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# "Moving Fourth": Introduction of a practical toolkit for shared decision-making to facilitate healthy living beyond HIV viral suppression

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## Abstract

***An extension of the UNAIDS 90-90-90 target proposes >90% of people living with HIV (PLHIV) should have good health-related quality of life (HrQoL); however, limited guidance exists. The "Health Goals for Me" framework, an individualized approach to HIV care, provides a framework to assess HrQoL. We analyzed several patient-reported outcome measures (PROMs) to develop a practical toolkit to facilitate shared physician-patient decision-making. HrQoL subdomains, actionable in the clinical setting and measurable as PROMs, were selected. PROMs were collated through systematic literature searches, scored by the authors on usability, validation, and availability, after which practical recommendations were made. Nine subdomains were selected across physical, psychological, social, and environmental domains; 46 validated PROMs were identified. After pre-screening, from 39 evaluated PROMs, we recommended PROMs in the following subdomains: fatigue/energy loss, frailty/resilience, sleep disturbance, substance use, anxiety/depression, cognition, sexual function and desire, and stigma. Using this toolkit, healthcare professionals and PLHIV can collaborate and mutually agree on individual care objectives. Following the "Health Goals for Me" framework, appropriate care interventions can be implemented and reviewed in a continuous cycle. We discussed how eHealth interventions, which will have increasing importance in the post-COVID era, can facilitate improved HrQoL for PLHIV by utilizing toolkits such as the one described here. Implementation of this practical framework and the PROMs toolkit could provide a useful approach to assessing HrQoL in PLHIV and could enhance the physician's ability to gain valuable insights into the patient's daily life across a broad range of HrQoL issues (AIDS Rev. (ahead of print))***

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## Key words

***HIV infection. Patient-reported outcome measure. Healthy living with HIV. Health-related quality of life.***

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# Introduction

As HIV has evolved to a manageable chronic condition, treatment strategies for HIV have been adapted[1]. Owing to the effectiveness and availability of antiretroviral treatment, mortality rates are now lower and very near to that of the normal population[2], but despite these encouraging improvements, long-term health of people living with HIV (PLHIV) remains poorer than the general population[2]. Specifically, PLHIV experience more physical and mental health issues and social discrimination[3,4].

Current treatment guidelines, rightly, still place emphasis on achieving access to antiretroviral treatment for all, viral suppression, management of comorbidities, and drug-drug interactions[5,6]. However, limited guidance is also placed on aspects such as evaluating and improving health-related quality of life (HrQoL)[5,6]. At present, data on the impact of ART or comorbidities on quality of life (QoL) in PLHIV are limited. A 2019 meta-analysis reported a small positive impact of ART (pooled odds ratio [OR] 1.04, 95% confidence interval [CI] 0.42, 1.66) on QoL[7]. In the same analysis, there was a negative impact of a CD4 count < 200 cells/mm$^3$ on patients' QoL (pooled OR 0.29, CI 0.22, 0.35). This paper also reported that the comorbidities hepatitis B or C infection or tuberculosis had no effect on patients' QoL (pooled OR 0.95, CI 0.32, 1.58). A study in Sweden found that the presence of comorbidities (hepatitis C, diabetes, high blood pressure, cancer, substance abuse, and mental illness) was one of the clinical components significantly associated with lower QoL, along with HIV-related physical symptoms and side effects of ART[8]. Patient perspectives, including overall function and wellbeing, of the long-acting (LA) regimen of cabotegravir-rilpivirine, have also been analyzed[9] and have indicated a high degree of satisfaction, acceptance, tolerability, and preference for the LA regimen over prior oral therapy. This finding is in line with a recent observation by Contreras-Macias et al.[10] that high levels of medication regimen complexity index correlate with worse QoL in PLHIV. The authors concluded that the care plan for PLHIV should be focused on optimizing overall patient care, including pharmacotherapeutic complexity and QoL, and not limited to viral load goal achievement alone.

A key goal for improving HIV management is underpinned by the "fourth 90" target[11,12] (extending the original UNAIDS 90-90-90 target[13]), which proposed that at least 90% of all PLHIV should have good HrQoL. The concept of "Health Goals for Me," an individualized approach to HIV management, supports the "fourth 90" target (Fig. 1). This concept has recently been used as the basis for a suggested framework to assess HrQoL in PLHIV, centered on effective collaboration between the healthcare professional (HCP) and the patient[14]. For improved long-term management of PLHIV, it has been suggested that this framework should become an intrinsic part of HIV care and that the "Health Goals for Me" concept should be used as a tool to facilitate healthy living for PLHIV beyond viral suppression[14]. However, for this to be implemented in a real-world, clinical setting, good HrQoL not only needs to be defined but also requires appropriate means to measure it. Moreover, since virtualized treatment approaches during and after the COVID-19 pandemic are gaining importance globally in all areas of healthcare[15], physicians involved in HIV management and PLHIV will require the appropriate tools to enable them to have meaningful virtual consultations.

Determination of HrQoL raises a number of issues. First, defining HrQoL is complex as it is not well defined and most definitions of HRQoL do not sufficiently differentiate the term from health or QoL[16]. Second, it is challenging to operationalize and measure HrQoL as it is a multifaceted concept; the need to adapt within different contexts can sometimes lead to a combination of generic and disease-specific measures being employed[17].

Further, many HCPs do not know or use HrQoL measures in clinical practice due to barriers such as time constraints and lack of clarity on methodological issues of QoL[18]. In HIV, concerns and priorities of the patient might differ from those reported by their physician[19]. One study highlighted that clear differences may exist between the ranking of factors influencing decision-making in HIV care for patients versus HCPs, with PLHIV indicating depression as the most important factor, while HCPs named nausea and diarrhea[19]. As such, collaborations between patients and HCPs should be strengthened and PLHIV should be encouraged to be engaged in their treatment plans, although an appropriate balance must be struck between increasing patient autonomy and the need for management to also take account of the wider social benefit of ensuring that no new infections occur.

