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Title

Towards person-centred care for people living with HIV: what core outcomes matter, and how might we assess them? A cross-national multi-centre qualitative study with key stakeholders

Running title

Person-centred outcomes in routine HIV care

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ABSTRACT

Objectives: People with HIV have multidimensional concerns requiring person-centred care. Routine use of patient reported outcome measures (PROMs) improves outcomes. No brief PROM currently reflects the breadth of HIV patients' concerns. This study sought to identify priority outcomes for HIV patients, model current practice, explore views on introducing PROMs into routine care, and devise a model for person-centred care incorporating the PROM.

Methods: Cross-national multi-centre study (London, Brighton, and Dublin). Semi-structured qualitative interviews with: adult HIV patients, HIV healthcare professionals and HIV commissioners (responsible for planning and commissioning services). Interviews were analysed using thematic and framework analysis.

Results: Patients (n=28), professionals (n=21) and commissioners (n=8) described concerns related to living with HIV across six domains: physical (e.g. pain, gastrointestinal), cognitive (e.g. memory, sleep), psychological (e.g. anxiety, depression), social (e.g. isolation, intimacy), welfare (e.g. finances, fears regarding change of immigration status), and information needs (e.g. long-term outcomes). Themes were highly inter-related, impacting across domains of need (e.g. physical and cognitive problems impacting on psychological and social wellbeing). Perceived benefits of using PROMs in routine HIV care included: improved person-centredness, patient empowerment, fewer missed concerns, increased engagement with services, and informed planning of services. Potential challenges included: heterogeneity of patients, literacy, and utility for those who struggle to engage with care.

Conclusion: This study presents a novel model of person-centred care incorporating an HIV specific PROM. The model reflects priorities of key stakeholders. Explicit use of PROMs in routine HIV care could afford benefits for the individual patient, clinical teams, and commissioners.

Keywords: HIV, outcomes, qualitative, PROMs, implementation, person-centred

BACKGROUND

From diagnosis onwards, people living with HIV have complex physical, psychological, and social needs(1) and poorer health-related quality of life (HRQoL) than the general population(2). Self-reported physical and psychological problems are associated with poorer antiretroviral therapy (ART) adherence(3), sexual risk taking(4), viral rebound(5), and poorer self-rating of health(6). Contrastingly, good psychosocial care and communication with HIV professionals(7), are associated with improvements in clinical outcomes, adherence and retention in care(8).

The recent UNAIDS global strategy ('90-90-90') set a target to improve rates of diagnosis, treatment adherence and viral suppression by 2021(9). However, respondents to this strategy, including HIV community representatives, advocacy groups, and experts in the field, have advocated for a fourth priority focused on improved HRQoL(10). Care that addresses the multidimensional concerns of HIV patients requires a person-centred approach—a core principle of quality healthcare(11). Person centred care, putting the individual at the centre of their care, helps individuals to access the care they need, when they need it, by involving them in their own care decisions. A person-centred approach enables professionals to deliver high quality care that is respectful and responsive to the needs of the individual(11). This is achieved through attention to the individual's personal situation and what matters to them, with communication and information provision oriented to their needs and preferences(12). Such approaches have been found to improve patient experience, care quality and health outcomes(13). The WHO global strategy for people-centred and integrated services recognises that, particularly for long-term conditions, care must respond to the individual's preferences and concerns, and be coordinated around their needs(14). Similarly, recent European initiatives have requested an integrated outcomes-focused, person-centred approach to long-term HIV care that incorporates national monitoring of outcomes(15). However, there has been little consideration of what these person-centred outcomes should be, and how they could be measured and integrated into standard care.

HIV professionals often miss patients' problems and concerns, especially non-physical ones⁽¹⁶⁾ reflecting the biomedical focus of current HIV care. Moreover, UK HIV outpatients perceive that care frequently does not address the broader issues that matter to them (physical and psychosocial) (17). This emphasises the need for person-centred care, valuing and recognising individuality(18), and approaching care decisions as a partnership between the patient and provider(19). Identifying the patient's priorities allows for individualised care to meet those person-centred outcomes(20). One potential solution is the 'personal outcome approach' incorporating person-centred care alongside valid PROMs(20). This promotes patient involvement in care decisions, improves relationships and communication between patients and professionals, and can improve treatment adherence(21). At an individual level, PROMS can help identify and monitor what matters to patients⁽²²⁾. At a service level, PROMS ensure that care is directed and measured around those outcomes, thereby promoting quality and equity(23). Whilst PROMs for single dimension outcomes (eg. depression, stigma, HRQoL) are applied in HIV clinical trials, there is no brief, patient-centred PROM that reflects the range of outcomes relevant to HIV patients to drive and evaluate routine care(24)(25).

This study is part of a programme of research to improve assessment of symptoms and concerns of HIV patients. The programme will develop a novel, brief patient-centred PROM for use in routine HIV care. After identification of the need for a new PROM specific to people living with HIV, the first stage of development is to gather information from key stakeholders, to define concepts and form a conceptual model to underpin the item generation(26). This paper reports the conceptual model of priority outcomes for key stakeholders to ensure face and content validity of the PROM(27), and views regarding the potential utility of such a PROM to ensure it is appropriate for use in routine HIV care.

The overall aim of this programme of research is to develop a novel brief patient-centred PROM for use in routine HIV care (PROM development and design not presented here). The objectives of the current study are: (1) to determine views, experiences and preferences of key stakeholders (HIV patients, professionals and commissioners) with respect to the problems and concerns for HIV patients; (2) to model current HIV care; (3) to determine views of key stakeholders on the utility of a HIV-specific PROM to enhance the person-centredness and quality of routine HIV care; and (4) to devise a new model for person centred care incorporating an HIV specific PROM.

METHODS

Design

This qualitative study follows the COSMIN taxonomy and guidance for relevance and comprehensiveness of PROMs(28, 29), and Rothrock guidance on the development of valid PROMs(26).

