

# MOVING FOURTH

Chapter 2:

## **ASK & MEASURE**

*A practical step  
towards Healthy  
Living with HIV*



## Conflicts of interest

**Dr. Giovanni Guaraldi** reports personal fees from Janssen, grants and personal fees from Merck, grants and personal fees from Gilead, grants and personal fees from VIIV;

**Dr Joop Arends** reports advisory board fees from Gilead, Janssen, Viiv, and MSD, outside the submitted work;

**Dr Thomas Buhk** has nothing to disclose;

**Mario Cascio** reports personal fees from Janssen and VIIV;

**Dr Adrian Curran** reports advisory board fees from Gilead, Janssen, Viiv, and MSD outside the submitted work;

**Dr Eugenio Teofilo** reports personal fees from Janssen, grants and personal fees from Merck, grants and personal fees from Gilead, grants and personal fees from VIIV;

**Dr Guido van den Berk** reports advisory board fees from Gilead, Janssen and Viiv, outside the submitted work.

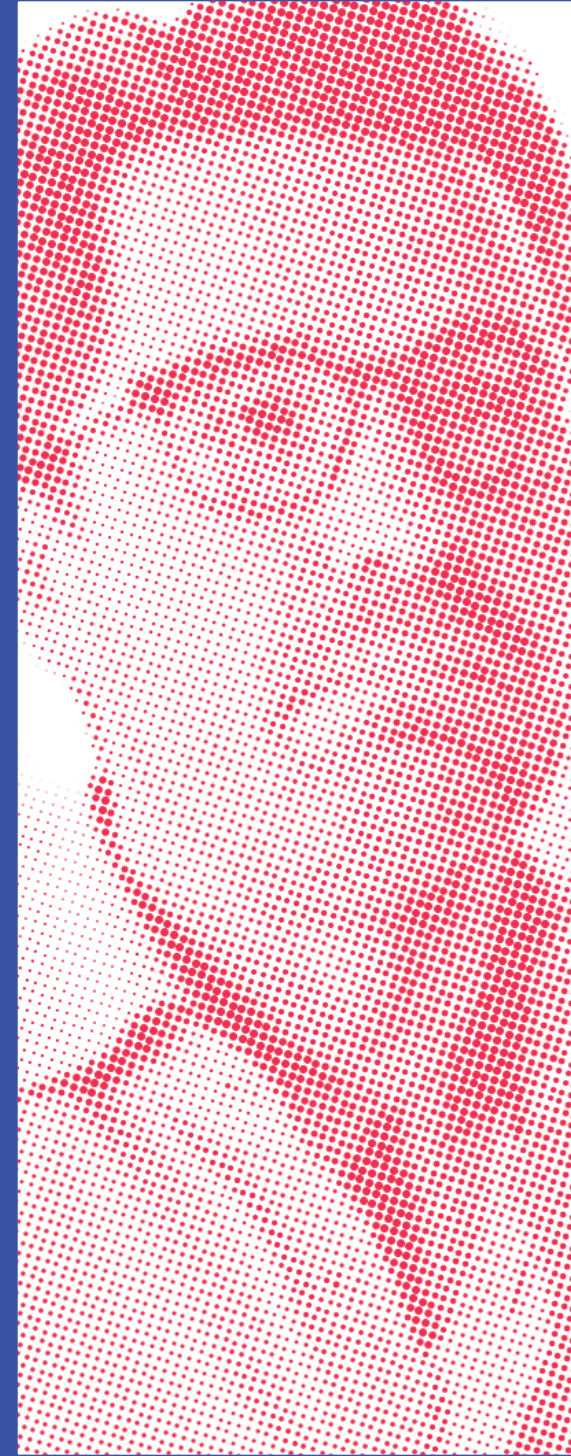
### **DISCLAIMERS:**

This White Paper was sponsored by Janssen. Each author received remuneration for the writing of the article and the fee for a medical writer was covered by Janssen. The views expressed herein are, however, the views of the authors and do not represent the views of Janssen.

All information listed on this page regarding the members of the Moving Fourth Steering Committee was correct as of September 2021



# Members of the Moving Fourth Steering Committee:



**Dr Joop Arends**

Internist, Infectious Diseases Physician, Department of Internal Medicine and Infectious Diseases, University Medical Centre Utrecht, The Netherlands



**Dr Thomas Buhk**

Internist, Infectious Diseases Physician, Centers for Infectious Diseases in Hamburg (ICH-Hamburg), Germany



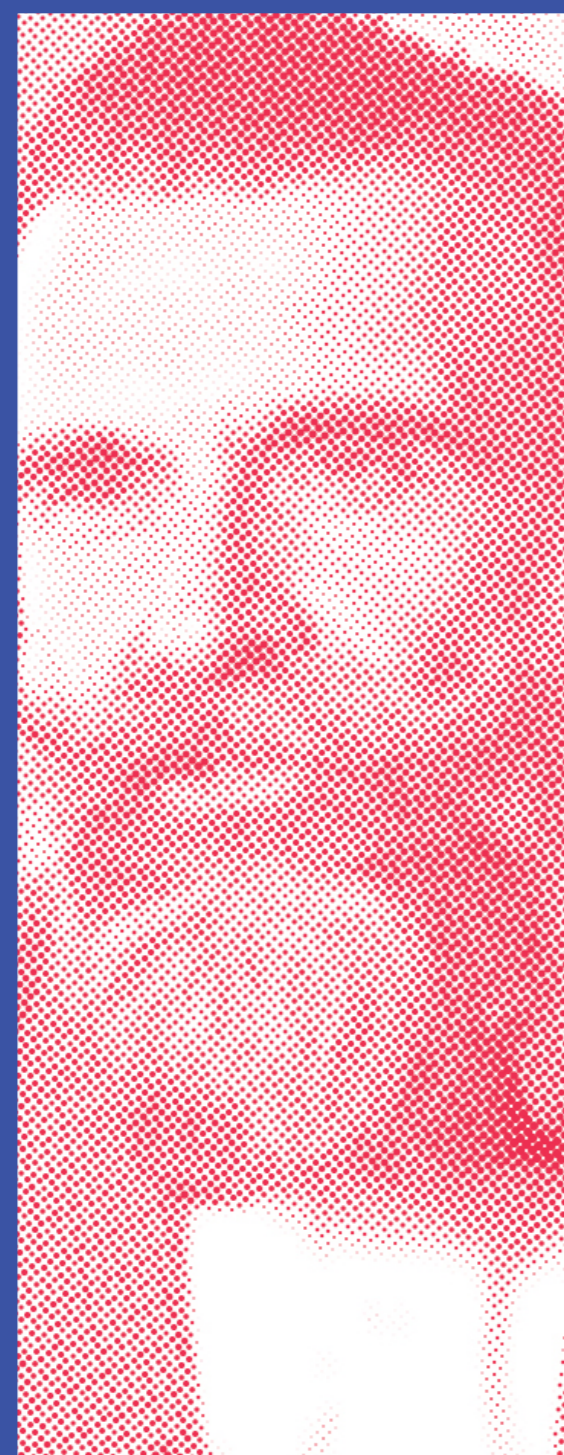
**Mario Cascio**

Programme Chair for Quality of Life, European AIDS Treatment Group (EATG), Italy



**Dr Adrian Curran**

Internist, Infectious Diseases Physician, Department of Infectious Diseases, Vall d'Hebron University Hospital, Barcelona, Spain



**Dr Giovanni Guaraldi**

(Chair)

Associate Professor of Infectious Disease and Head of the Modena HIV Metabolic Clinic (MHMC), Italy