Patient engagement has demonstrated hugely positive effects on treatment adherence and clinical outcomes[20] and expert patients have added value to ART services in HIV clinics, further enhancing a positive PLHIV-HCP partnership[21]. First-hand assessment by a

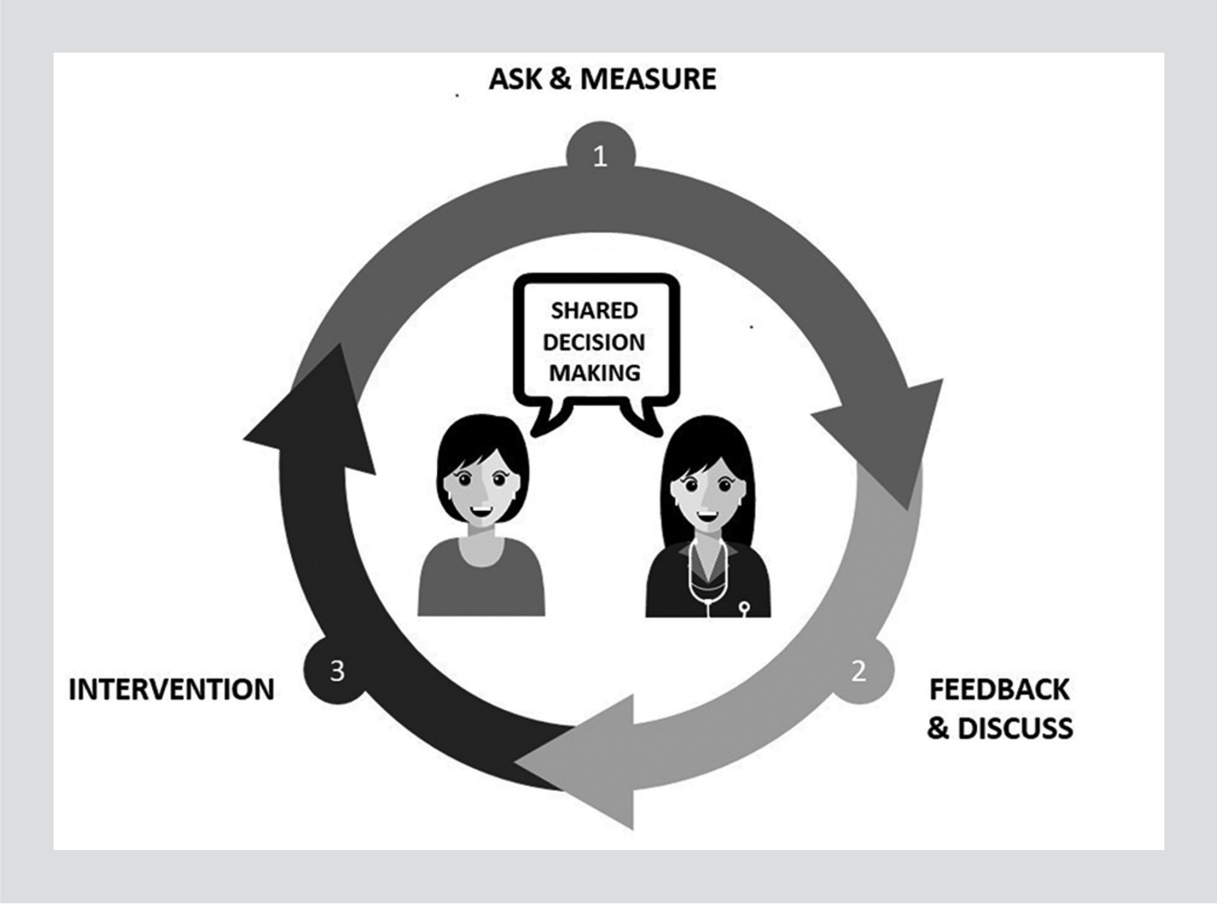


**Figure 1**. *The 'Health Goals for Me' concept forms a continuous cycle involving the patient and the physician at all stages of the process.*

patient can offer an invaluable source of information to aid the relationship with HCPs; however, concerns regarding the appropriate "tool" to implement this present a challenge[22].

Use of questionnaires or patient-reported outcome measures (PROMs) in HIV outpatient care holds promise as a tool to enhance the quality of care[23]. To date, PROMs have mostly been used as a tool in clinical trials to obtain more patient data. However, both patients and providers have indicated that PROMs are potentially useful clinical tools to improve detection of sensitive issues such as substance use and mental health in PLHIV[24].

The aim of this analysis was therefore to provide a practical ("Ask and Measure") toolkit that could be used to facilitate shared decision-making (both face-to-face and virtually) between physicians and PLHIV as an aid to promote individualized, optimal care to achieve healthy living. To reach this goal, we examined the HrQoL domains which HCPs should discuss with their patients and gave recommendations on appropriate PROMs to provide a guided framework for HCPs and patients to facilitate shared decision-making.

## Methods

We, the seven authors, constitute HIV-physicians from across Europe as well as a patient advocacy representative. As a group (using a Delphi-like process with a majority decision where required), we followed a multi-step process to ultimately select a number of PROMs that could be used in the real-life clinical setting – a toolkit that can assist with the "Ask and Measure" stage of the "Health Goals for Me" framework.

### *General HrQoL domain identification*

Initially, we identified the HrQoL performance domains that have the potential to effectively be used in the real-life clinical management of PLHIV. We adopted the domains recommended within the World Health Organization QoL Instrument (WHOQOL-BREF)[25,26] as it assesses four major domains: physical health, psychological health, social relationships, and environmental aspects (Supplementary Table 1) and is applicable cross-culturally[26].