Research Governance

Ethical approval for the study in England was granted by Research Ethics Committees in the UK (HRA: 16/LO/1453) and Ireland (RECR:2017/05).

Setting

HIV patients and professionals were recruited from three large teaching hospitals in London and Brighton (UK) and Dublin (Ireland). Clinicians at each site approached participants regarding the study (in person, by telephone or email) using their preferred means of communication. HIV professionals were also recruited through the British HIV Association via self-referral to the study. Commissioners of HIV services were recruited in England via direct contact.

Recruitment

HIV Patients

HIV patients were purposively sampled (to achieve a maximum variation sample across key demographic and clinical criteria) by age, gender, ethnicity, sexual orientation, time since diagnosis, and comorbidities to meet the predefined sampling frame.

Inclusion Criteria: Adult (≥ 18), living with HIV, currently under the care of specialist HIV services at participating sites.

Exclusion Criteria: Individuals: aged < 18 , lacking capacity to consent to the study, or too unwell or distressed to participate. Patients' capacity and suitability for participation was assessed by their clinician.

HIV Professionals

HIV professionals were purposively sampled by profession: doctors; nurses; and allied health and social care professionals.

Inclusion criteria: Professionals working in HIV services at the recruitment sites or with professional membership of the British HIV Association.

HIV Commissioners

Commissioners of HIV services (responsible for planning, prioritising, purchasing and monitoring of services) were purposively sampled by role/employer (local authority (council) or health service (NHS) employees) and regional HIV prevalence.

Inclusion criteria: Commissioners of HIV services in England.

Data Collection

Semi-structured interview schedules were informed by a literature review of priority health related outcomes for HIV patients and developed by the project steering group (HIV patients, HIV professionals and researchers). Interviews were undertaken by KB in the UK (experienced qualitative methodologist), and KM in Ireland (new to qualitative research, but trained by KB). All interviews were conducted face-to-face in the interviewee's preferred location (clinic rooms, research facilities, individual's homes and libraries), except three commissioner interviews which were completed over the telephone. Participants were not known to the interviewers prior to interview.

Interviews commenced with demographic questions followed by open questions exploring: problems and concerns for HIV patients, if and how these were currently disclosed, discussed and managed in routine care. The second section of the interview investigated views on PROMs in the context of HIV, and discussion of key domains for inclusion in a PROM. The third section examined the utility of an HIV specific PROM in routine care, including potential benefits and challenges to its use. Interviews were digitally audio recorded, transcribed verbatim and pseudonymised (identifiable information removed and study identification number allocated). Transcripts were not returned to participants for checking. A diary was utilised to record emergent themes from interviews, which informed the assessment of thematic saturation.

Analysis

Interviews were analysed (KB, RH) using inductive thematic analysis, in six stages: familiarisation; coding; searching; reviewing; and defining themes; and reporting(30). Using an iterative process the initial coding frame was constructed, refined (KB, RH), and subsequently applied to all interviews across participant groups. A secondary framework analysis was undertaken, including creation of a matrix, charting and mapping, to enable comparison within and across stakeholder groups(31). Analysis was reviewed by the project steering group, and revisited to develop a theoretical model of standard care, and person-centred HIV Care Incorporating an HIV specific PROM. Analysis was supported using NVivo qualitative data analysis software (V.10), and reported in accordance with the consolidated criteria for reporting qualitative studies (COREQ)(32).

RESULTS

Participants

Fifty seven key stakeholder were recruited (see Table 1): n=28 HIV patients, n=21 HIV professionals n=8 HIV commissioners (n=8). Purposive sampling targets were achieved.

(Insert table 1 here)

Findings

Findings are presented in two broad themes: priorities, problems and concerns for HIV patients; and potential utility of an HIV specific PROM. Themes and sub-themes are displayed in Tables 2 and 3. Interview quotes to exemplify themes are presented in Table 4.

1. Priorities, problems and concerns for HIV patients

Participants across all stakeholder groups described problems and concerns for HIV patients across six broad domains: physical, cognitive, psychological, social, welfare, and information needs (Table 2). However problems and concerns were rarely described in isolation and were highly inter-related, with concerns often impacting upon patients across domains of need (e.g. physical and cognitive problems impacting on psychological and social wellbeing Quote 1, Table 4).

(Insert table 2 here)

i. Physical

Participants described a breadth of physical problems associated with living with HIV and taking ART. Pain and discomfort were frequent concerns (headache, joint pain and neuropathy), as were gastro-intestinal symptoms (bloating, constipation, diarrhoea, nausea, vomiting, reflux, dry mouth and loss of appetite). These burdensome problems, alongside frailty, fatigue and lack of mobility, impacted upon individuals' abilities to carry out routine day-to-day tasks (quote 2). Across all stakeholder groups, participants spoke of the importance of exploring difficulties taking medication in clinical consultations. However for HIV professionals, particularly doctors, the focus was on adherence, viral load and physical symptoms or side effects rather than impact of the daily tablet burden (quote 3).

ii. Cognitive

Alongside the physical burden described above, HIV patients also shared problems with their ability to concentrate and focus on activities. Sleep problems were common, compounding their fatigue (quote 4). Concurrent dizziness and light-headedness, and memory problems, were described by HIV patients and professionals as common concerns (quote 5). These varied cognitive concerns impacted heavily on individuals' ability to work, which in turn affected their welfare and financial stability.

iii. Psychological

For many, living with HIV was associated with significant psychological morbidity. Taking ART was a daily reminder of their condition and the associated stigma. Participants, including commissioners, described the impact of stigma on decisions regarding disclosure of HIV status (quote 6), particularly when this was out of their control (e.g. by ex-partners). Anxiety was frequently described by HIV patients, particularly among those who had experienced negativity previously around disclosure, resulting in withdrawal from relationships or intimacy (quote 7). Individuals also described self-stigma, sadness and shame associated with contracting HIV, including, for some, unresolved anger relating to HIV acquisition (quote 8). The traumatic experience of multiple losses in the early part of the epidemic remained with those diagnosed many years previously (quote 9). HIV professionals described the high prevalence of depression and mood problems, exacerbated by the physical impact of HIV on patients' mobility and fitness, and unwelcome body changes, resulting in poor body image and low self-esteem (quote 10).

