

Healthcare professionals' perspectives on working with patient-generated data for supporting person-centred HIV care

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BACKGROUND

People living with HIV who are stable on treatment still face challenges impacting their wellbeing and quality of life (QoL). Patients' self-reported information can help Healthcare Professionals (HCPs) deliver **Person-centred Care**, to illuminate patients' lived experience of managing their condition, and to set targets for achieving QoL with them. HIV HCPs are starting to use **Patient Reported Outcome Measures (PROMs)** questionnaires, for capturing Patient-generated Data (PGData).

We report on a UK study with HCPs providing routine HIV adult care, to understand their experiences of working with PGData including PROMs, with the aim to inform the design of supportive tools for Person-centred Care.

PROMs offers potential tools for Person-centred HIV Care, and could add value to routine consultations, by improving: patient-provider communication; patient-involved assessment; and patient involved decision-making. An HIV-specific PROMs prototype has been validity-tested and found to be efficacious (Bristowe et al. 2020).

However, PROMs have not yet been embedded in UK HIV care standards. More guidance is needed about which instruments HCPs should use; tools need to be developed to detect HIV-related changes or experiences of HIV Stigma and comorbidities, for particular settings or cultural contexts.

RESULTS

Patient involvement at the routine consultation

The consultation was highlighted as a key moment in routine care to cover both physical and psychosocial aspects of patients' health and wellbeing. Overall, HCPs described their practice of facilitating a patient-led agenda by giving patients the opportunity to self-report their concerns and, in turn, they would adjust the medical agenda to address these within the consultation timeframe. However, whilst the need for patients to be listened to was recognised, physicians also highlighted time constraints and the need to balance patient agendas with clinician agendas, highlighting the practical reality of time constraints for achieving this balance.

'There's always a balance between the patient's agenda and the clinician's agenda. They need to be held in balance with each other. One implication of this is, you could foresee, is that the power balance swings more towards the patient agenda and sometimes there's some correction needed' (Physician B1).

Nurses and psychologists highlighted wider patient circumstances impacting personal information sharing, plus health inequities shaping access to Internet-mediated tools. Post-pandemic, preference for in-person consultation was emphasised for enabling good communication and sense-making of one's experience.

'Communication is also not just about the talking. It's about the visual cues. It's about how somebody's looking. You know how somebody's sitting. You know, if they're looking away, if they're looking down, the tone of the voice...' (Physician A4).

CONCLUSION

Interview findings evidence UK HIV Healthcare Professionals' perspectives on how PGData including how PROMs may support Person-centred Care, plus considerations for designing supportive data collection tools. More research is needed to investigate how this information may be meaningfully captured, interpreted and processed by HCPs in ways that are trusted by patients, and how supportive tools may be designed inclusively, and personalised to address individual needs around language, literacy and culture. We further acknowledge how, within the multi-disciplinary team, HCPs hold differing specialist expertise, and designs should be customisable to be made appropriate for use by HCPs with particular expertise and responsibilities within and beyond the context of the routine clinical consultation.

METHOD

Semi-structured (individual and group) interviews were conducted (March 2020 to October 2022) with 15 HCPs (5 men, 10 women) from multi-disciplinary teams at: a large London HIV outpatient clinic (A); an Infectious Diseases service in Northern England (B). Due to COVID-19, all but one interview took place online. The 90-minute interviews were supported by persona-based scenarios and infographics, prompting participants' engagement with individual lived experiences. Transcribed audio-recordings were coded using Reflexive Thematic Analysis (Clarke and Braun, 2021). The sample comprised: seven physicians; three psychologists; two nurses; a health advisor; a pharmacist; a peer support worker. This reflected the multi-disciplinary expertise at each clinic. Two physicians, one nurse, and one psychologist at Clinic B participated in follow-up interviews focussing on PROMs.



LUCAS
they, them, their
I am a 21-year-old English man and identify as transgender.

KATHRYN
she, her, hers
I am a 42-year-old British woman living on my own in the North East of England.

> Our persona-based scenarios introduced two characters at interview.