### *Selection of subdomains for suitability as PROMs*

Using the WHOQoL-BREF's four domains as a guide, we, the seven authors, collectively (as a group with a majority decision) identified the facets or subdomains which, based on our clinical experience, expertise, and individual views, would be most beneficial to assess in the real-life clinical management of PLHIV (Supplementary Table 1). From this list, we further selected the subdomains that met the requirements to be *actionable* in a clinical setting and, based on our clinical experience/understanding, known to contribute significantly to a patient's QoL. At this stage, any subdomains that were not considered to be quantifiable by patient input were eliminated.

### *Literature search to identify PROMs within each selected subdomain*

For each of the subdomains selected, PROMs were identified using systematic searches of: published literature in the last decade (full publications using both PubMed and Europe PMC from January 1, 2010, to May 21, 2020); recent HIV congress posters and abstracts (January 1, 2017, to December 31, 2019; detailed in Supplementary Table 2). Each systematic search used specified keywords and criteria within each subdomain, suggested and agreed upon during a moderated group discussion of all authors. The full search strategies and number of hits are detailed in supplementary table 3. Next, titles and abstracts of the hits obtained during the searches were screened; duplicates, non-English, and publications not relevant to the subdomain in question or not containing PROMs were excluded from the study. Those publications that passed the screening stage were read in full to identify PROMs to be scored during the next stage. In addition, general internet searches using the title of the specific PROM and "validation" were performed to confirm whether the PROMs had been validated in a patient population (preferably an HIV population) in the previous 20 years. Validation was confirmed if a published article was found to have validated the specific PROM within the last 20 years. All authors agreed that, given author expertise, if any other PROMs were put forward to be evaluated, they could also be included within the analysis to ensure a more expansive search.

### *Scoring of PROMs*

Following the literature searches, we scored all identified PROMs (n = 46) using criteria in three categories as being critical for practical implementation in the real-life clinical setting; these three categories – ease of use, validation, and availability – were firstly unanimously agreed by all seven authors. Next, the authors collectively devised a scoring system (Supplementary Table 4) based on these three key criteria.

Ease of use was chosen as it is recognized that time constraints in the clinic are a universal concern, and this applies in both face-to-face and virtual consultations. Hence, for the ease of use scoring, this was based on the number of questions or time taken to fully complete the questionnaire. To save time for HCPs, all authors agreed to penalize questionnaires where specialist knowledge was required to administer it. In addition, the authors also acknowledged that patients may experience "questionnaire fatigue," especially when several domains are investigated.

Validation was chosen because ideally PROMs should be validated and proven to be effective. PROMs that are validated in HIV and/or were specifically developed for HIV were preferred; otherwise, PROMs validated in other disease areas and/or chronic conditions were also considered. For validation scoring, this was related to widespread use of PROMs in an HIV-positive population.

Availability was chosen because ideally the PROMs must be freely available online and translated into major European languages (including English, French, German, Italian, and Spanish). The scoring was based on how easily accessible the questionnaire is for physicians (available online, multi-language) and whether the PROM is free or not.

### *Evaluation of PROMs*

All scored PROMs, in each identified subdomain, were evaluated collectively by all authors. An initial pre-screening was performed to eliminate some of the lower-scoring PROMs in subdomains where several PROMs had been identified: in subdomains where $\geq 5$ PROMs had been identified, PROMs scoring $\geq 6$ were included for evaluation. In subdomains where $< 5$ PROMs had been identified, all PROMs were included for evaluation.

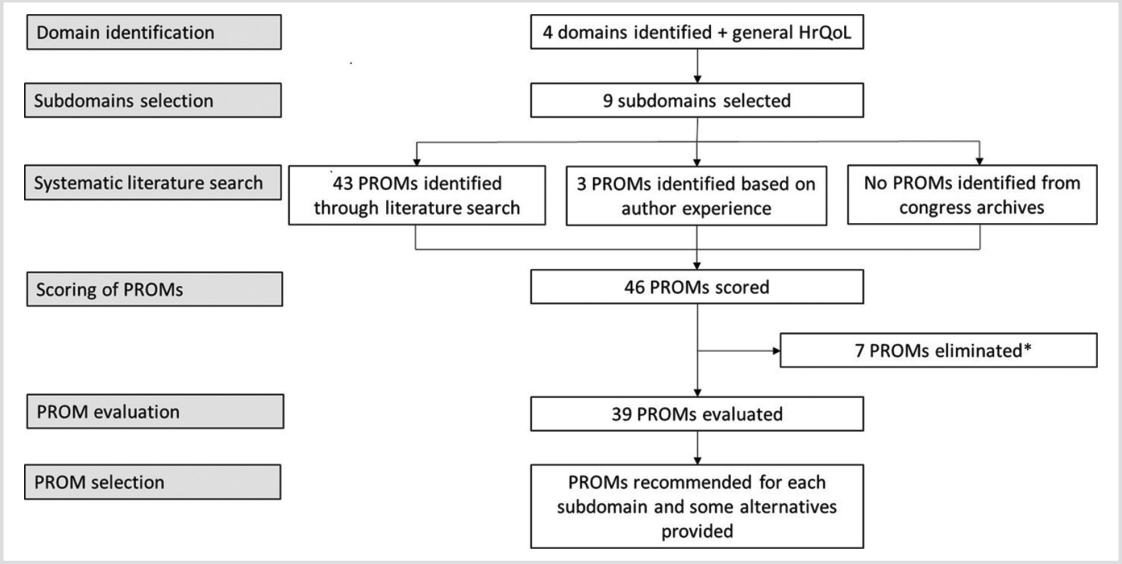


**Figure 2**. *Summary of the 6-step process used to select PROMs for inclusion in a practical toolkit to facilitate shared decision-making. *based on lower scoring in the subdomains where multiple PROMs were identified.*

**Table 1. Total number of PROMs identified within each domain and subdomain**

| Domain | Subdomain | No. of PROMs that met criteria | Total per domain |
|---|---|---|---|
| Physical health | Fatigue and energy loss | 6 | 21 |
| | Frailty and resilience | 5 | |
| | Sleep disturbance | 4 | |
| | Substance use (alcohol, drug abuse, smoking) | 6* | |
| Psychological health | Anxiety and depression | 7 | 12 |
| | Cognition | 5 | |
| Social | Sexual function | 4 | 8 |
| | Sexual desire | 4 | |
| Environmental | Stigma | 5** | 5 |
| Total | | | 46 |

For detail around each of the PROMs, Supplementary Table 5.
*Including two additional PROMs that were added to the literature search results based on author experience.
**Including 1 additional PROM that was added to the literature search results based on author experience.

