the researchers' privacy assurances and practices make the context of the interview only up to a certain extent. Interviewees make sense of this context according to their

preconceived ideas and expectation and enact privacy practices to co-construct or deconstruct research practices. This is reflected in some of the spatial and temporal contingencies discussed in the following section.

4.3 Getting into place, and staying there

The importance of 'getting into place' has long been emphasised in ethnographic research [20]. Indeed, the requirement of spending long periods of time in 'the field' is one of the hallmarks of ethnographic practice. Although there are many reasons given for this, one of them is to build trust and encourage disclosure from research participants. Another is to be able to garner insights through participation and observation over a period of time. However, both of these can be challenging when dealing with issues that are particularly sensitive to privacy concerns. In the preceding two sections we discussed various aspects of getting into place in relation to the case studies under consideration. Here we shift focus to how being in certain places at certain times contributes to the construction of a specific 'field site', which has implications for researching privacy.

The term 'field site' highlights the spatial characteristic of doing ethnographically informed research, where defining exactly what constitutes this field is an important activity [11]. Despite the centrality of this notion of the 'field' ethnographers have challenged the assumption that it represents a taken for granted, spatially bound, culturally relative location [21][27][29]. In the case studies presented here, the placing and timing of numerous research practices influenced the outcome of the research both in terms of who took part in the research and what was observed.

In study two a deliberate choice was taken to make the HIV outpatient centre the primary site of participant recruitment. This had the benefit of the researcher being introduced to patients by healthcare practitioners whom they trusted. Of course, this meant that participants who were unhappy with their care were less likely to take part in the research. This limitation was balanced by conducting focus groups at community groups, as well as speaking to practitioners and volunteers about problems or concerns patients raised in relation to healthcare practitioners. In addition, the location and timing of the introduction played a role in participants' willingness to take part in the research.

The researcher and healthcare practitioners on duty were very conscious of the risk of inadvertently coercing patients to take part in the study and patients did not have to give any reasons for not wanting to take part, were allowed to take the information sheet home and decide at their leisure and, if they decided they did not want to take part, were never asked again. The information sheets clearly stated that not taking part in the study would not have repercussions on patients in any way, a reassurance that was also expressed verbally. Indeed, many of the patients eligible for the study decided not to take part. While being introduced by a trusted third party was a crucial element of gaining access to privacy sensitive individuals in this study, it was not sufficient.

The researcher spent a considerable amount of time sitting in the clinics and speaking to patients informally. As HIV patients come into the clinic relatively regularly for blood tests and consultations (usually every three months) as well as for other appointments, such as with the psychologists or the nutritionist, this meant they often saw the researcher more than once. Potential 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 then volunteered themselves. Interestingly, these were often very good interviews in terms of richness of content and length as participants had actively decided to take part over an extended period of interaction with the researcher. The research 'site', so to speak, was not only constituted spatially but also temporally.

In addition to these temporal elements, structural factors in the clinics also played a role in easing or complicating interaction with patients pre and during interviews. In the interviews these same structural factors were raised by participants as making them feel more or less comfortable in terms of their privacy when attending the clinic for appointments. Pre-eminent amongst these were the differences between clinics, or waiting rooms within clinics, that were for HIV patients only against those combined with other sexual health services. In HIV-only waiting rooms patients usually avoided eye contact with 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 as well as the study and after those kinds of discussions one or more patients usually 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 primarily HIV patients, this was not always the case and so patients could not be approached directly by the researcher 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 on the recruitment of participants. To overcome this, healthcare practitioners were requested to give the information sheets in private consultations and if permission was given to provide the researcher with the patients' contact details.