Conversely, some individuals described a sense of acceptance and resilience, often associated with a renewed focus on health, fitness and living well, in the light of living with a chronic condition. HIV had, in this sense, been the driver to re-evaluate life, reinforced by the regular health review within routine HIV care (quote 11).

iv. Social

Across the stakeholder groups it was recognised that physical, cognitive and psychological concerns impacted heavily upon HIV patients' ability to engage in social events (quote 12), work, education and other activities, resulting in isolation and loneliness (quote 13). Presence of support networks was variable, particularly as many felt unable to share their status. This resulted in a self-imposed sense of concealment or dishonesty, and a resultant distancing from potential support (quote 14). For many, support groups at the HIV clinic, or provided by HIV charities, were important, as were faith-based and community networks. However, HIV professionals described fears of disclosure negating access to these for some patients (quote 15).

Participants described the impact of living with HIV on intimate relationships. For some, diagnosis led to complete withdrawal from intimate relationships, particularly for those diagnosed when there were no or few treatment options (quote 16). For others, HIV served as an additional barrier. The prospect of disclosing their HIV status to a potential sexual or romantic partner became overwhelming, resulting in further

withdrawal (quote 17). Concerns around intimacy spanned sexual and reproductive health: safe and reliable contraception, conception, and starting, or extending, a family.

v. Welfare:

Welfare concerns were multifaceted. HIV professionals described patients expressing concerns regarding inadequate or insecure housing exacerbated by the need to keep antiretroviral medication concealed (quote 18): those in shared housing rarely disclosed their HIV status, increasing anxiety levels. For some, complexities of immigration status was an added burden, particularly maintaining access to care should their immigration status change.

In addition, HIV patients were concerned about their general wellbeing and ability to maintain a healthy lifestyle and diet. This often felt unattainable due to fatigue, immobility and limited finances when unable to work. For some, reliance on alcohol or drugs as a means of managing their psychological health was a concern, and an important area of consideration within their HIV care (quote 19).

vi. Information

HIV patients felt they lacked relevant information about longer-term health outcomes of HIV and ART (quote 20). HIV professionals recognised this concern, and for many this formed part of their rationale for focusing on test results (viral load and CD4), adherence, and problems with medications (quote 21). Within HIV clinic appointments, the first topic raised was usually test results. However for HIV patients, often the stress, and subsequent relief or concern, associated with these results led to individuals failing to raise other problems they had identified prior to the appointment, exacerbated by their memory and concentration problems (quote 22).

2. Model of Current HIV care

HIV patients generally felt well-informed about ART, and felt able to approach pharmacists if not. However, other symptoms and concerns (particularly non-physical ones) were often unresolved, or not addressed within consultations (quote 23). Within our sample, while HIV professionals and commissioners recognised the broad range of symptoms and concerns for patients, they prioritised discussion of medication, adherence, and physical problems related to taking ART within consultations (quotes 24 & 25). This current standard biomedically-driven model of HIV care that prioritises treatment and its outcomes, derived from our data, is shown in figure 1.

(insert figure 1 here)

The priority within consultations in this standard model is on ART, blood results and physical concerns, with access to information about medications. Other problems and concerns (including psychological, cognitive, social, and welfare) are peripheral, not routinely discussed, and access to support for these issues is dependent on the patient having the confidence and opportunity to raise the subject themselves.

3. Utility of an HIV specific PROM

The utility of an HIV specific PROM to identify, assess and monitor problems and concerns for HIV patients was also explored within the interviews (Table 3).

(Insert table 3 here)

i. Benefits: person-centred care

The potential benefits for patients of an HIV-specific PROM were readily described.

a. Model of person-centred care incorporating an HIV specific PROM

Utilisation of PROMs in routine HIV care was viewed as a person-centred approach, as demonstrated by the model in figure 2 (derived from the data), empowering HIV patients to raise concerns, feel that all their concerns are heard and validated, and to facilitate discussion of potentially sensitive problems that they may not otherwise voice (quote 26). This personal outcome approach would in turn foster resilience, help HIV patients feel confident in the care they receive, and potentially increase engagement with services and treatment adherence. Whilst discussion of blood results, ART and physical concerns remain a core part of HIV care, other priority symptoms and concerns could be identified by the patient through integration of the PROM within discussions.

(Insert figure 2 here)

ii. Benefits: interactional, service and commissioning level

Perceived benefits were also identified for relationships and interactions between HIV patients and professionals. PROMs were described as an excellent means of 'getting to know' patients, establishing a baseline and tracking changes in outcomes over time, whilst avoiding assumptions and ensuring concerns are not missed (quote 27). PROMS could also inform treatment decisions, and encourage appropriate referrals.

At a service level, PROMs were viewed by commissioners as an efficient means of engaging effectively with patients, establishing a baseline of need for the specific clinic population (quote 28). They would enable needs to be understood, and changes to be monitored over time. Lastly, they would allow comparisons within and across services. From a management and commissioning perspective, PROMs could therefore: support service design and delivery, allow a move beyond adherence and satisfaction as markers of success, and be used to evaluate current, and inform future, resource allocation (quote 29).

iii. Challenges

Potential challenges in implementing an HIV-specific PROM were also raised by HIV professionals, including how a single PROM could be designed to accommodate the heterogeneous HIV population both in demographics, and time since diagnosis (quote 30). As HIV evolves to a chronic condition, one HIV patient questioned whether it would remain the primary concern for patients over other comorbidities, and therefore whether it warrants a specific PROM (quote 31).

Challenges were also raised about the utility of a self-completed PROM in populations with reduced literacy, or where individuals struggle to engage with services (quote 32). Lastly, the development of an HIV-specific PROM raised concerns about validation (what should it be validated against) and a lack of comparability with other conditions (often critical in commissioning).