**Dr Eugenio Teofilo**

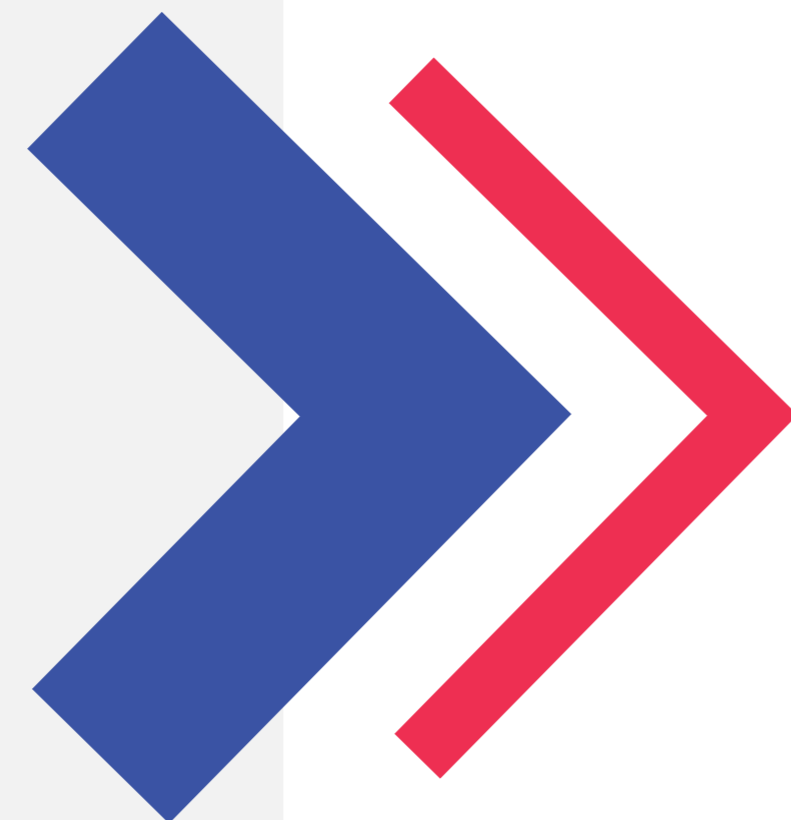
Department of Internal Medicine at Hospital Dos Capuchos, Lisboa, Portugal



**Dr Guido Van Den Berk**

Internist, Infectious Diseases Physician, Department of Internal Medicine, OLVG, City Hospital of Greater Amsterdam, The Netherlands

# Executive summary



In the first chapter of Moving Fourth, the Steering Committee (SC) delivered the initial step toward their vision for healthy living with HIV beyond viral suppression

»The proposed Health Goals for Me framework is a three-step plan to help achieve long-term healthy living with HIV through close collaboration and mutual decision-making between healthcare professionals (HCPs) and people living with HIV (PLHIV)

This next chapter of Moving Fourth takes the Health Goals for Me framework closer to clinical practice, by providing a system of practical recommendations around its first step: ASK & MEASURE

The SC focused on ASK & MEASURE during this chapter of Moving Fourth because it requires practical guidance to be correctly deployed

The system of practical recommendations around ASK & MEASURE presented in this chapter of Moving Fourth includes:

»**ASK:** identifying which quality of life (QoL) domains and factors HCPs and PLHIV should consider during each visit or consultation

»**MEASURE:** A recommended set of patient-reported outcome measures (PROMs) that HCPs and PLHIV can use to investigate the current status of the QoL domains and factors in question

»**How and when to implement ASK & MEASURE:** recommendations on initial implementation, and measuring progress through follow ups

»Discussion of the benefit and pertinence of using electronic PROMs (ePROMS) in ASK & MEASURE

»Establishing the right mindset for both HCP and patient so that regular implementation of the ASK & MEASURE system can be adopted in clinical practice

The SC hope that this deep dive of practical recommendations around the ASK & MEASURE system will serve as a useful resource for HCPs and PLHIV everywhere

# Moving Fourth

## Chapter 1: A look back

While diagnosis, access to antiretroviral therapy (ART) and viral suppression remain cornerstones of the World Health Organisation's 90-90-90 target\*<sup>1</sup> to end the AIDS epidemic, it is also now widely recognised that PLHIV should not merely survive with their condition but thrive with it.<sup>1</sup>

Today, many of us involved in HIV care are united under a common goal – to help PLHIV achieve a good QoL – also known as the 'fourth 90'.<sup>1</sup>

In 2019, we, the Moving Fourth Steering Committee, delivered our first contribution towards achieving this fourth 90 – through the Health Goals for Me framework, conceptualised against our vision of achieving healthy living with HIV.<sup>2</sup> We function in countries across Europe, combining our clinical experience at a national level to truly highlight what is important for PLHIV.

The framework allows HCPs and PLHIV to move from a 'goal for all' approach to treatment (i.e diagnosis, access to ART and viral suppression) towards a 'goals for me' (i.e. healthy living with HIV based on what the individual has reason to value).

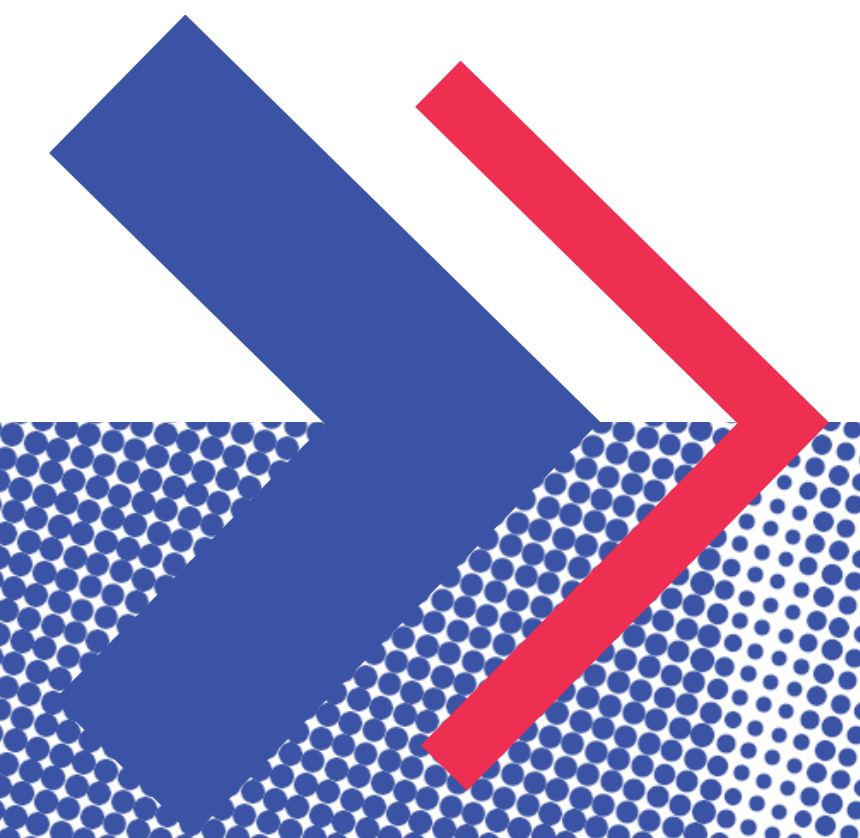
The Health Goals for Me framework is built on the values of collaboration and mutual responsibility between PLHIV and HCPs. Accomplishing good QoL for PLHIV is not solely the doctor's responsibility.

PLHIV are often experts of their own condition; regardless of a doctor's proficiency, only the patient truly knows how they feel.<sup>2</sup> Therefore, the Health Goals for Me framework is designed to facilitate continuous collaboration between HCPs and PLHIV, ensuring that both stakeholders meet the wider objective of healthy living with HIV.



\*Since the proposal of the Health Goals for Me framework, UNAIDS have announced an updated 95-95-95 target to help end the AIDS epidemic. Despite this update, the Moving Fourth SC believe improving QoL remains a key goal to achieve healthy living with HIV. As such, the framework should still be considered an important component of HIV care.

