



Background

Understanding data sharing in HIV care is timely given the shift to remote consultations during COVID-19¹ and increasing expectations for self-management, particularly through digital means². We conceptualise the 'data sharing ecosystem' in HIV care by analysing HIV healthcare professional (HCP) beliefs and practices around sharing diverse types of service user and clinic-generated data across multiple contexts.

Table 1: Demographic characteristics of HCP participants.

Characteristic	N=	%
Gender		
Female (including trans women)	8	57
Male (including trans men)	5	36
Prefer to self-describe	1	7
Same as Sex at Birth?		
Yes	12	86
No	1	7
Missing	1	7
Years working in HIV care		
1-5 years	4	29
6-10 years	5	36
11-15 years	0	0
16-20 years	3	21
21-25 years	0	0
26-30 years	1	7
31-35 years	1	7
Job Title		
Consultant	5	36
Specialist Registrar	3	21
Specialist Nurse	2	14
Health adviser	2	14
Pharmacist	1	7
Clinical Psychologist	1	7

[1] British Association for Sexual Health and HIV. COVID-19 Sexual Health 'Clinical Thermometer' Survey. Available at: <https://members.bashh.org/Covid-19>. Accessed: 31 March 2021.

[2] Cooper V, et al. EmERGE Consortium. mHealth interventions to support self-management in HIV: a systematic review. *Open AIDS J.* 2017;11: 119-132.

[3] Bussone A, et al. 2020. Trust, identity, privacy, and security considerations for designing a peer data sharing platform between people living with HIV. *Proc. ACM Hum.-Comput. Interact.* 2020;4 (CSCW2): 173.

Methods

- 14 semi-structured interviews (9 face-to-face and 5 remote) with HCPs working in a large UK HIV outpatient service between February–October 2020.
- Participants engaged in a card sorting task informed by Bussone et al.³, sorting 33 data types routinely shared in HIV care into categories (comfortable/not comfortable/not sure) across three data-sharing contexts: data sharing from service users to HCPs in (a) consultations; (b) from HCPs to GPs; and (c) HCPs to non-HIV HCPs.
- Participant demographics were analysed using descriptive statistics (Table 1). Simple counts of card sorts were explored using thematic analysis of interview data.



Results

HCPs were comfortable with:

- A wide range of clinical and personal health data being shared with them by service users in consultations.
- Sharing data with GPs and other non-HIV HCPs in two broad categories: (a) demographic data (e.g. age), and (b) non-sensitive data related to general health (e.g. sleep).
- Less comfortable sharing sensitive information about HIV status, sexual health, behaviour and identity, perceiving them as not relevant to care provided by other HCPs or as risking stigmatisation.
- Service user consent and relevance of data to sharing context were key determinants of data sharing comfort.

- Our findings have informed the development of the concept of the data sharing ecosystem in HIV care, highlighting the ecological nature of data sharing, where data travels between service users, health care providers, public health surveillance, and others, which may include peers and third sector organisations.

Conclusion



With a growing emphasis on self-management of HIV and remote care provision, understanding the context of data sharing in HIV care is increasingly important, particularly given the perceived durability of current service changes as a result of COVID-19. A complex interplay of data types, relationship dynamics, and contexts of care provision shape the data sharing ecosystem in HIV care and HCPs' comfort with data sharing. Developing guidance on the sharing of service user and clinic-generated data in HIV care must account for these complexities.

"I guess my fear with sharing [about sexual behaviour] with a GP is that it's perhaps not so usual for them to interpret. And I would be worried about their stigma towards the patient..."



"I would be comfortable sharing [data about recreational drug use], completely comfortable with sharing it if it's relevant...to the other healthcare professionals' assessment...and the caveat is if the patient is happy for us to share it."