At an individual level, concern was raised particularly by HIV professionals as to whether providing patients with a list of symptoms and concerns may cause anxiety by making them more aware of potential problems (quote 33), although this was not expressed as a concern by HIV patients. Other concerns focused more on responses to the data generated by an HIV-specific PROM. For example, how to proceed when patient and professional priorities differ, and ensuring that PROM data drives care (i.e. not a 'tick box exercise'). HIV professionals also raised concerns about best practice in responding to needs identified by the PROM (accompanying guidance), and how to respond to concerns where resources may be limited, for example the current reduction in funding for social work or psychological therapies (quote 34). However, respondents felt that this should not stop professionals from asking about symptoms and concerns, i.e. care must be centred on the expressed needs of patients (see figure 2).

(Insert table 4 here)

DISCUSSION

This study advances the understanding of person-centredness in the context of HIV, and presents a novel multidimensional conceptual model of person-centred care to inform the development of an HIV-specific PROM. By identifying priorities for patients, this study will enable a move beyond unidimensional measures and abstract concepts of HRQoL, to a set of specific actionable and measurable clinical outcomes. This approach is critical for HIV patients who have highly inter-related symptoms and concerns across broad-ranging domains. The cumulative impact of this necessitates an approach to care that addresses these domains collectively, not in isolation – a person-centred approach. The multi-level sample in the present study (across key stakeholder groups) optimises the acceptability of the new PROM, enabling it to be utilised by patient and their clinicians, to drive care commissioning, and to enhance care quality and outcomes.

In the standard model of HIV care (see figure 1), treatment-related and physical concerns are prioritised in HIV consultations. Other concerns including social, psychological, cognitive, welfare and information needs can be overlooked(16), relying on patients to raise them in order for them to form part of their assessment and management. Evidence suggests that care that incorporates all elements of need for patients results in better virological outcomes(33). In the present study key stakeholders welcomed the development of an HIV specific PROM to increase person-centredness, improve communication between HIV patients and professionals, empower patients to raise concerns that may otherwise be missed, and focus discussions on their priorities. This model of person-centred care incorporating an HIV specific PROM (see figure 2) would enable more individualised care, with equal emphasis on the six broad domains described above (physical, cognitive, psychological, social, welfare and information) alongside discussion of treatment and its effectiveness.

An HIV-specific PROM could also afford benefits at the service level, informing our understanding of prevalence of problems and concerns, allowing comparison within and across services, and development of the service to best fit those needs. At the commissioning level, data from the PROM could provide regular meaningful outcome data to both evaluate current spending and guide future funding in light of the changing picture of HIV. There are potential challenges to the implementation of an HIV specific PROM for routine practice, including the heterogeneity of the population and their needs.

Recent national, international and global strategies have recognised the need for person-centred care for long-term conditions(14), and the importance of integrating outcome measurement into HIV care(15). The current study provides evidence that the use of an HIV specific PROM within routine care, addressing the multi-dimensional needs and concerns of patients, is welcomed and necessary, and can contribute towards these global aims. In addition, evidence across health settings has found that the integration of PROMs can improve interactions between professionals and service users, thus improving satisfaction with care and treatment adherence(34, 35) – a key priority for HIV clinical services(9). Lastly, HIV services, with the regularity of review and appointments, are ideally suited to integration of a PROM to deliver and utilise outcome data: at an individual level to monitor changes in health status over time; and at a service and commissioning level to ensure that HIV services are best managed to meet the evolving needs of the population.

Limitations

Recruitment of patients was limited to three large urban clinics. It is possible that priority outcomes of HIV care may differ in other settings, however commissioners of services outside of these settings were also recruited. Although we were able to recruit black African, black Caribbean and black British participants, we were unable to recruit participants from other minority ethnic communities. Our sample was diverse in terms of age, sexual orientation, duration since diagnosis and other comorbidities, however we were unable

to recruit any trans participants. Our sample was strengthened by the inclusion of Dublin as a recruitment site, which offered access to a specific populations with unstable HIV and those with a history of, or concurrent, complex social situations and drug problems.

Conclusion

This study advances current understanding of person-centred care in HIV through identification of priority patient-centred outcomes. This will inform the development of a brief patient-centred PROM that reflects outcomes relevant to HIV patients to drive and evaluate routine care. This in turn will enable a shift from unidimensional or abstract conceptualisation and measurement of HRQoL, to a set of specific measurable outcomes consistent with global strategies. Adopting a personal-outcome approach, incorporating the principles of person-centredness alongside the routine use of PROMs in HIV, can afford benefits at individual, service and commissioning levels. Specifically, it may improve person-centredness through assessment and management of priority outcomes (which may also enhance engagement and retention in care); targeting services to the needs of the specific clinic population; and shaping HIV care and services to meet the changing needs of the HIV population.

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Competing Interests

All authors have no competing interests to declare.

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Table 1: Participant Characteristics (n=57)

HIV Patients (n=28)	
Gender	Male (n=14), Female (n=14)
Sexual orientation	Gay (n=10), heterosexual (n=17), bisexual (n=1)
Ethnicity	White British (n=12), White Irish (n=8), Black African, Black Caribbean, or Black British (n=8)
Relationship status	Single (n=14), in a relationship (n=14)
Age(years)	Range 23-81, median 45.5
Years since diagnosis	<5 years (n=7), 6-15 years (n=5), 16-20 years (n=9), over 20 years (n=7)
Comorbidities	None (n=3), 1-2 (n=12), 3 or more (n=13) (Hypertension, diabetes, history of stroke, heart failure, chronic obstructive pulmonary disease, atrial fibrillation, aortic aneurism, history of liver transplant, Hepatitis B, Hepatitis C, renal failure, osteopenia, osteoarthritis, osteoporosis, polyarthropathy, rheumatic arthritis, gout, anaemia, hyperparathyroidism, hyperlipidaemia, gastro-oesophageal reflux disease, coeliac disease, history of bowel cancer, anxiety, depression, personality disorder, bipolar disorder, and drug dependence (on methadone)).
Interview duration (minutes)	Range 13-111, median 53.5
HIV Professionals (n=21)	
Gender	Male (n=8), Female (n=13)
Profession	Doctors (n=7), nurses (n=7), Allied Health and Social Care Professionals (n=7) (welfare officer, psychologist, dietitian, physiotherapist, phlebotomist, and two pharmacists).
Interview duration	Range 13-84, median 55 minutes
HIV Commissioners (n=8)	
Gender	Male (n=3), Female (n=5)
Role / Employer	NHS (n=4), Local Authority (n=4)
Region	London (n=4), out of London (n=4)
Regional Prevalence	Very High (n=2), High-Very High (3), Low-Very High (3)
Interview duration	Range 38-69, median 57 minutes