# **The Health Goals for Me framework**



## The Health Goals for Me framework

# ‘Health Goals for Me’

**The Health Goals for Me framework outlines three steps to ensure HCPs and PLHIV work together in every aspect of the treatment plan:**

### ASK & MEASURE:

*Empower each PLHIV to engage with the management of their long-term healthy living:*

- » HCPs will use PROMs to inform questions that will help to assess each PLHIV’s health status
- » Through this exchange of information, HCPs and PLHIV will build trust and identify problem areas that help to guide effective therapeutic decision making

### FEEDBACK & DISCUSS:

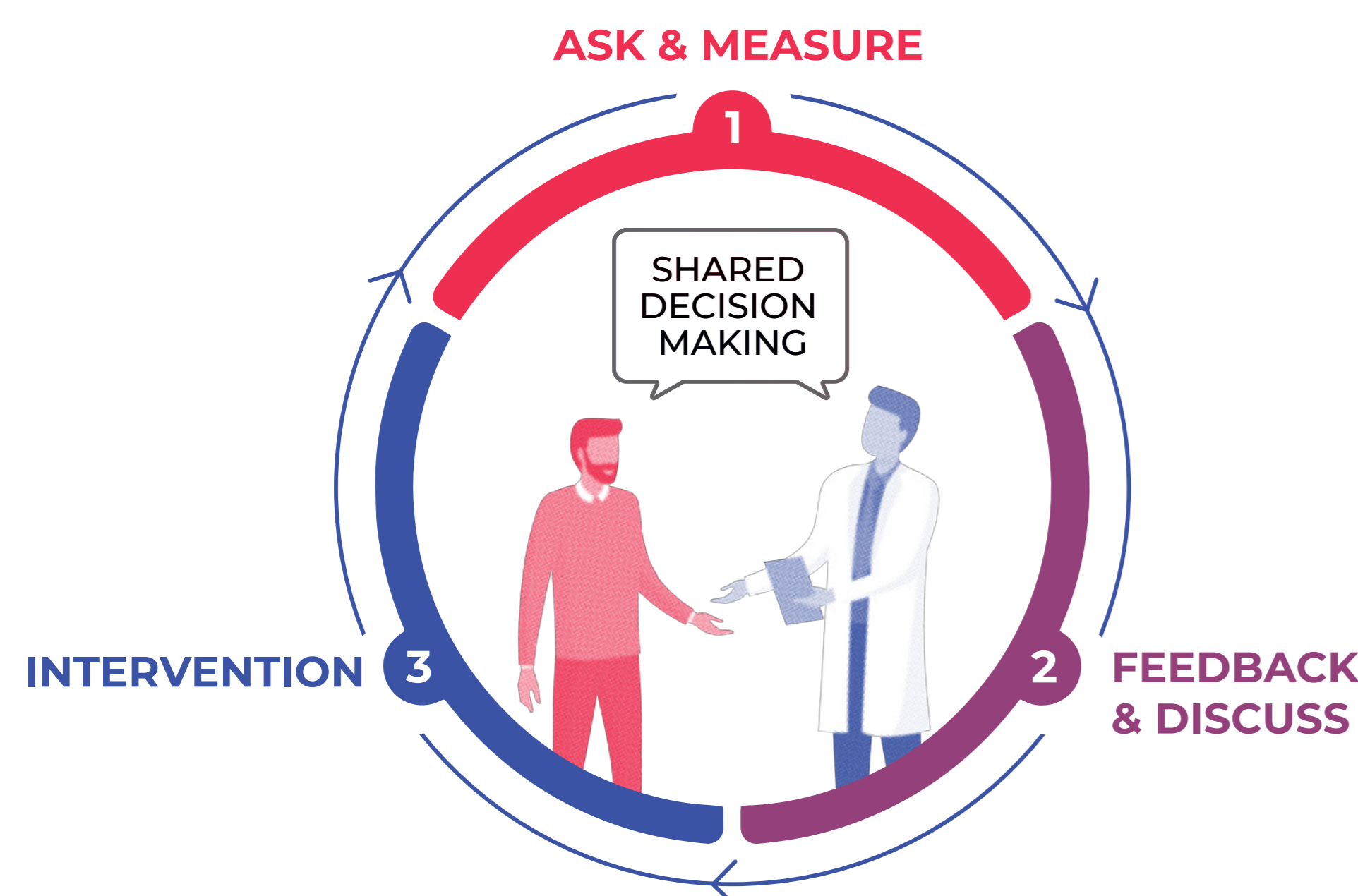
*Give back the health status information in a format that the PLHIV can interpret, so they can discuss its relevance to the choice of appropriate intervention in partnership with their HCP*

- » Once health status is measured, the HCP gives this information back to the PLHIV
- » As PLHIV build awareness of their own health data and see the impact it has on their outcomes, they are more likely to make meaningful changes to their lifestyles and general approach towards health
- » In turn, PLHIV may feel more motivated to discuss any problems with their HCPs as a result of receiving direct feedback based on their health status information

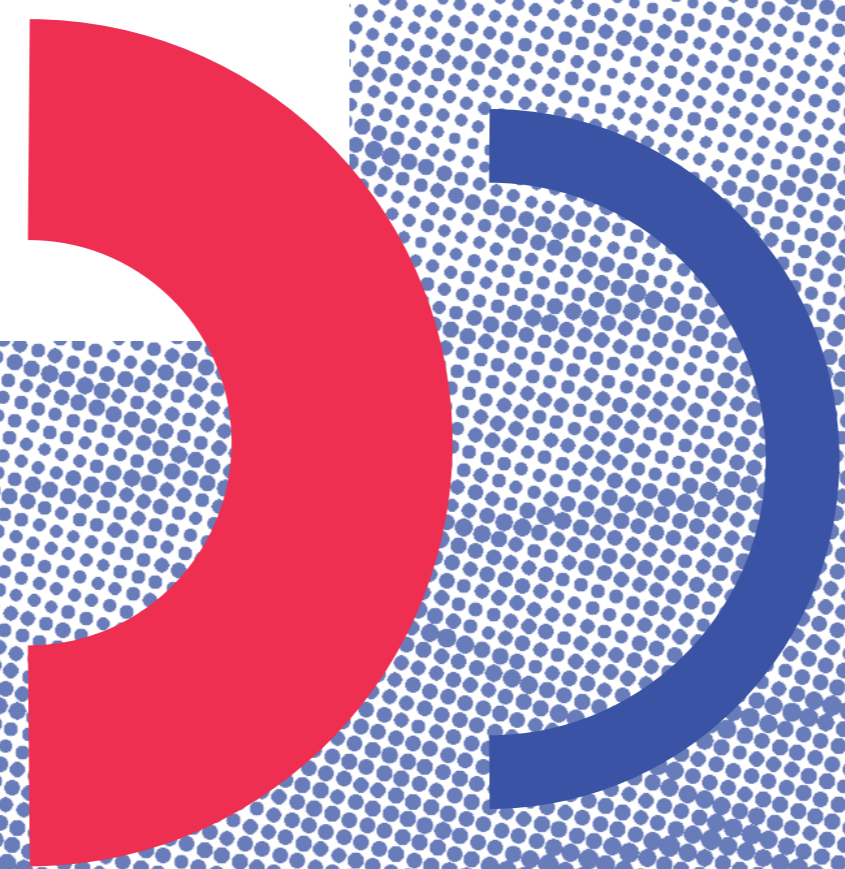
### INTERVENTION:

*Measurements and feedback are used to establish common goals and a hierarchy of interventions are determined through shared decision-making by the HCP and PLHIV*

- » The information that is gathered during the previous two steps informs the HCP to make an intervention
- » Discussing what has been measured and why, will allow the PLHIV to be involved in the choice of intervention - whether this involves adopting new lifestyle changes or alternative treatment options
- » The crux of the Health Goals for Me framework is to ensure collaboration from both stakeholders in building individual objectives for care and selecting interventions to achieve them



**Moving  
forward**





## Moving forward

# Moving Fourth Chapter 2: A practical guide to ASK & MEASURE

As a concept, we agreed that the Health Goals for Me framework could work well in achieving long-term healthy living in HIV.

Moreover, shifting the attitudes of PLHIV from a passive 'subject' of healthcare to an empowered partner who can participate in shared decision-making where appropriate may help relieve time and resource burdens on healthcare systems.

However, the detailed steps behind the Health Goals for Me Framework must be easily reproducible in a clinical setting to be of real value to both clinicians and PLHIV – therefore, practical recommendations must be made around the framework to ensure its implementation in everyday clinical practice.