## *Selection of primary recommendation and alternative PROMs*

Based on the above evaluations, specific practical consolidated recommendations to help HCPs and patients in clinical practice were then made collectively by the authors, with universal agreement. For each subdomain, a primary recommendation was made, with an alternative PROM selected in cases where the primary recommendation would not be considered suitable.

## Results

Figure 2 summarizes the numbers of PROMs across the 6-step process culminating in the selection of PROMs for inclusion in the practical toolkit.

### *General HrQoL domain identification*

Physical health, psychological health, social relationships, and environmental aspects were considered to be the critical domains for assessing overall health in PLHIV in the real-life clinical setting.

### *Selection of subdomains for suitability as PROMs*

Within the above domains, the subdomains considered the most relevant are shown in table 1. There were differences in the number of subdomains considered to be relevant within each domain, for example, for physical health, four subdomains were selected, but for environmental factors, only one (stigma) was selected (Table 1). Subdomains that were not considered suitable for a PROM are detailed in supplementary table 1.

### *Literature search to identify PROMs within each selected subdomain*

Based on the pre-specified literature search criteria, a total of 43 PROMs were identified; table 1 illustrates the total number of PROMs that met the audit criteria for each subdomain. In addition, three PROMs were added to the literature search based on author experience. All individual PROMs identified are listed in supplementary table 5. All PROM questionnaires that were included in the scoring process were found to be validated. The additional searches of conference poster archives revealed no additional PROMs (Fig. 2).

### *Scoring of PROMs*

The results of the scoring of the 46 individual PROMs are shown in supplementary table 5.

### *Evaluation of PROMs*

#### Inclusions

Overall initial pre-screening eliminated seven of the lower scoring PROMs in the subdomains where multiple PROMs had been identified (two in physical health; four in psychological health; one social, and none in environmental) (supplementary table 5). In addition, in the fatigue subdomain, although the HRFS-56 PROM was eliminated during pre-screening, it was included in the evaluation, based on author expertise to ensure a more expansive analysis.

#### Exclusions

Two PROMs were excluded from the collective agreement discussions, as shown in supplementary table 5. In the sexual desire subdomain, Sexual Desire Inventory (SDI) was omitted because it was a longer version of the SDI-2, which was already included. Second, in the cognition subdomain, given that all other PROMs in this subdomain were HIV specific, the non-HIV-specific PRECIS was omitted.

### *Recommended and alternative PROMs selected*

Recommended and alternative PROMs for health subdomains (with literature sources, including validation) are summarized in supplementary table 6.

#### General health

For assessment of general QoL, the preferred PROM was the World Health Organization QoL Instrument WHOQOL-HIV BREF, a shorter form of the WHOQOL-HIV adapted for use in the HIV population[27], chosen because it is comprehensive and recognized as having more relevance to PLHIV while being extensively used and cross-culturally valid in HIV (Supplementary Table 6).

#### Physical health

The recommended PROM around fatigue and energy loss was the well-established Fatigue Severity Scale (FSS) (Supplementary Table 6). Although no specific PROM exists for frailty and resilience, the Pictorial Fit-Frail Scale (PFFS) or FRAIL scale was recommended (Supplementary Table 6). Early identification of frailty and resilience could allow intervention and delay disability[28]; patients with a biological age >40 years, have comorbidities or are post-menopausal women should be screened. The Insomnia Severity Index (ISI) was primarily recommended for sleep disturbance (Supplementary Table 6). For substance use, both the Two-Item Conjoint Screen (TICS) for Alcohol and Other

Drug Problems along with the 5A rule for smoking cessation (Ask, Advise, Assess, Assist, and Arrange) were recommended due to their simplicity, comprehensiveness, and patient-centricity (Supplementary Table 6).

### Psychological health

Within the psychological health domain, the preferred PROM for measuring anxiety and depression was the Hospital Anxiety and Depression Scale (HADS); it is widely used, validated in hospital and HIV, and approved by NICE (Supplementary Table 6). Furthermore, it is short and convenient (14 items) and focuses on real anxiety and depression rather than physical complaints. The preferred PROM for cognition was identified as the three screening questions from EACS guidelines[5], which has the benefit of being very simple (Supplementary Table 6).

### Social relationships

Since there is no appropriate social relationship domain, the social relationship subdomain does not measure non-sexual relationships; accordingly, these are not gauged within the framework. The recommended PROM for use in sexual function assessment is gender-dependent; for men, it is the International Index of Erectile Function (IIEF-5) (Supplementary Table 6). This is recommended in the EACS guidelines[5] and well used in clinical practice. For women, the recommended PROM is the Female Sexual Function Index (FSFI) (Supplementary Table 6). Although assessment of a patient's sexual desire is a new area in HIV, we believe this is an important aspect for physicians to capture. HIV-specific questionnaires do not yet exist in this domain and therefore awareness of the "Undetectable equals Untransmittable, (U = U)" paradigm and its connection to stigma cannot be gauged – this could be important to understand in the future.