Table 2: Priorities, problems and concerns for HIV patients

<p>Physical problems and concerns</p>	<p>Pain and discomfort (<i>Headache, neuropathy, pins and needles, joint pain</i>) GI Symptoms (<i>Bloating, constipation, diarrhoea, lack of appetite, nausea, vomiting, reflux, dry mouth</i>) Body and/or weight changes Fatigue Frailty and mobility Skin reactions Sweating Other (<i>warts or herpes, and eye problems from early HIV treatments</i>) Problems taking ART</p>
<p>Cognitive problems and concerns</p>	<p>Dizziness Memory problems Sleep Disturbance Difficulty concentrating</p>
<p>Psychological wellbeing</p>	<p>Negative experiences (<i>Anxiety, worry or fear, depression or low mood, stigma and discrimination, concerns around disclosure, shame, self-stigma, guilt, anger, unresolved issues relating to diagnosis or means of contracting HIV, body image, lack of confidence, low self-esteem</i>) Positive experiences (<i>self-esteem, self-worth, confidence, acceptance regarding diagnosis, happiness, meaningfulness, motivation, resilience and coping</i>)</p>
<p>Welfare, lifestyle and safety problems and concerns</p>	<p>Welfare (<i>financial, housing, immigration, safety at home and in relationships</i>) Self-care (<i>diet and lifestyle, recreational drug use, alcohol consumption, smoking</i>)</p>
<p>Social wellbeing - ability to live their life as they would like to</p>	<p>Relationship status (<i>sex, intimacy, initiating new relationships and concerns about having a child</i>) Social support (<i>Family, friends and community, support groups, organisations, faith groups</i>) Isolation or marginalisation Independence Impact of HIV on social wellbeing (<i>socialising, employment, education, travel</i>)</p>
<p>Information needs</p>	<p>Knowledge that HIV is under control Knowledge about the future, prognosis and aging with HIV Knowledge about HIV and treatments</p>

Table 3: Utility of an HIV specific PROM for use in routine care – Benefits and Challenges

BENEFITS	
For HIV patients	<ul style="list-style-type: none"> Enable person-centredness Help patients to raise concerns Enable patients to feel heard and valued Support patients to share sensitive information Empower patients Help patients develop resilience and self confidence Encourage referral to available services Reduce assumptions and establish a baseline for each individual Identify person centred outcomes beyond survival and adherence
Within appointments	<ul style="list-style-type: none"> Get to know new patients Identify 'missed' concerns Encourage referrals Inform treatment or medication decisions More efficient use of time Increase engagement and adherence See change over time Understand particular challenges of HIV
Service Level	<ul style="list-style-type: none"> Establish a baseline, level of need for the service/population To inform service design and delivery Tailor service to needs of population
Commissioning Level	<ul style="list-style-type: none"> To understand changing picture of HIV Allow regional comparison To improve care provision Move beyond experience measures Improve efficiency and reduce inappropriate service use Understanding patterns and risks Justify current spending
CHALLENGES	
Viability of PROM	<ul style="list-style-type: none"> Heterogeneity of HIV Population Heterogeneity of needs - depending on point of, and duration since, diagnosis Literacy Utility for those who struggle to engage with services HIV changing rapidly HIV very medicalised environment No cross condition comparison possible What to validate it against Aversion to questionnaires due to overuse within HIV
In Practice	<ul style="list-style-type: none"> Highlighting potential symptoms may cause anxiety Asking about areas that they cannot help with (e.g social housing) Added time burden and duplication of work Managing conflicting priorities (HIV patients and HIV professionals) Needs guidance and plan of how to respond to concerns
Data Related	<ul style="list-style-type: none"> Data needs to be used - not tick box exercise Quality of the data - honesty, truthfulness

Table 4: Quotes from Key Stakeholders: HIV patients, HIV professionals and HIV Commissioners