As ASK & MEASURE consists of universally validated and accessible measures, it can be explained and replicated in clinical practice. In contrast, the remaining two steps of the framework, 'FEEDBACK & DISCUSS' and

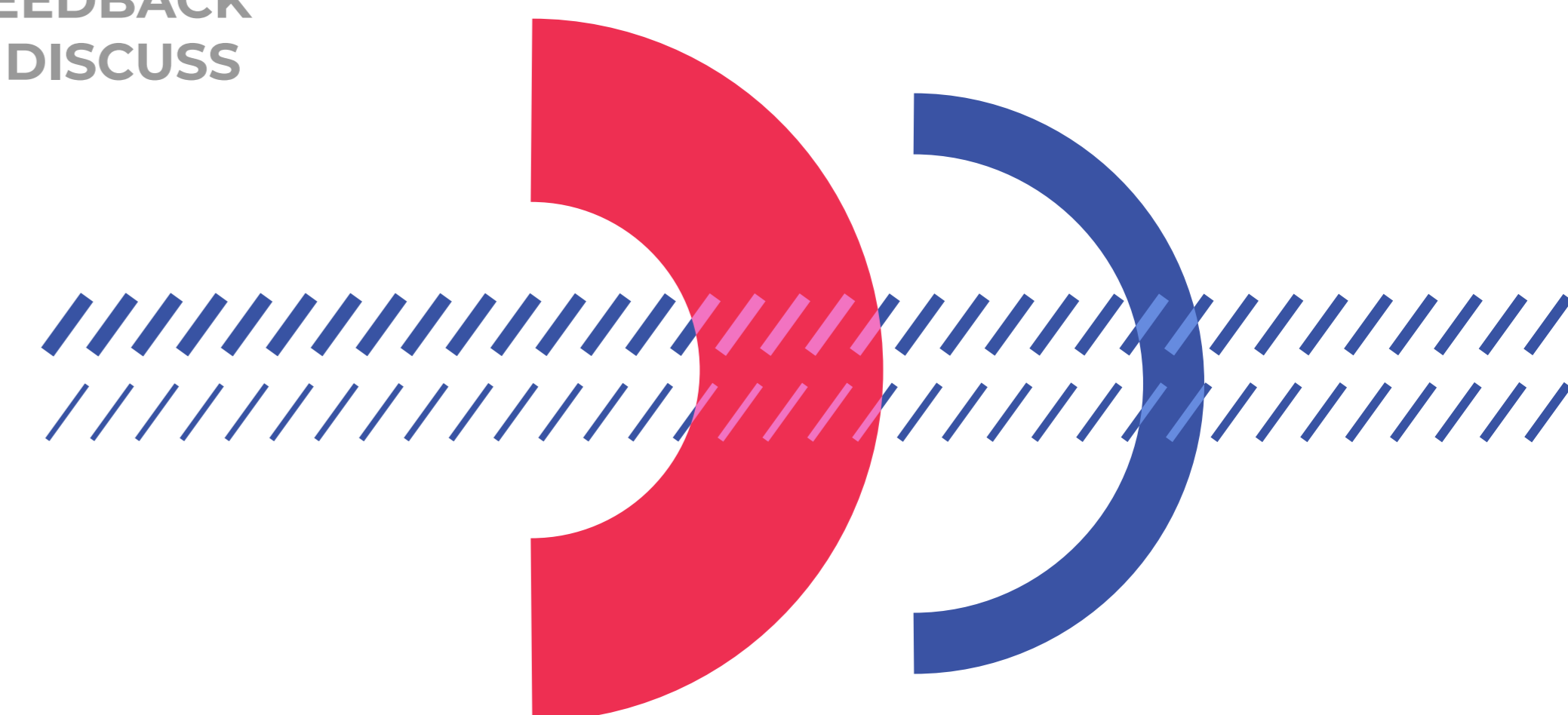
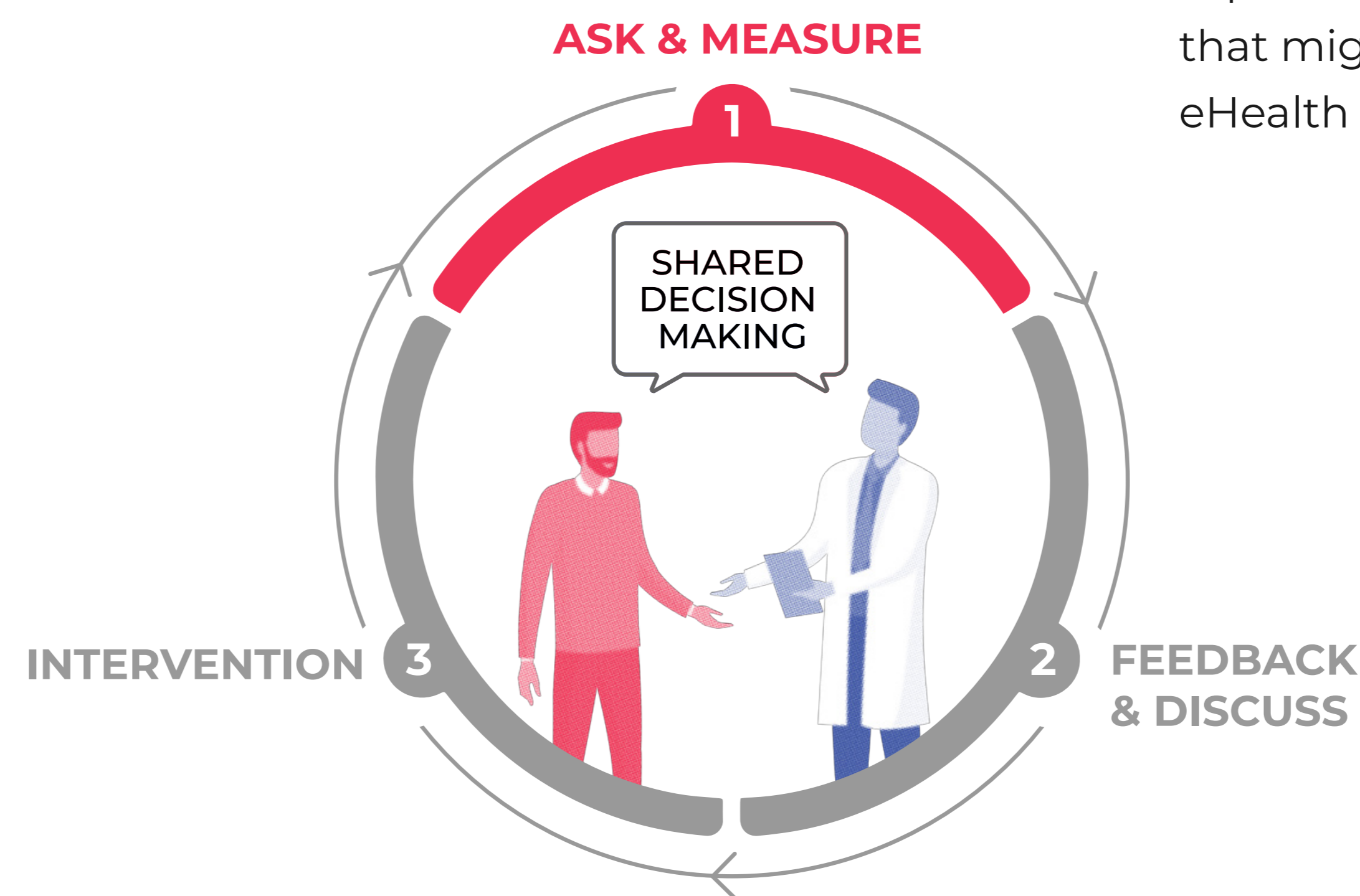
'INTERVENTION', will differ depending upon local practices and access to resources.

Hence, this next chapter of Moving Fourth focuses on presenting a practical system of recommendations toward the first step of the framework: ASK & MEASURE

## **ASK & MEASURE can be split into two distinct parts:**

**ASK** – determining exactly what questions HCPs should ask PLHIV and why

**MEASURE** – how HCPs and PLHIV can accurately collect beneficial data on different aspects of the PLHIV's overall health status, that might be facilitated by in-clinic or eHealth interventions





# **What to Ask**

## What to ask

# ASK: QoL domains to assess

QoL is a multi-faceted and complex measure – defined as an all-encompassing phrase for “*an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.*”<sup>3</sup>

As such, QoL can be impacted by an intricate combination of physical, mental, social and environmental factors that make up a person’s everyday life.<sup>3</sup>

Determining QoL is not easy, and this is especially true for PLHIV. They experience depression, anxiety and pain more often than the general population.<sup>4,5</sup> They are more likely to abuse substances<sup>6</sup> and more commonly face stigma.<sup>7</sup>

There are over 40 QoL measures, both general and HIV-specific, knowingly used in clinical studies and practice today.<sup>8</sup> These measures vary in their completeness; The Health Utilities Index focuses on physical and mental factors, whereas the World Health Organization Quality of Life Instruments (WHOQoL-BREF) additionally covers social and environmental factors.<sup>8</sup>

Therefore, for the sake of identifying specific domains to include in the ASK & MEASURE system, we turn to the WHOQoL-BREF – one of the most extensively-used and cross-culturally valid QoL measures in HIV.<sup>8</sup>

### The ASK framework

We agree that the four QoL domains can be impacted by a multitude of factors, i.e. ‘Physical health’ could be impacted by sleep quality or ‘Mental health’ could be impacted by anxiety.