Participant label	Gender	Role	Clinic
Physician A1	Male	Consultant Physician	A
Physician A2	Female	Consultant Physician	A
Physician A3	Female	Specialty Registrar	A
Psychologist A	Male	Clinical Psychologist	A
Pharmacist A	Female	Senior Clinical Pharmacist	A
Health Adviser A	Female	Sexual Health Adviser	A
Physician A3	Female	Consultant HIV Physician	A
Nurse A	Female	Specialist HIV nurse	A
Peer Support Worker A	Male	Senior Peer Support Worker	A
Nurse B	Female	HIV Specialist Nurse	B
Physician B1	Male	HIV and ID Consultant	B
Psychologist B1	Female	HIV Specialist Psychologist	B
Physician B2	Female	Infectious Diseases Registrar	B
Psychologist B2	Female	HIV Specialist Psychologist	B
Physician B3	Male	Infectious Diseases Registrar	B

> Demographic table of participants

PGData in Person-centred Care

Participants raised the need to use validated tools, and to agree on a format and timeline for capturing PGData. Four participants said they would find it helpful to receive summaries of PGData ahead of their consultations. Visual and graphical formats were deemed valuable for communicating an overview of information, and for highlighting critical instances in the data. This led us to discuss the potential of PROMs at the consultation.

The value of PROMs in HIV care was perceived in: facilitating face-to-face conversation with patients who struggle to articulate problems or discuss difficult topics; co-defining an agenda; helping both parties ask the right questions and acquire contextual information; tracking progress; helping meet BHIVA standards; capturing and evaluating experience of attending services; and tailoring services.

PRO data could be shared ahead of the consultation with HCPs to facilitate a patient-led agenda, [by] 'using the questionnaire to think about what [patients] want to bring to the appointment' (Psychologist B1). PROMs could also play a critical role in care to consider the whole person and therefore help support a more systematic delivery of care.

'Something like PROMS would hopefully make sure 100% of patients were asked about their psychological wellbeing and emotional health' (Psychologist B1); 'If it's done properly and consistently by everybody, for everybody, then everyone's getting the same level of care' (Nurse B).

Perceived challenges of using PROMs for HIV care included: patients' confidentiality concerns; questioning validity of PGData - honesty in self-reports, context of capture and language or translation needs; time constraints for interpreting data; system interoperability for data processing / access by HCPs and patients.

For instance, participants questioned PROMs' flexibility to address health literacy and language when English is not patients' first language; also, how confidentiality would be maintained if PRO data were shared across the wider health system (i.e. with GPs) and how PROMs would work with the existing IT system:

'If it's done electronically, it would be great to be able to merge it with the IT system so it's part of the consultation but, I mean, the IT system we use for doing consultations is, well, it's silly. It's just not fit for purpose' (Nurse B).

Design considerations

- * The capture of PGData can support patients to collect rich information for discussion at the routine HIV consultation. More design research is needed to support the curation and communication of PGData for Person-centred Care.
- * Visual presentation of PGData including PRO data should be further explored for facilitating data capture and sense-making over time, and for supporting the review of such data at the consultation. Readability, discretion and accessibility should be considered together with personalisation.
- * Bespoke tools could be developed enabling HCPs to choose relevant questions for patients based on individual patient needs, depending on where they are in their journey. Or questions could be skipped or marked as not relevant.
- * Personalisation of PROMs and the use of audio-visual content or visual aids could also help address barriers related to language, culture, and health literacy.
- * To address time constraints, PROMs could also be tailored to the needs of HCPs and their role within the multidisciplinary team for supporting care.
- * Digital technologies provide rich opportunities for PROMs but more research is needed to investigate how such sensitive information could be shared remotely and securely, to address the trust, security and privacy concerns of people living with HIV.



K. Bristowe, F. E. M. Murtagh, P. Clift, R. James, J. Josh, M. Platt, J. Whetham et al. 2020. The development and cognitive testing of the positive outcomes HIV PROM: a brief novel patient-reported outcome measure for adults living with HIV." *Health and Quality of Life Outcomes* 18, no. 1 (2020): 1-10.

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