1	<p>"I think, living with HIV is a bit hard and tricky. Sometimes, you just feel down, you feel lethargic, tired. The aches and pains in your body, physical... Yes, so it's all physical, mental... Most of the people I talk to kind of feel the same. Especially with lethargy and tiredness, low mood...Yes, I know everyone gets stressed and depressed, but if you are on the medication, it's a different feeling that you're feeling in your body...Sometimes, it's the time. If you take them late, which means in the day time, you still have the hangover effect. That's the difficult bit. You just move, but you still have the kind of hangover...Sometimes, for me, I get foggy and forgetful, muddled. Like, I was going to college. I stopped going to college because I could hear the teacher talking, but I couldn't process what she was saying or what was going on. It was just useless for me to keep going to college." HIV patient:5</p>
2	<p>There are some mornings I sail through it blindly, pop the pills, fine, get on with the day. There are other days when it might be a good couple of hours of real sort of rolling stomach. You think, "Actually particularly with my digestion problems anyway it is best I don't go out for a while until this has settled down". HIV patient:6</p>
3	<p>"It just feels very separate. So I think, you know, if we talk about holistically treating a person, then I think yes, it has an impact on whether you feel like taking the medication or not. And all those things all kind of- I think your wellbeing, how you feel in yourself does impact on your physical health. So it does seem a little bit- you know, and I don't think that there's one person living with HIV who doesn't have those sorts of issues or hasn't at some point in their, you know, diagnosis had those sorts of issues. It seems like you're doing a bit of a disservice to not really highlight that stuff." HIV patient:10</p>
4	<p>"To be perfectly honest, I can't remember the last time I had a full night's undisturbed sleep. Since before this happened, I don't think I've had one, to be honest...It's important to me, anyway, the fact that it can affect your sleep patterns. When I wasn't working, when I was off sick for the first time, which was probably about two months in the beginning, it didn't matter so much. Because even if I wasn't sleeping, I could just lie on the sofa and watch TV all day. But now, I have to get up and come to work, and things like that. If it affects your sleep and affects your memory, then it does have an adverse effect on you." HIV patient:3</p>
5	<p>"Things like people often report as they are maybe slightly starting to age challenges with concentration, memory, forgetfulness, those sorts of things, just basic cognitive function. I know that people bounce around from health professional to health professional desperately hoping that someone is going to recognise they have got a problem and it never really being addressed. I think actually having something like that in a questionnaire saying, "We recognise this is a problem for people living with HIV, are you struggling with that? Maybe we can look at whether we need to signpost you to somebody." HIV professional:14</p>
6	<p>"In a lot of communities there is still stigma and discrimination. There are people who, because they have disclosed, their relationship with their partner breaks down. There are people who, because they have disclosed to their spouse or their community, they are shunned. Nobody wants to know them anymore. I think disclosure is an important area. Even though things have moved on, it is still an issue." HIV commissioner:8</p>
7	<p>"I think that a lot of my anxiety has stemmed from trying to deal with the HIV and feeling closed off and the stigma. It also brings low self-esteem sometimes, and things like that, and it does affect you. So I think that that is, because my mother also has anxiety and my brother, who also... So I don't think it's just me, I think it's something that comes with it, is this constant anxious state, because obviously you have this secret inside and it affects you. Probably more than you realise." HIV patient:11</p>
8	<p>"I think it's two things, really: One is that I'm pretty stoic, and I kind of think, "Well, it's not really affected me dramatically so far," so I carry on doing what I'm doing. Then, there's another side which is more... I don't know, really. I don't dwell on it, I don't dwell on it at all. But, I'm a bit, I suppose, furtive about it, in that because I've not disclosed to my family, if there's a programme on TV about HIV or AIDS, or a film or something, and then my son might make a rather snide comment or something, I think, "Well, that puts me in a really weird position." HIV patient:19</p>
9	<p>When they died, they didn't just die; they went really thin, went really frail, couldn't speak, couldn't eat, got sores all over them. They just went to skin and bone. We watched young people turning into old, frail women and men, and then dying of AIDS. ... To be quite honest, I'd like them to have more time to talk to me about what I'm feeling, because they don't have it. ...It's affected my life terrible. Terrible." HIV patient:25</p>
10	<p>"I think HIV can really impact on things like body esteem and disorders. But, we all have body esteem, and I think being positive can really just alter that generic way of how people look at their body and feel about their body, and generally feel that it is spoilt." HIV professional:11</p>
11	<p>"My medication works, you never know what's going to happen and I guess that means you- It sounds cheesy but you try to make the most of what you've got. I'm not saying I feel like I have a terminal illness. I don't, I have HIV, I don't have AIDS, but I got my shit together after my diagnosis because I started taking life a bit more seriously. I started realising what life is for and that- I'd say that is still a worry but it just means that I make much more of my time than I ever used to." HIV patient:4</p>
12	<p>"They all affect each other. I think the key thing is relations, relationships. You know, intimate and broader. Because once you can relate to people, and go out with people, the burden lifts a little. You're, kind of, not showing what you have, with HIV, you might not want to necessarily disclose to people, but you're beginning to open up, and you might find somebody who you'll be able to share, you know, what your diagnosis is. You never know, the person might be positive as well." HIV professional:16</p>
13	<p>"I know quite a lot of people that don't [go out]. Which is where things like [charity group], all come in very useful. Because as I say the peer groups, sometimes they can be awfully depressing. "God, they are going to be boring". But at least it is out the house and meeting people...I think there is probably, I suppose because we are at the peer</p>