However, HCPs and PLHIV cannot realistically explore every factor that may influence QoL. For the sake of creating practical guidance, we recommended identifying specific factors within each domain that we believe should be investigated in the ASK & MEASURE system.

The following figure indicates the four key domains of QoL as determined by WHOQoL-BREF:<sup>3</sup>

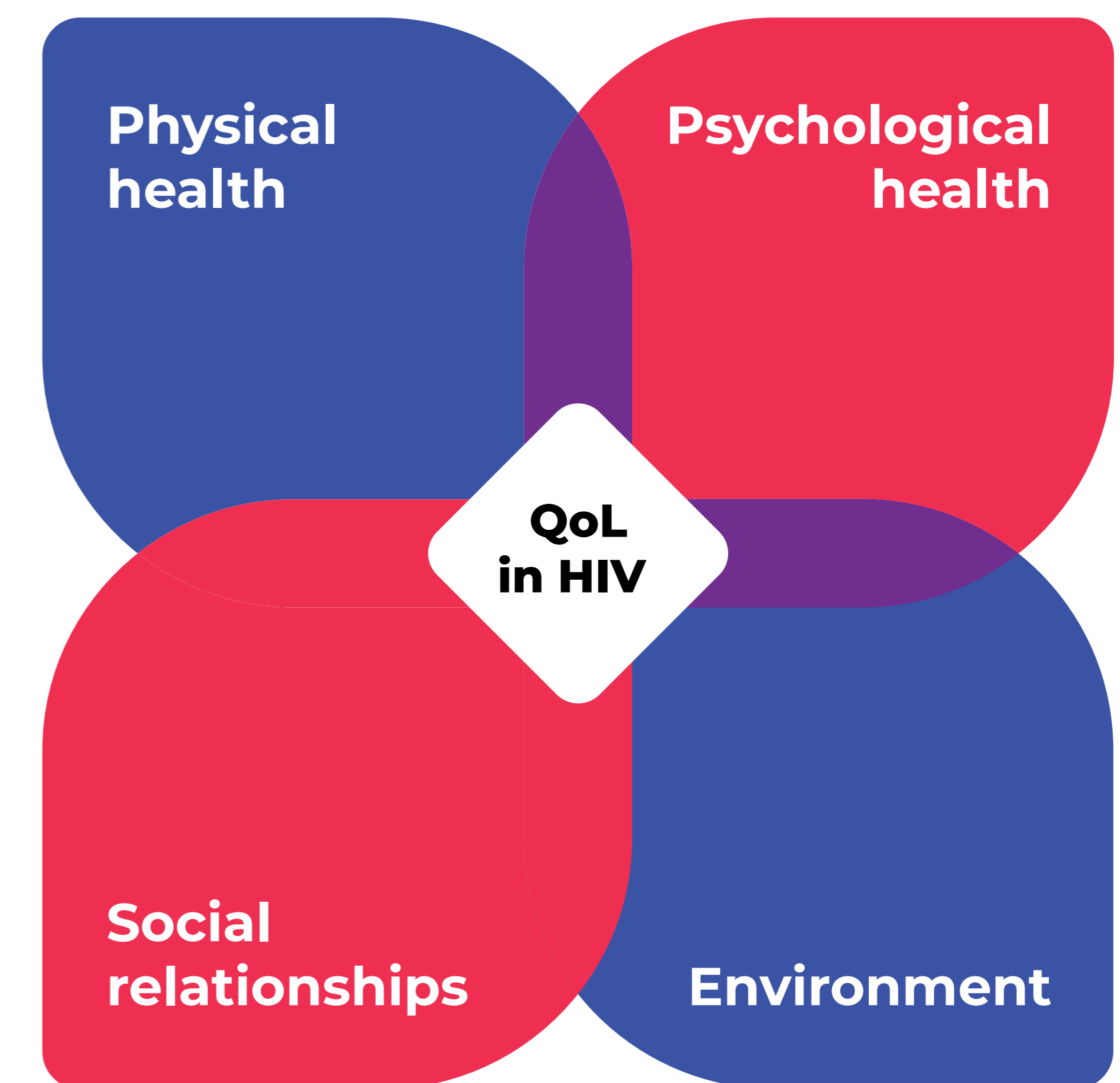


Fig 1: The four key domains that comprise QoL according to the WHOQoL-BREF

## What to ask

### *We proposed that any appropriate factors to include in these practical recommendations against ASK should:*

» Be known to *contribute significantly* to a patient's QoL, in literature and based on the clinical experience of the SC members;

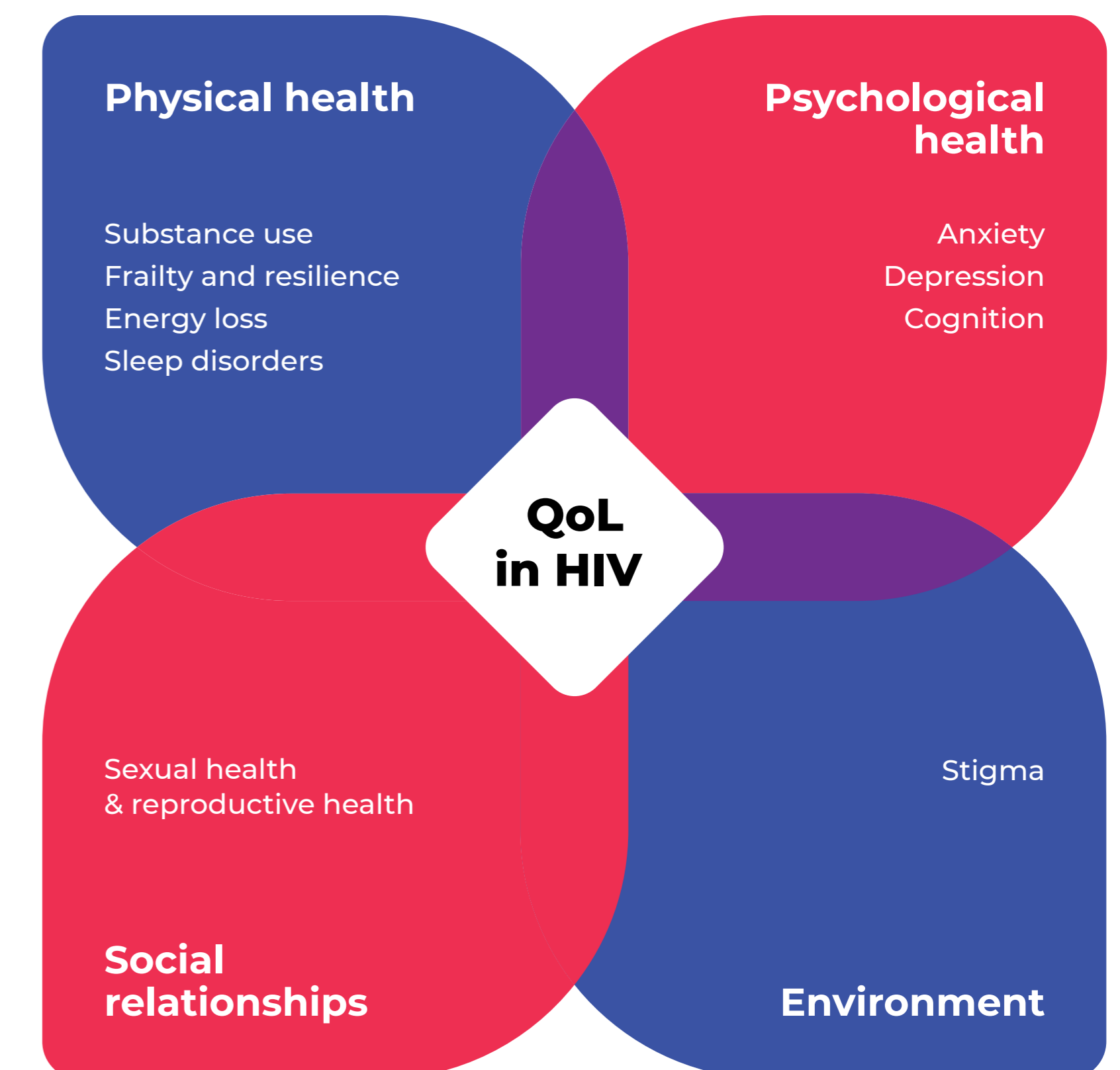
and

» Be *actionable* – as the Health Goals for Me framework will be applied in a clinical setting; it must target areas that are accessible for and manageable by HCPs - e.g. While HCPs do not have influence over a patient's home environment or financial status, HIV-related stigma is often encountered even within care systems<sup>7</sup>– and as such, may be under the influence of the HCP once identified as an issue