### Environmental aspects

Stigma is a challenging area for PLHIV where little progress has been made in effectively addressing the multi-faceted aspects related to both external (e.g., social discrimination) and internal (self-perceived) stigma[29]. The recommended PROM to use for this assessment is the Berger HIV Stigma Scale (HSS), which is HIV-specific, validated, and widely used (Supplementary Table 6). Although this PROM does not address the reduction in stigma, this PROM fulfilled the other criteria and it was selected as the most appropriate.

## Discussion

In our experience, in many cases, suboptimal well-being is regarded as "normal" for PLHIV and some patients assume that the HIV virus being undetectable is the maximum that the physician can do for him/her. One factor in this is that HCPs often do not know what questions to ask to get a full picture of an individual's health status while, at the same time, the patient is not always aware when an issue is actually related to HIV or antiretroviral therapy. Therefore, a framework that will allow effective collaboration between the HCP and a patient to assess HrQoL in PLHIV would benefit both patients and HCPs[14]. We believe that our recommended toolkit of PROMs provides HCPs and PLHIV with an effective approach for achieving the "Ask and Measure" stage of the "Health Goals for Me" framework. Implementation of this framework will enhance the physician's ability to gain meaningful insights into the patient's holistic health status across a broad range of HrQoL issues.

To build our recommendations, we used a systematic approach of identifying the PROMs that have proven to be beneficial in the real-life clinical setting. The value of, and rationale for, using PROMs has been recognized despite there being little to no consensus as to which PROMs are best to use in various scenarios[22,30]. Indeed, most of the included PROMs will be familiar to many clinicians as they are freely available as resources (Supplementary Table 6). Although patients may not have such familiarity with these types of measures, the toolkit can readily be adapted to the specific needs of each individual and should be presented as a method of empowering the patient.

Over 100 HIV-specific PROMs have been identified[22] and numerous QoL measures have been used in clinical studies and practice[25]; therefore, we narrowed our HrQoL selection to those domains recommended within the recent WHOQOL-BREF[26]. Several factors were critical in our selection of the PROMs. First, the ideal PROM should already be widely used in HIV clinical practice and be designed to accurately assess the impact of factors on HrQoL. It should be patient-centric, quick, and easy for the patient to complete and freely available in multiple languages. Both HCPs and patients may have busy schedules and thus time restriction is a real-world barrier to the implementation of any new aides such as PROMs[18].

We recognize that there are several barriers to implementation across a variety of levels, including HCP knowledge and experience of the importance of HrQoL in clinical practice[18]. Physicians may be faced with the

need to discuss specific topics of health such as sexual or psychological issues where they may lack knowledge. In our opinion, as HrQoL is unfamiliar territory compared with other objective measures, HCPs may feel decision-making is more difficult when QoL factors are considered. It could also be perceived that the consultation may become too "mechanistic" and replace a trusting patient-HCP relationship[31]. This perception is further compounded by the use of eHealth, which then raises additional concerns around data privacy and security[32]. Patient concerns may also exist over disclosing confidential information to HCPs[33]. Furthermore, unless patients understand the rationale for completing PROMs and see the associated benefits, they are unlikely to have continued participation in such an initiative. Should the potential benefits in the use of PROMs not be discussed during the consultation, resistance to filling in further questionnaires is likely to emerge. We believe it is important for HCPs and PLHIV to see PROMs as diagnostic instruments (like x-rays or blood tests) and that it is worth investing time in completing them. Other patient challenges to implementation may include: health or technological literacy, not feeling empowered to engage in their healthcare, time (due to length of surveys), too structured (allowing no space to voice individualized concerns), concerns about data protection[31], or cultural and language barriers[31,34]. Healthcare systems may also provide barriers to the adoption of the new toolkit, for example, medical administrative support will be required to manage the workload and collect and process information[31]. Finally, a lack of connectivity with Electronic Health Records may also be a potential issue and sharing patient-generated data can impose privacy burdens on hospitals[35].

We discussed the potential solutions to the above barriers with the purpose of aiding the implementation of the "Ask and Measure" process. To overcome the issue of time constraints, webcam consultations or nurses collecting information to share with other HCPs were identified as potential solutions. If patients are able to self-assess through PROMs, HCPs can divert resources for specific groups of patients that need them more, as well as making the clinical visits more efficient by investing the time in those areas that the patient needs most. In terms of perceived resistance from HCPs to HrQoL measurement, it should be explained that PROMs are there to facilitate the conversation rather than replace it. In many cases, the act of simply listening may be sufficient. Both HCPs and patients should be educated by careful framing and clear messaging to encourage engagement and uptake. It is very important to raise awareness of the benefits of completing PROMs and ultimately improving the patient's care and QoL. More practical issues such as dealing with electronic healthcare systems require technical solutions, for example, allowing patients to link their device with their hospital electronic health records. This would allow patients to enter data directly into the electronic health record so that HCPs and patients can see how their scores change over time. The potential use of eHealth to facilitate the use of PROMs is endorsed by the increasing use of digital medicine as well as personal wearable technologies. A review of the use of eHealth in the HIV treatment and care cascade found encouraging evidence of the benefits and concluded that eHealth interventions have an important role to play[36]. Innovative solutions such as chatbots could also be utilized in the future to enhance the patient experience. Moreover, the use of eHealth facilitates remote patient care – PROMs may be downloaded and completed by the patients themselves and returned to the HCP before, or instead of, a clinic consultation. In the post-COVID-19 era, where we may see a shift toward virtual healthcare and "telehealth," once again, HIV clinicians may have the opportunity to lead the way in patient care and change clinical practice. The toolkit developed in this work and the results presented here could be a valuable resource for HCPs involved in HIV care and PLHIV during this COVID-19 pandemic.