	groups then there are going to be a higher proportion of people that do feel isolated, otherwise they might not be there... Yes, and also of course isolation can be part of depression. I think, whether people have sufficient social networks around them is very important. That is something that for me, I am trying to address at the moment, actually ways of finding a new social network, or starting to build one. If people don't have it, it does make things very, very difficult ...Yes, so if people don't have a sufficient social network, certainly I found it very, very difficult. Because you need a couple of good mates to bounce things off and that will actually come round and say, "I know you don't want to come out. But get dressed. We are going out. We are going to such and such, because you have not been out for days and we are going". I think you actually need that sometimes. If people don't have that, like in my case I might not go out the door. I think 10 days was the longest without going out the front door." HIV patient:6
14	"On a day-to-day basis, when other people talk about their health conditions and stuff, I feel like a bit of a fraud sometimes because I don't feel I can talk about mine. You get people talking about stuff in the office or socially and you feel a little dishonest about the fact that you aren't participating. I'm not saying I would hijack every health conversation by maybe playing a trump card or something like that, but it would just be good to be able to have that transparency with your friends and colleagues and I don't." HIV patient:4
15	"I think if you don't address it you completely neglect a key population of people who have a faith, who have a spirituality. I think in the context where we work we define spirituality as what adds meaning to your life... I think faith and spirituality are very different things personally. I think having that opportunity to put that down because it can be so meaningful to people...For some people it may be because of the stigma and discrimination they fear and experience it may have an impact on their ability to participate in faith and spiritual communities." HIV professional:14
16	"Before that I used to go out, but since that I've just stopped. Because it was a shock to me that I had HIV, because I won't- I know they say gay guys are promiscuous, but I wasn't at all. I only had two relationships and then when it happened, I thought obviously the last person I went out with has betrayed me and so forth. So I just stopped all contact with people. In a physical way. And that's it." HIV patient:1
17	"I can, kind of, be all right at the start, but then I always have this fear and anxiety around transmitting HIV, even though I'm, kind of, undetectable, and I know it's difficult. And that does, kind of, get in the way. And that did cause an issue with us and being intimate." HIV patient:14
18	"Housing, yes. a big issue. Housing, alcohol and drug misuse. I think when people don't have stable housing, it's very difficult for anything else to be managed, so that has to come into it." HIV professional:19
19	"So, I've always been very open about my use of alcohol and recreational drugs because, you know, I'm concerned about any, like, interactions with the medication. But I've never felt, like, judged in any way. And I know that sometimes there can be interactions between the drugs and the medication, so it's, you know, you've got to be a bit... I think I'd like to know about those things...And I've got my issues with alcohol, and I've got a drink problem, I think. And I get asked about it periodically here, and it helps me focus and think, "Well, I need to do something about it." And whether, you know, that using alcohol or drugs too much can lead to missing doses of your medication. So, for me personally, I think it's a good question to ask." HIV patient:14
20	"Then there is greater risk of quite a lot of things for people with HIV, you know, things like cataracts and all those kinds of things. With age, obviously there is more risk of those with age full stop, but the sort of additional risk with HIV. I suppose one of the things I am not clear about is if you are undetectable, does that mean that those risks are reduced, or do they remain the same? I am not sure about that. I suppose the fear that actually things will only get worse long-term. Obviously the HIV is not going to go away. Or probably they are not going to find a way to make it go away in my lifetime. I think it is the uncertainty, which I don't think anybody likes uncertainty, but it is one of those things that I hate." HIV patient:6
21	"I always think with HIV particularly, although with all illnesses, it's quite useful for the patient to have a reasonable understanding of their condition. I think we try to explain a bit about the natural course of HIV. I guess patients reporting a good knowledge of HIV would be useful. I think it's probably more reassuring than it is worrying, if you see what I mean, if you, as a patient, actually do know what it means and what it means to be on treatment and undetectable and healthy, how little they can expect, illness-wise, in that circumstance...It's probably very, very reassuring, compared to the preconception a lot of people come with when they're first diagnosed. So I guess that would be quite a good outcome measure: 'How well do you understand your condition? Are you able to see a future with this illness? Are you able to imagine your life in 20 or 30 years' time?' Which, obviously, those diagnosed in the '80s probably couldn't. Whereas, actually, now, they absolutely should do." HIV professional:6
22	"That is very confusing because over the years you would think there of a lot of stuff to ask and then when you get there, your apprehension takes over and your mind goes blank and there is just the anxiety to hear the results. When the results come out, you get a sigh of relief, luckily enough and then more or less you forget. You say, "Well, I'm out of here as fast as I can," but as time goes on, in my situation, when you develop other related problems, you're very conscious that you have to inform, you need to inform your consultant where you have other issues because it's not just now HIV." HIV patient:8
23	"The consultant should be saying to you, other than okay, CD4 and all that, they say, "Okay, how is the mobility? Are you doing something about that? Are you able to exercise? Are you able to walk? Are you able to work?" The next thing is sleep, "Are you sleeping?" These questions aren't asked; so then really it's down to you. ...I said at the very start of the conversation, you really forget, after you hear your results your anxiety just sort of goes zoom, you know, and then exhaustion takes over and you don't want to face anymore. I think if it's imposed upon you, like on a questionnaire saying, "Right well we've dealt with that. Okay, let's have a little look at what else is going on. How is your mobility? How is your sleeping pattern? How is your diet? Do you need to see the dietician? Do you need to see PE?" I've had to do all of those things on my own. I have had to ask different departments." HIV patient:8

24	<p>“But, from my perspective, it is, are their blood results all okay? And I normally have looked at those before I get them in the room, so I don’t, you know, I don’t get a surprise when, you know...Are they managing to take their medication, you know, are they getting side effects? Are they managing the physical aspects of actually having enough medication and swallowing it, and taking it at the right time? Does it interact with anything else that they’re on?” HIV professional:5</p>
25	<p>“I’d expect adherence to be discussed in their clinic appointment. I’d expect them to be updated on their latest blood results. I’d expect partner notification or their relationship status, any changes in their relationship status and ongoing discussion around partners and maybe partner notification as well, because that can’t just stop, people have relationships that change.” HIV commissioner: 2</p>
26	<p>“Well, I think it could have a, potentially, a very positive effect, because it, sort of, gives them, it just tips the balance of power a little bit further, you know, into their favour. And it is, after all, about them. It’s not about me. So that has to be a good thing, generally.” HIV professional:5</p>
27	<p>“Patients will volunteer a cancer diagnosis, but won’t be able to tell their family about a HIV diagnosis. That must be very scary. You must feel very isolated, to constantly feel like there is a part of your life that you are hiding from potentially your nearest and dearest. Having outcome measures relative to people living with HIV will be slightly different to someone with diabetes or... A lot of the time when people come to clinic it’s about being in a safe place and feeling like they can just talk about their condition openly and honestly. To have an outcome measure that was specific to people living with HIV, would make us better at seeing what they want as well. Again, you can do your best, but no one’s perfect.” HIV professional:13</p>
28	<p>“We have really good biological outcomes in the cohort of HIV positive patients in the [country], and particularly in [city], so we are really proud of that. But we could be missing some aspect of need that is not, we are not aware of, is not collected. So in that respect it could provide an insight into an area that we haven’t really identified as key.” HIV commissioner:3</p>
29	<p>“I think one of the things that we have to be able to justify is how we're spending money and how we're investing the money. I think if we can demonstrate that we're investing money that's being well-utilised and well-received and is having the knock-on effect that we want it to have, so obviously we've got an aim of improving healthcare for people and if we can do that and demonstrate that we're doing that, that support, continued investment or enhanced investment if there's an issue, so I think if we had some tangible outcome measures that would help to feed into that mix. If we're putting a business case through for any policy or something like that then it helps to support that.” HIV commissioner:4</p>
30	<p>“The single tool needs to be voiced in a way that it is relevant for people at different stages of their disease pathway. So it needs to be sensitive enough and... It is complex. It is not “flexible”, the word I am trying to find, but it needs to, it needs to relate to people at different stages of the disease, it needs to be important for them at whatever stage of the disease they are.” HIV commissioner:3</p>
31	<p>“Well, as far as I'm aware, the HIV seems not to be having any effect on me at the moment, so I'm not unduly concerned about it...Well, they ask me if there's been any significant change to my overall health, whether there are any psychological issues, or I'm finding any problems with it. But as I said, I'm not really experiencing, as far as I'm aware, any particular problems with the treatment. They certainly help with this stuff at the clinic...I don't think that the HIV issue is the main issue with my health at the moment. That's my own opinion” HIV patient:3</p>
32	<p>“It depends on the person. Some people are quite open to it and I guess it really depends on their own beliefs about HIV and about treatment and the sorts of things that they’re worried about. Most people will talk about it. The harder ones are the ones that won’t engage. If someone is in your room then generally speaking they’re engaging but it’s the ones that don’t engage that are the hard ones...” HIV professional:1</p>
33	<p>“I think you have to... you are going to ask about memory and function and stuff like that. But if you are someone that is positive sitting down with one of these questionnaires and you don’t have problems, having a question like that almost reinforces that you are more likely to have memory concerns and potentially dementias if you have HIV. That has been a powerful discourse over the years in HIV. That is all. But you can’t help but keep producing that discourse when you are doing this kind of work really.” HIV professional:11</p>
34	<p>HIV professional 7: “I suppose it might make the consultation longer, because it might bring up things that haven’t been discussed before, but hopefully that will be worth investing that time. If there are things that are out of our hands, that would be frustrating. I wouldn’t want to give false hope that you can tell us these things and we can cure or whatever.” Interviewer: “Yes, opening a can of worms?” HIV professional 7: “Yes. Yes, but it’s better to open it, have a look inside and check it and see what you can do.” HIV professional:7</p>