Using the WHOQoL-BREF's four domains as a guide, we provided a list of factors, based on our clinical experience, expertise and individual views, that we believed were the most important to assess in the current HIV patient population and landscape.

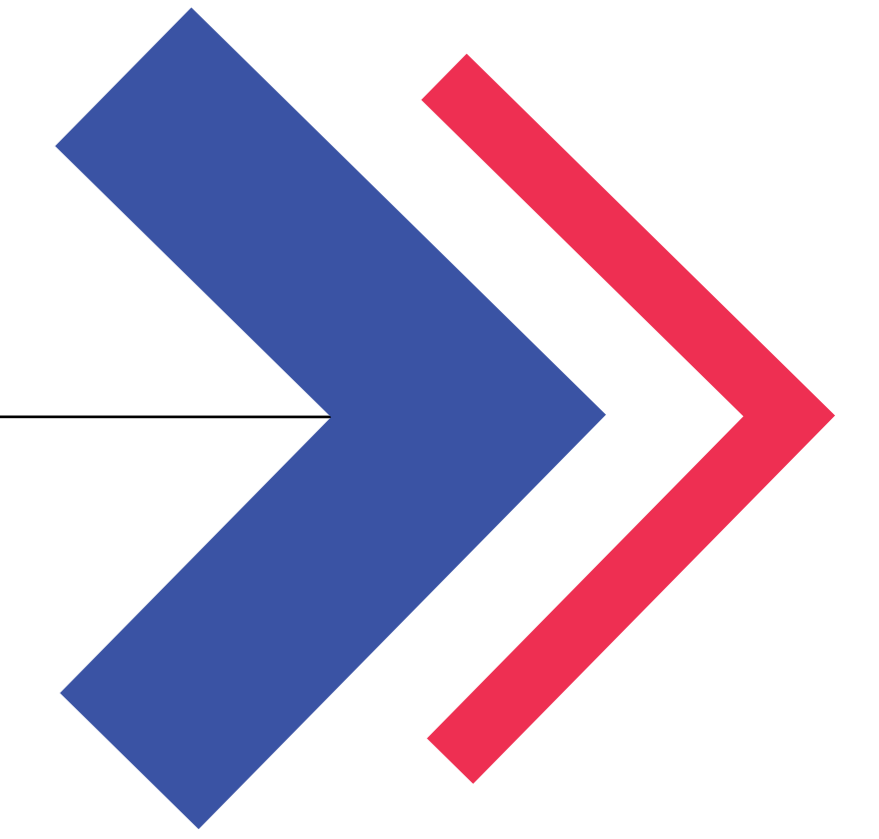
From this initial list, we considered which factors were measurable using PROMs, contributed significantly to a patient's QoL and were actionable by HCPs. At this stage the list of factors was further streamlined, in the interest of simplifying the process for both HCPs and patients, and to avoid 'questionnaire fatigue.' Some comorbidities such as metabolic syndrome and anal cancer were not included in ASK & MEASURE as they were not found to be quantifiable by patient input.

Therefore, based on the literature, our clinical experience and the criteria we chose (whether a factor is measurable using PROMS, significantly affects QoL and is actionable in the clinic), we identified the following nine factors across the four QoL domains to be included in the ASK & MEASURE system:



## How to measure

# Now that we've identified the QoL factors to focus on, how can we accurately measure their current impact on an individual patient?



We suggest the use of PROMs as a valuable instrument to systematically gather information on the health status of PLHIV.

PROMs can be defined as “any report of the status of a patient’s health condition that comes directly from the patient.”<sup>9</sup>

There is significant evidence of the benefits of PROMs in other therapy areas, including oncology. In a 2015 study by Basch *et al*, cancer patients who self-reported symptoms had a significantly lower decline in health related QoL (HRQoL) than those whose symptoms were monitored at their doctor’s discretion.<sup>10</sup>

PROMs are also an effective tool in HIV for both HCPs and PLHIV for several reasons:

» They are an efficient way to measure the multidimensional facets of a patient’s health status<sup>9</sup>

» They are proven and validated in clinical practice, and are often used as primary or secondary endpoints in pharmacological trials<sup>11</sup>

» They help to engage the patient in their own care, which can lead to better clinical outcomes<sup>12</sup>

» Time is scarce in the clinic for both HCPs and PLHIV. PROMs vary significantly in length and response format, but widely used and comprehensive PROMs, such as the EQ-5D and WHOQoL-BREF, take less than 5 minutes to complete<sup>8</sup>

- ePROMs are also a timesaving method of data collection for both PLHIV and HCPs<sup>9</sup>

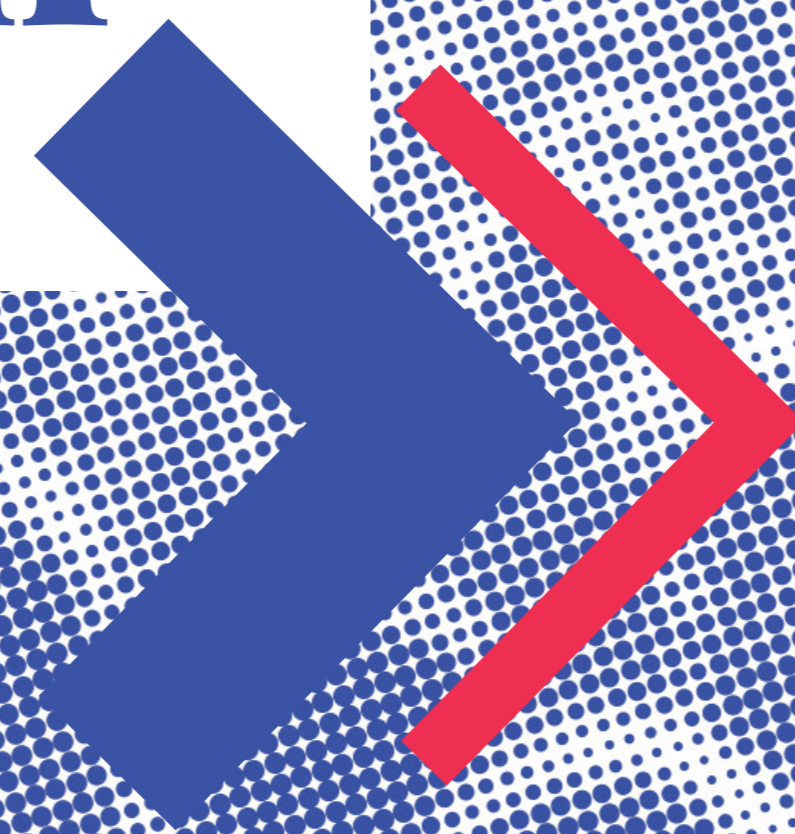
We unanimously agree that a general QoL PROM may help to ‘paint the picture’ of PLHIV’s overall health at an initial consultation. This could be compared to asking that general question often posed at

the beginning of each consultation: ‘How are you doing, overall?’

Depending on the patient’s response to the general QoL PROM, the HCP can then dive deeper and investigate potential problem areas with more specific questions that aim to identify exactly how problem areas have been affected. This is equivalent to following up that first question with more specific ones: ‘How are you sleeping?’ ‘How’s your energy?’ ‘How have you been feeling, mentally?’