For practical implementation of the toolkit in the real-life clinical setting, both patients and HCPs will need to be receptive to utilizing tools to aid their discussion during consultations. We encourage all HCPs to recognize the benefits of this "Ask and Measure" stage of the framework. "Health Goals for Me" must be viewed as an integral part of HIV care to achieve better QoL and healthy living for PLHIV. To aid implementation, we suggest the following approach for embedding this toolkit in the process of HIV care as part of "Health Goals for Me." First, it is critical to have a comprehensive assessment of patient's overall HrQoL at the initial consultation. By doing so, this will highlight areas of concern. By then jointly agreeing which subdomains of HrQoL are the priorities, the areas that are suitable for patients to measure using PROMs are identified as part of the "Ask and Measure" process (Fig. 1). After the patient completes the relevant PROMs, the next stage of the "Health Goals for Me" process, "Feedback and Discussion," can take place, either in the clinic setting or as part of a virtual consultation. This allows the HCP and patient to enable priority setting and possible

interventions. The continuous cycle is then completed and the outcomes of the interventions can be reviewed at the next consultation. The "Feedback and Discussion" and "Intervention" stages of "Health Goals for Me" may change in each clinical setting; however, these stages lie outside the scope of this manuscript.

One weakness of our findings is that although a systematic approach was taken during PROM identification, the recommended selections are largely based on expert views. The judgments made were transparent and followed a predefined structure and voting system. Moreover, the HrQoL domains examined were primarily based on those presented in the WHOQOL-BREF, which ensured that all the domains included provide clinical relevance to worldwide management of HIV. A limitation of this study is that, although this was performed using a Delphi-like methodology, the findings are based on expert opinion and as such, reflect the experiences of the individuals. To address any bias around PROM selection, we ensured that the experts involved in the process encompassed a broad range of European physicians with multidisciplinary management being well-positioned to reflect real-life clinical practice; moreover, the expert group included a patient advocacy representative.

## Conclusion

We have presented a practical toolkit to help HCPs and patients implement the "Ask and Measure" part of the "Health Goals for Me" framework that can change clinical practice in the real-world setting, both virtually and within the clinic. Through this initiative, HCPs and PLHIV can collaborate and mutually agree on individual objectives for care based on a continuous cycle of sharing information which helps move toward the goal of long-term healthy living with HIV.

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## Authors' contributions

All authors as a group (led by Giovanni Guaraldi, Adrian Curran, and Joop Arends) identified relevant HrQoL domains, selected subdomains, decided on suitable PROMs for evaluation across the selected health subdomains, and made specific recommendations.

## Conflicts of interest

Giovanni Guaraldi reports personal fees from Jansen, grants and personal fees from Merck, grants and personal fees from Gilead, grants and personal fees from VIIV; Joop Arends reports advisory board fees from Gilead, Janssen, Viiv, and MSD, outside the submitted work; Thomas Buhk reports advisory board fees from Janssen, Viiv, and Gilead; Mario Cascio reports personal fees from Janssen; Adrian Curran reports advisory board fees from Gilead, Janssen, Viiv, and MSD, outside the submitted work; Eugenio Teofilo reports advisory board fees from Janssen; Guido van den Berk reports advisory board fees from Janssen.

## Data statement

The data sharing policy of Janssen Pharmaceutical Companies of Johnson and Johnson is available at https://www.janssen.com/clinical-trials/transparency. As noted on this site, requests for access to the study data can be submitted through Yale Open Data Access (YODA) Project site at http://yoda.yale.edu.

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PERMANYER

**AIDS** Rev. (ahead of print)

# "Moving Fourth": Introduction of a practical toolkit for shared decision-making to facilitate healthy living beyond HIV viral suppression

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**Supplementary Table 1. Domains and subdomains examined in the analysis. Subdomains that were selected for PROM suitability based on their ability to contribute significantly to a patient's QoL are shown in bold**

| Domains | Subdomains |
|---|---|
| Physical health | **Fatigue and energy loss** |
| | **Frailty and resilience** |
| | **Sleep disturbance** |
| | **Substance use** |
| | Restricted mobility |
| | Impact of disease on daily living |
| | Presence of pain or discomfort |
| | Perceived working capacity |
| Psychological health | **Anxiety and depression** |
| | **Cognition** |
| | Body image |
| | Self-esteem |
| | Personal beliefs |
| | Positive self-concept |
| | Spirituality |
| | Suicidal tendencies |
| Social relationships | **Sexual function** |
| | **Sexual desire** |
| | Personal relationships |
| | Social contacts and support |
| Environmental | **Stigma** |
| | Freedom |
| | Quality of home environment |
| | Physical safety and security |
| | Financial status |
| | Recreational activity |
| | Health and social care quality and accessibility |

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**Supplementary Table 2. Literature search criteria for PROMs audit**

| Category | Full publications | Abstracts and posters |
|---|---|---|
| Search tool | PubMed and Europe PWC | Manual searches of HIV conference poster archives (EACS, CROI IDWeek, IAS/AIDS)* |
| Language | English | English |
| Time frame | January 1, 2010-December 31, 2020 | January 1, 2017-December 31, 2019 |
| Additional PROMs inclusion criteria | Freely available<br>Short, focused and hence less time consuming<br>Preferably HIV specific (if this was not possible, valuable [in our opinion] non-HIV specific were included)<br>Require no adaptation<br>Preferably validated in a patient population (preferably HIV) in the previous 20 years** | N/A |

*EACS: European AIDS Clinical Society Congress 2017, 2019; CROI: Conference on Retroviruses and Opportunistic Infections 2017, 2018, 2019; IDWeek: 2017, 2018, 2019; IAS/AIDS: IAS Conference on HIV Science, 2017.
**Criteria were expanded where appropriate to include PROMs that were also non-HIV validated and published within the past 20 years, to ensure that sufficient number of PROMs was captured per subdomain, particularly with regard to subdomains that retrieved < 5 PROMS.