Therefore, the place of recruitment and the amount of time spent in that place influenced gaining access to privacy sensitive research participants in study two. In study one, however, the salience of place and time played out in a different way. The problem here was centred less on getting participants to take part in the study, although that did require a considerable amount of work, and more on actually gaining access to their views on privacy, in an organisational setting where this topic is of paramount concern. Depending on the context in question some people tended, as is to be expected, to present only certain aspects of the situation and their attitude towards it, usually the organisationally accepted one. 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, she 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. As Marshall and Rossman state 'confidence and trust emerge over time through complex interactions' [28], and therefore, taking time with people, participating in their social events and talking about topics unrelated to research in every opportunity proved valuable to establishing good relationships. More natural situations such as staff meetings or cases where for example people in the office discussed putting research files in locked cabinets provided more information on the daily practices of privacy management. By genuinely engaging in these matters the researcher was able to improve her understanding of them.

4.4 Micro-negotiations around privacy in interview settings

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) were often more complicated than anticipated. For example, in study two sometimes patients who were interested in taking part in the research felt uncomfortable signing informed consent forms. Although this is designed to protect participants, in cases such as this, where participants are highly sensitive about their privacy, signing their name to a sheet of paper that will be kept by a researcher before being destroyed was considered a significant risk, and sometime 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 for some reason incapable of signing the informed consent form. This raises questions on the tension between accepted research practices designed to protect participants and participants' desire to protect their privacy in relation to their participation in research.

In a similar vein, the audio recording of interviews posed a problem for some privacy sensitive research participants. Significantly, those more 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 and hence represented the hardest group to reach. In order to mitigate this, the researcher was flexible and took notes in such interviews.

In study one, 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. This was not unexpected as a period of avoidance and delay had preceded the interview. However, the majority of the interviewees seemed comfortable with the methods employed and the privacy practices enacted during the interaction and did not request further proof or protection. Apart from the provision of confidentiality assurances, gatekeeper sponsorship or approval was, in this study, the main reason for participation. This, however, did not ensure cooperation and defensive answers to privacy topics were commonly received at the beginning of the research. In addition to providing reassurances and also using the interview as a space for explaining privacy practices around the research, in study one, a mix of passive and active interviewing techniques were employed. In shifting between these two interviewing styles the researcher sometimes adopted an intentionally naïve stance in order to avoid imposing her own assumptions on the interviewees responses. At others the researcher challenged participants' responses to gain insight into their privacy perceptions on a different level.

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 [3]. In study two, 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. 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.

The kinds of negotiations that took place in interviews in study two can be seen in the extract below. After agreeing to take part in the research, going to a private room and signing the informed consent form, the participant, a woman who has been living with HIV for 10 years and has had considerable medical complications asked:

> **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.
>
> **Participant:** So how is that one going to help us?
>
> **Researcher:** It's a good question. I hope that at the end of the research the doctors and people working in HIV in the UK with have a better idea of how patients feel about information and what they need. So not just what information they are giving them but also to try and understand how it makes patients feel. So I hope it will help in that way, but it's hard to say for sure if it will do this, but I hope it will be able to make different people more informed.

After this the participant went on to give a very long interview and met with the researcher for a second time, inviting her to her house.

5. CONCLUSION

In this paper we documented two studies on HIV care, privacy and technology. More specifically, we focused on how our research experiences related to broader methodological challenges of studying privacy. We described the methods used to study the highly sensitive context of HIV clinics in London, and analysed them as a means of better understanding how researchers and

research participants enact privacy through a range of practices. Of particular interest were methods in relation to reaching privacy sensitive individuals, both data users and subjects, and situations where privacy is politically loaded. Within this, we emphasised four main themes: the role of institutional, organisational and personal gatekeepers; identity politics around research topics, researchers and participants; the temporal and spatial contingency of practices of disclosure, and micro-negotiations around privacy in interview settings.

More generally, this analysis has relevance to privacy methodology through advocating a reflexive approach to how privacy is enacted as part of research practices. Researchers and participants are often faced with a choice between disclosure and withholding information, which can be studied as an object of analysis, but also be used as an instrument to elucidate some of the complexity of privacy. By doing this, areas of conflict and tension around how privacy is generated as an object of study can be highlighted. Furthermore, by embedding research situations within the analysis in privacy research some of the problematics around the distinction between attitudes and practices can be tackled.

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