

Researching Privacy in HIV Care: an Ethnographic Analysis of Methods

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Methodological Issues

- Privacy paradox
- Priming of privacy sensitive responses
- Studying privacy sensitive groups and topics
- Definition of privacy

Our Approach

- Privacy as a situated concept and the importance of studying action *in situ*
- Qualitative methods
- Making the practices of research in relation to sensitive groups and topics the *object* of analysis
- Analysing these interactions *ethnographically* as privacy making situations

Case Studies

Study One

- Changing information privacy conditions in the context of the integration of Electronic Patient Records (EPR) from specialist HIV outpatient centres into central university hospital systems
- 26 semi-structured, in-depth interviews with staff mainly in one HIV outpatient centre in east London
- Non-participant observation for an average of 2 days a week over a period of 3 months and participation in staff meetings. Other sources of data include documentation material, email communication and minutes of meetings

Study Two

- Health-related internet use by African women living with HIV in London
- 41 qualitative interviews with women from 13 African countries, interviewed once or twice and recruited from three HIV specialist outpatient centres in east London
- Non-participant observation for 2-3 days a week, 2 focus groups at community organisations, 6 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



Four Themes

- Gatekeeping and access
- Perception of researcher identity
- Temporal and spatial considerations
- Micro-negotiations around privacy in the interview setting

Gatekeeping and Access

- Institutional and organisational gatekeepers → Research in privacy sensitive contexts requires a great deal of forward planning and trust building
- Constantly re-negotiating access and legitimacy → Necessary to adopt different roles to access different kinds of data
- The ways gatekeepers introduced the study influenced the type and amount of information research participants were willing to disclose
- Compliance due to occupational commitments or commitments towards gatekeepers → Privacy practices were enacted, manifesting variously in the location chosen for the interview, consent to recording and disclosure

Perception of Researcher Identity

- Reflexivity: ‘an unavoidable feature of the way actions are performed, made sense of and incorporated into social settings’ (Lynch 2000)
- How perceptions and management of identity influence disclosure in research settings:
 - External appearance characteristics
 - Well-known university
 - Introduction to interviewees and presentation of study
- Interviewees make sense of the interview context according to their preconceived ideas and expectations

Getting into Place and Staying There

- Being in certain places at certain times contributes to the construction of a specific 'field site', with certain implications for researching privacy
- Spatial and temporal construction of the research 'site'
- Structural factors in the clinics played a role in easing or complicating interaction
- Actively managing temporal and spatial considerations

Micro-negotiations around Privacy in the Interview Setting

- Informed consent forms: tension between accepted research practices designed to protect participants and participants' desire to protect their privacy in relation to their participation in research
- In study one, a mix of passive and active interviewing techniques were employed
- The motivation for taking part in research is an important issue to take into consideration when researching privacy sensitive groups

Conclusion

- This paper is advocating a reflexive approach to studying how privacy is enacted as part of research practices
- Such an approach can highlight areas of conflict and tension around how privacy is generated as an object of study
- 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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