**Supplementary Table 3. Full search strategies used in PubMed for the identification of PROMs within subdomains of physical health, psychological health, social relationships, and environmental (search dates 2010-2020)**

| Subdomain | Hits | Search |
|---|---|---|
| Fatigue and energy loss | 402 | "Fatigue OR energy loss AND HIV AND patient questionnaire AND validation" |
| Frailty and resilience | 150 | "Frailty AND HIV AND patient questionnaire AND validation" |
| Sleep disturbance | 291 | "Sleep disturbance AND HIV AND patient questionnaire AND validation" |
| Substance use (alcohol, drug abuse, smoking) | 864 | "Substance use AND HIV AND patient questionnaire AND validation" |
| Anxiety and depression | 957 | "Anxiety AND depression AND HIV AND patient questionnaire AND validation" |
| Cognition | 431 | "Cognition AND HIV AND patient questionnaire AND validation" |
| Sexual function | 358 | "Sexual dysfunction AND HIV AND patient questionnaire AND validation" |
| Sexual desire | 303 | "Sexual desire AND HIV AND patient questionnaire AND validation" |
| Stigma | 741 | "Stigma AND HIV AND patient questionnaire AND validation" |

**Supplementary Table 4. PROM scoring criteria**

| Allocated score | Ease of use | Validation | Availability |
|---|---|---|---|
| 3 points | If < 20 questions<br>OR 3-5 min to complete the questionnaire | If 1) HIV-specific AND<br>2) Widely used AND<br>3) Validated in an HIV-positive population | If freely available online AND translated into ≥ 3 other languages |
| 2 points | If 20-30 questions OR 5-10 min to complete the questionnaire | If two of the above three criteria met | If freely available online in English only |
| 1 point | If > 40 questions OR > 10 min to complete the questionnaire | If one of the above three criteria met | If not freely available online |
| Minus 1 point | If HCP administered | - | - |

**Supplementary Table 5. Individual PROMs retrieved within each domain and subdomain, and associated score based on PROM scoring criteria (shown in Supplementary Table 4).** ***PROMs that were pre-screened out of the evaluation stage are shown in italics***

| Domain | Subdomain | PROMs that met criteria | Overall PROM score |
|---|---|---|---|
| Physical health | Fatigue and energy loss | Fatigue Severity Scale (FSS)[1] | 7 |
| | | PROMIS Fatigue Short Form (PROMIS F-SF)[2] | 7 |
| | | Visual Analog Scale to Evaluate Fatigue (VAS-F)[3] | 6 |
| | | Modified Fatigue Impact scale (MFIS and MFIS-5)[4] | 7 |
| | | *A bespoke PROMIS-based instrument to measure fatigue*[5] | 4 |
| | | *HIV-related Fatigue Scale-56 (HRFS-56)**[6] | 4 |
| | Frailty and resilience | Pictorial Fit-Frail Scale (PFFS)[7] | 6 |
| | | The FRAIL scale[8] | 6 |
| | | Edmonton Frail Scale (EFS)[9] | 6 |
| | | Tilburg Frailty Indicator (TFI)[10] | 6 |
| | | SHARE Frailty Instrument (SHARE-FI)[11] | 6 |
| | Sleep disturbance | Insomnia Severity Index (ISI)[12] | 7 |
| | | Pittsburgh Sleep Quality Index (PSQI)[13] | 6 |
| | | Epworth Sleepiness Scale (ESS)[14] | 7 |
| | | (Reduced) Functional Outcomes of Sleep Questionnaire (FOSQ-10)[15] | 7 |
| | Substance use (alcohol, drug abuse, smoking) | 2-item conjoint screen (TICS)**[16] | 7 |
| | | 5A rule**[17] | 7 |
| | | The Alcohol, Smoking and Substance Involvement Screening Test (ASSIST)[18] | 7 |
| | | Alcohol Use Disorders Identification Test (AUDIT)[19] | 6 |
| | | The Drug Abuse Screening Test (DAST-10)[20] | 5 |
| | | The Addiction Severity Index-Lite (ASI-Lite)[21] | 4 |
| Psychological health | Anxiety and depression | Hospital Anxiety and Depression Scale (HADS)[22] | 8 |
| | | Center for Epidemiologic Studies Short Depression Scale (CES-D 10)[23] | 7 |
| | | General Anxiety Disorder (GAD-7)[24] | 8 |
| | | PHQ-9 Depression[25] | 8 |
| | | *The Montgomery–Åsberg Depression Rating Scale (MADRS)*[26] | 4 |
| | | *Hamilton Anxiety Rating Scale (HAM-A)*[27] | 3 |
| | | *Hamilton Rating Scale for Depression-17 item version (HAM-D)*[28] | 3 |
| | Cognition | Three screening questions from EACS guidelines[29] | 9 |
| | | International HIV Dementia Scale (IHDS)[30] | 8 |
| | | Modified HIV Dementia Scale (M-HDS)[31] | 7 |
| | | Alzheimer's Disease Cooperative Study-Activities of Daily Living Inventory-Mild Cognitive Impairment (ADCS-ADL-MCI)[32] | 6 |
| | | *Patient reported evaluation of cognitive status (PRECiS)*[33] | 5 |
| Social | Sexual function | Female Sexual Function Index (FSFI)[34] | 7 |
| | | International Index of Erectile Function (IIEF-5)[35] | 7 |
| | | The National Survey of Sexual Attitudes and Lifestyle (NATSAL-SF)[36] | 5 |
| | | International Index of Erectile Function (IIEF-15)[37] | 7 |
| | Sexual desire | Sexual Desire Inventory-2 (SDI-2)[38] | 6 |
| | | New Sexual Satisfaction Scale (NSSS) and NSS-Short form (NSSS-S)[39] | 5 |
| | | Female Sexual Function Index (FSFI)[34] | 7 |
| | | *Sexual Arousal and Desire Inventory (SDI)*[40] | 3 |
| Environmental | Stigma | PLHIV Stigma Index 2.0**[41] | 7 |
| | | Berger HIV Stigma Scale (HSS)[42] | 7 |
| | | 12-item HIV Stigma Scale[43] | 6 |
| | | Sowell HIV Stigma Scale[44] | 6 |
| | | Internalized Stigma of HIV/AIDS Tool (ISAT)[45] | 6 |

*PROM prescreened out of the evaluation stage but subsequently reintroduced based on author expertise.
**PROM added following the initial literature searches based on authors' experience in their clinics.