# Criteria for PROM selection



# Selecting PROMs to recommend for the ASK & MEASURE system



PROMs work in HIV care, and the evidence is out there. Decision-making, capturing symptoms and patient-clinician communication all benefit from their use.<sup>9</sup> In some cases, PROMs have better captured patient experience and clinical outcomes, such as hospitalisation or death, than measures reported by the HCP.<sup>13</sup> But despite this, there remains some uncertainty amongst experts *when* and *where* PROMs are best deployed.

To identify relevant PROMs for ASK & MEASURE in the Health Goals for Me framework, we conducted a PROMs audit, using the names of QoL factors as search terms.

We agreed on the following inclusion criteria:

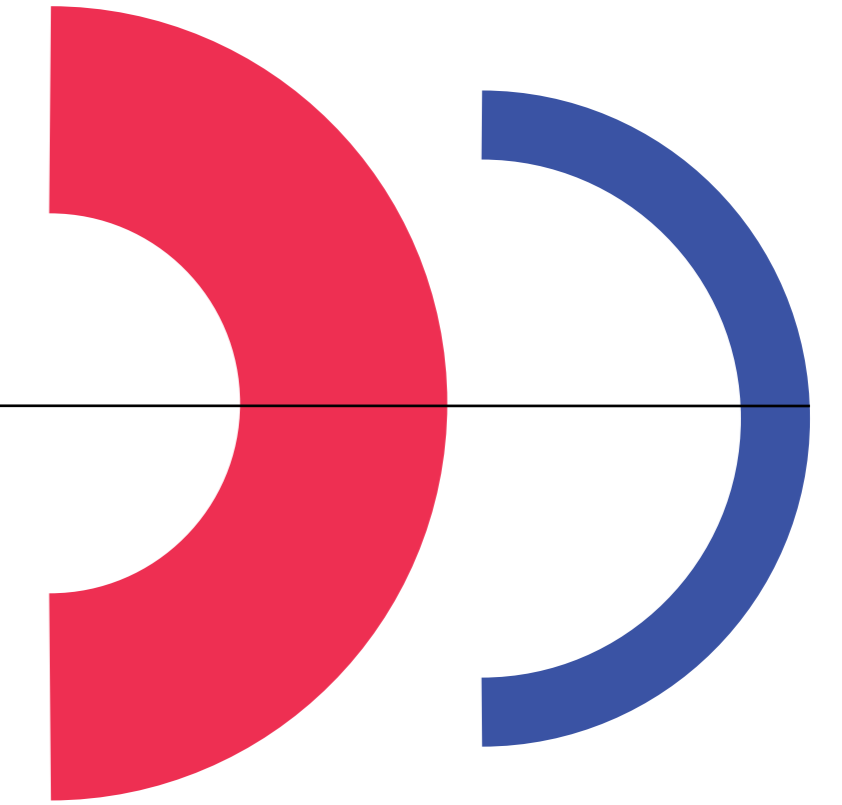
- » English publications
- » Freely available PROMs
- » Short, focused and less time-consuming PROMs
- » Preferably HIV specific, although if this was not possible, valuable non-HIV specific PROMs were included
- » PROMs that require no adaptation
- » PROMs validated in a patient population (preferably a HIV population) in the previous 20 years

The PROMs audit obtained 53 PROMs across the four domains.\*

\* As well as the 50 PROMs identified through the PROMs audit, we highlighted three PROMS during the February Steering Committee Meeting that we or our colleagues had used successfully in clinical practice



## Criteria for PROM selection



As part of our aim to provide practical recommendations for ASK & MEASURE, we scrutinised the PROMs that were appropriate for each identified factor.\* In doing so, we have formulated fundamental guidance to help HCPs and PLHIV apply the framework in everyday clinical practice.

We assessed and scored PROMs against three key criteria – **Ease of Use**, **Validation** and **Availability**.

### Ease of use

- » Clinical time constraints are a universal concern for HCPs and PLHIV alike. The quicker a PROM can be completed, the better
- » Similarly, PLHIV may experience ‘questionnaire fatigue’ if a PROM requires too many questions and there are multiple domains and/or factors to investigate

### Validation

- » Without question, PROMs must be validated and proven to effectively measure for the symptom in question
- » Where possible, PROMs that have been validated in PLHIV and/or specifically designed for HIV studies are preferred; otherwise, valuable PROMs authenticated in other disease areas and/or chronic conditions may also be considered

### Availability

- » As much as possible, PROMs should be freely available for use online, and translated into major European languages, including English, French, German, Spanish and Italian

\*As with all research and review processes, while every effort was made to include all PROMs available under each factor, PROMs that are not widely used and not readily available may have been excluded in the process





## Practical recommendations: PROMs

Based on the results of the scoring process for the three key criteria outlined above, we recommend the use of the following PROMs for each of the identified QoL factors in ASK:

### OVERALL QoL

### WHOQoL-HIV BREF

#### Anxiety & depression

**Preferred:**

The Hospital Anxiety and Depression Scale (HADS)

**Alternative:**

Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

#### Fatigue & energy loss

**Preferred:**

Fatigue Severity Scale (FSS)

**Alternative:**

The HIV-Related Fatigue Scale – 56 (HRFS-56)<sup>‡</sup>

#### Sexual function

**Preferred:**

International Index of Erectile Function (IIEF-5)

Female Sexual Function Index (FSFI)<sup>§</sup>

#### Cognition

**Preferred:**

3 screening questions from EACS guidelines

**Alternative:**

International HIV Dementia Scale (IHDS)

#### Stigma

**Preferred:**

Berger HIV Stigma Scale (HSS)

#### Sexual desire

**Preferred:**

Sexual Desire Inventory-2 (SDI-2)

FSFI<sup>§</sup>

#### Sleep disorders

**Preferred:**

Insomnia Severity Index (ISI)

**Alternative:**

Pittsburgh Sleep Quality Index (PSQI)

#### Frailty & resilience

**Preferred:**

Pictorial Fit-Frail Scale (PFFS), Edmonton Frail Scale (EFS) or FRAIL scale

**Alternative:**

Edmonton Frail Scale (EFS)

#### Substance use

**Preferred:**

Two-Item Conjoint Screen for Alcohol and Other Drug Problems (TICS)\*\*  
5A rule for smoking cessation\*\*

**Alternative:**

Alcohol, Smoking and Substance Involvement Screening Test (ASSIST) or Alcohol Use Disorders Identification Test (AUDIT)

We have selected preferred and alternative PROMs in this table. In clinical practice and where appropriate and feasible, we recommend that the preferred PROM should be used in the first instance. This may not be possible in some situations; in which case the alternative PROMs can be used as a substitute.

<sup>‡</sup> The HRFS-56 is not freely available, however it is the only HIV-specific PROM available for fatigue. Based on this, we agreed to include the HRFS-56 as the alternative PROM for fatigue.

<sup>§</sup> The FSFI was duplicated for both Sexual Desire and Sexual Dysfunction to provide a PROM for females, alongside the IIEF-5 and SDI-2 for males

\*\* These PROMs were identified during the SC meeting based on our clinical experience