Figure 1: Model of current standard HIV care

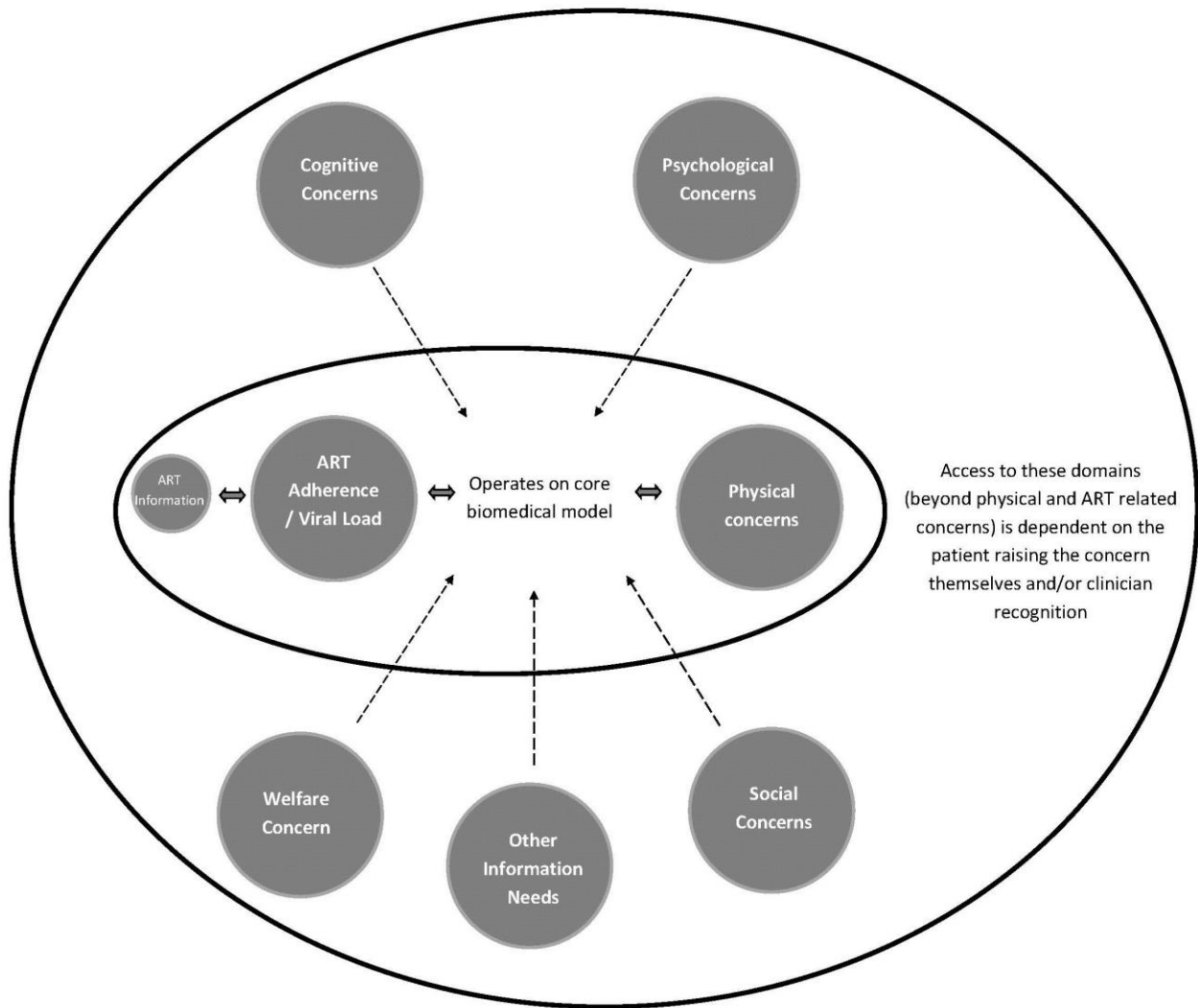


Figure 2: Model of person-centred care incorporating an HIV specific PROM