**Supplementary Table 6. Overview of PROMs to be included in "Ask & Measure" toolkit**

| Health domain | Subdomain | Recommended PROM | Rationale/Comments | Alternative PROM | |
|---|---|---|---|---|---|
| General QoL | | WHOQoL-HIV BREF<br>https://www.who.int/mental_health/publications/whoqol_hiv_bref.pdf[46] | Extensively used and cross-culturally valid QoL measure in HIV, covers social and environmental issues also | None | - |
| Physical | Fatigue and energy loss | Fatigue Severity Scale (FSS)<br>http://www.best.ugent.be/BEST3_FR/download/moeheid_schalen/FSSschaal_ENG.pdf[1] | FSS is short, self-administered, and widely used | The HIV-Related Fatigue Scale-56 (HRFS-56)<br>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3867537/[6] | The HRFS has a shorter version available; however, it has only been validated by one group |
| | Frailty and resilience | Pictorial Fit-Frail Scale (PFFS), or FRAIL scale<br>https://www.dal.ca/sites/gmr/our-tools/pictoral-fit-frailty-scale.html[7] | An initial screening questionnaire could be provided for patients to self-administer prior to the HCP's involvement. An advantage of the PFFS is that it is almost completely visual and tick box based which would overcome any language or literacy barriers. Disadvantages include the need for the questions to be adapted for patient use; it is a new scale, not yet widely used in HIV | Edmonton Frail Scale (EFS)<br>https://www.nscphealth.co.uk/edmontonscale-pdf<br>https://edmontonfrailscale.org/<br>https://www.sciencedirect.com/science/article/pii/S1743919115001624?via%3Dihub#appsec1[9] | Although most widely used, the EFS has the downside of needing a clinician to administer it. As it is now feasible for individuals to track sleep quality and quantity themselves, data will soon allow comparison of objective and subjective measures |
| | Sleep disturbance | Insomnia Severity Index (ISI)<br>https://www.ons.org/sites/default/files/InsomniaSeverityIndex_ISI.pdf[12] | ISI is short and evaluates both insomnia and sleep quality | Pittsburgh Sleep Quality Index (PSQI)<br>http://www.goodmedicine.org.uk/files/assessment,%20pittsburgh%20psqi.pdf[13] | It should be noted that it is possible to experience insomnia without sleepiness |
| | Substance use | TICS (alcohol and drug use) or 5A rule (smoking cessation)<br>https://www.mirecc.va.gov/visn22/TICS.pdf[16] | Simple, comprehensive, and patient centric. PROMs that seek the patient's opinion of their own issues are useful but in some cases, a more objective measure is required if patients are unaware that they have a problem | ASSIST or AUDIT<br>https://www.who.int/substance_abuse/activities/assist_v3_english.pdf?ua=1[18,47]<br>https://www.drugabuse.gov/sites/default/files/files/AUDIT.pdf[19] | ASSIST or AUDIT is objective measures; ASSIST is cumbersome but comprehensive |
| Psychological | Anxiety and depression | The Hospital Anxiety and Depression Scale (HADS)<br>https://www.svri.org/sites/default/files/attachments/2016-01-13/HADS.pdf[22] | Widely used, validated in hospital and HIV, and approved by NICE; short and convenient (14 items), and focuses on real anxiety and depression rather than physical complaints. The scale has a good cutoff score, indicating clearly when to intervene. A limitation is unreliable results when medium to high cognitive impairment or dementia is present. Socioeconomic elements are missing (since many PLHIV have lost jobs and/or have no retirement pay, they may have depression – the clinician would need to pick up on these factors) | Center for Epidemiologic Studies Short Depression Scale (CES-D 10)<br>https://www.brandeis.edu/roybal/docs/CESD-10_website_PDF.pdf[23] | A major limitation of CES-D 1- is that it only measures depression |
| | Cognition | Three screening questions from EACS guidelines<br>https://eacs.sanfordguide.com/prevention-non-infectious-co-morbidities/neurocognitive-impairment[29] | The EACS guidelines which has the benefit of being very simple but there is an additional need for a more "fit for purpose" questionnaire. A limitation is there is no cutoff to indicate action or intervention and no way of monitoring over time. The 3-EACS questions could be considered as just a screening tool and as it is not discriminative (many non-HIV people suffer cognitive problems also) | International HIV Dementia Scale (IHDS)<br>https://www.hiv.uw.edu/page/mental-health-screening/ihds[30] | IHDS is available as a full or modified version, however, they must be administered by the physician. Only available in English and Spanish |
| Social | Sexual function | Female Sexual Function Index or International Index of Erectile Function (IIEF-5)<br>https://www.fsfiquestionnaire.com/FSFI questionnaire2000.pdf[34]<br>https://qxmd.com/calculate/calculator_377/international-index-of-erectile-function-iief-5[35] | The IIEF-5 may be potentially less suitable for homosexual men as it asks about erection in the context of penetration | None | - |
| | Sexual desire | Sexual Desire Inventory-2 (SDI-2)<br>http://www.midss.org/content/sexual-desire-inventory-2-sdi-2[38]<br>Female Sexual Function Index<br>https://www.fsfiquestionnaire.com/FSFI%20questionnaire2000.pdf[34] | | None | - |
| Environmental | Stigma | Berger HIV Stigma Scale (HSS)<br>https://elcentro.sonhs.miami.edu/research/measures-library/hss/HIVSS_Items_Eng_Spa.pdf[42] | The Berger HSS is HIV specific and widely used; a shorter version with 12 items exists but is not free of charge | None | - |

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