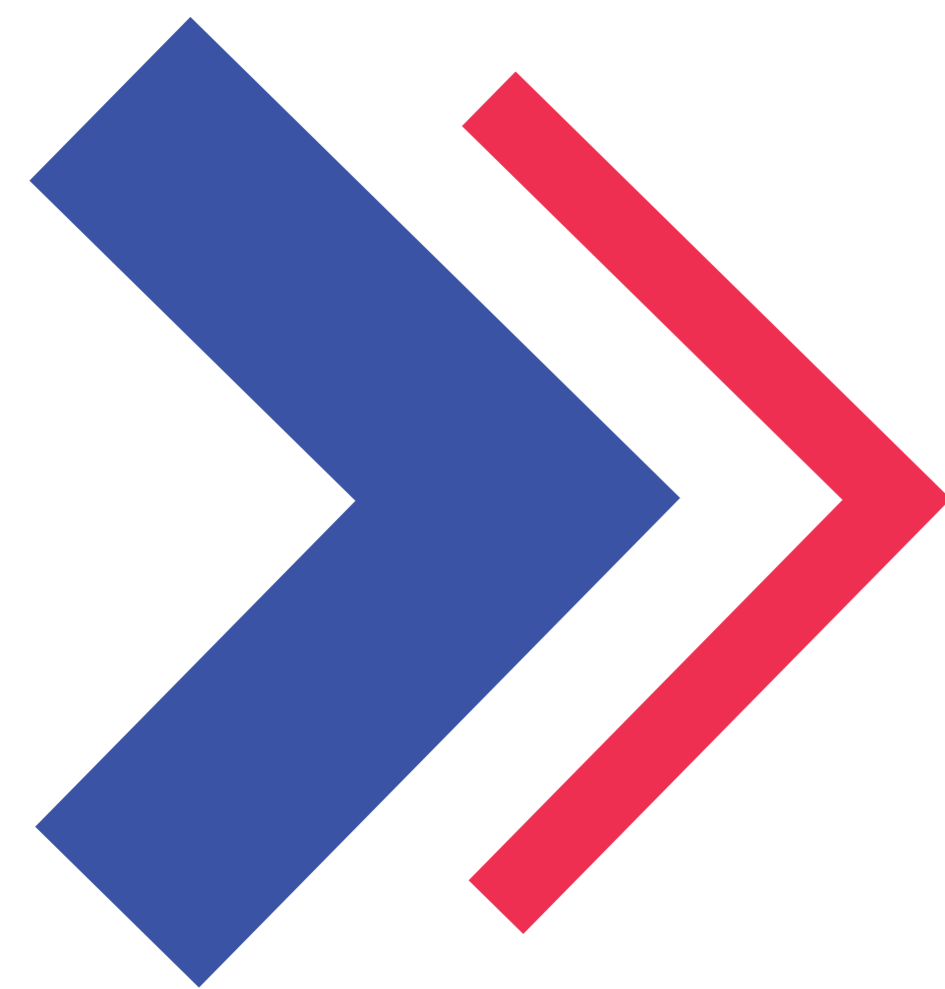
# How and when to implement ASK & MEASURE



## How and when to implement ASK & MEASURE

Correctly applying ASK & MEASURE is the first step to the Health Goals for Me Framework. We believe that this process should follow a 'zoom out–zoom in' concept, where PROMs are used to assess QoL factors.

It is equally important to focus on the macro and the micro in ASK & MEASURE. Therefore, we provide our practical recommendations on how to successfully implement this critical initial phase in everyday clinical practice:



1

Start with a comprehensive assessment of the patient's overall QoL – using a general QoL PROM (i.e., WHOQoL-BREF) – at the initial or next possible appointment – *zoom out*:

- » to gain a holistic, multi-dimensional view of the patient's current health status
- » to identify and better understand which domains require further investigation in future

*How would you rate your quality of life?"*

*"How satisfied are you with your health?"*

*"How much do you enjoy your life?"*

Questions from the WHOQoL-BREF<sup>3</sup>

2

Once it is clear which domains are of most concern or importance for HCP and/or patient, each future visit can focus on detailed investigation of the identified factors using specific PROMs i.e. sleep disorders and the ISI – *zoom in*:

*"How satisfied/dissatisfied are you with your current sleep pattern?"*

*"How noticeable to others do you think your sleep problem is in terms of impairing the quality of your life?"*

*"How worried/distressed are you about your current sleep problem?"*

Questions from the Insomnia Severity Index<sup>4</sup>

3

After QoL domains and factors have been identified, and FEEDBACK & DISCUSS and INTERVENTION followed (as per the Health Goals for Me framework), we circle back around to ASK & MEASURE – and take another 'zoom out' assessment with the overall QoL PROM in step 1 to determine whether interventions are making a measurable impact on the individual's QoL

*How would you rate your quality of life?"*

*"How satisfied are you with your health?"*

*"How much do you enjoy your life?"*

Questions from the WHOQoL-BREF<sup>3</sup>

## Employing eHealth to enhance ASK & MEASURE

---

eHealth, which is defined as “the use of information and communication technologies for health”<sup>15</sup> can be effectively used in HIV. This has been seen in the successful Happi application, which focuses on measuring and improving HRQoL and comorbidity management.<sup>16</sup> Moreover, Farmalarm, an app originally used in stroke patients and now being explored for potential benefits in patients with different diseases such as HIV infection<sup>17</sup> may help to optimise ART adherence, increase disease knowledge and improve communication between PLHIV and their HCP. Smartphone technology now has the potential to monitor and track PLHIV’s health outcomes,<sup>16</sup> as well as potentially enable better communication between patient and doctor, and we recognise its value in the modern era of HIV care.

Practically, how can eHealth and ePROMs enhance ASK & MEASURE? One advantage of ePROMs is that they can be downloaded and completed remotely. This can reduce time burdens for both the patient and HCP, and potentially make clinical visits more efficient by allowing discussions to focus on the patient’s

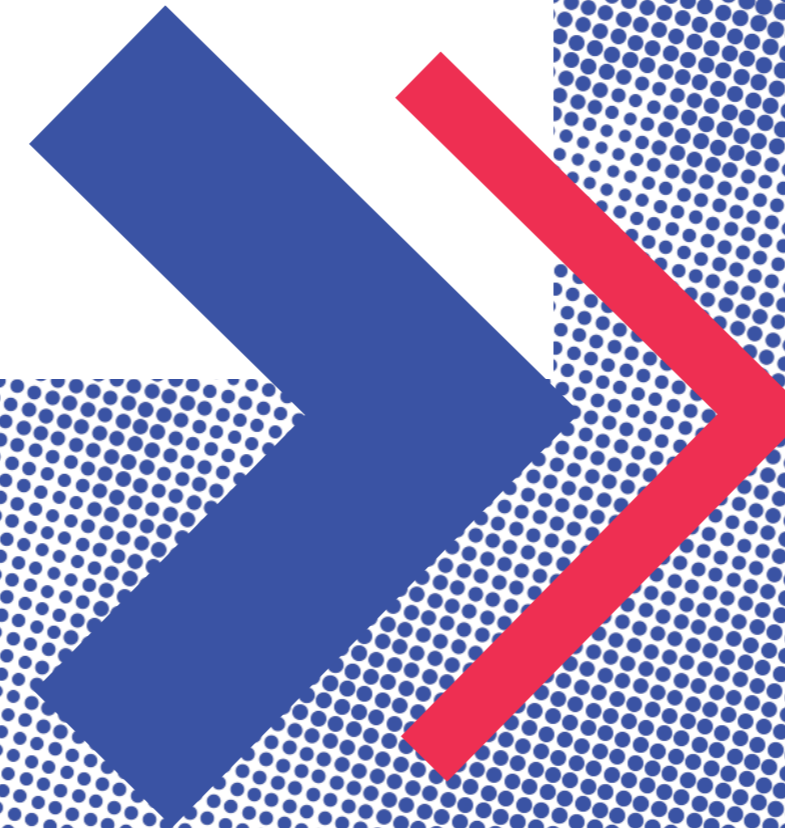
concerns rather than answering PROMs. They also allow data to be securely shared between patient and HCPs and presented in user-friendly figures and graphs, enabling PLHIV to further take control of their health.<sup>9,16</sup>

The new reality of the COVID-19-era makes the use of eHealth and ePROMS even more pertinent. Many clinics, consultations and discussions between HCPs and PLHIV are now remotely facilitated via telephone or teleconferencing, and patients who are better informed of this switch to virtual will likely have better care experiences.

While healthcare resources are stretched and PLHIV are avoiding clinics, it is important we continue to monitor the health status of HIV patients. Integrating ASK & MEASURE into an eHealth platform and allowing ePROMs to be completed and fed back at a distance will provide a pragmatic solution to help both patients and HCPs adapt to remote patient care. The importance of eHealth interventions and our knowledge of the HIV pandemic should inform our clinical practice during the current health emergency and continue to do so into the future.



# Realistic assessment



# ASK & MEASURE: A realistic assessment for practical implementation

Taking a theoretical concept from the whiteboard to the clinic is a difficult process. There are multiple cultural, privacy, knowledge and systemic barriers which can undermine the efficiency of ASK & MEASURE in the clinic.

We discussed the following obstacles to ASK & MEASURE, and suggested solutions in each case:

### Time Poverty

#### Barriers

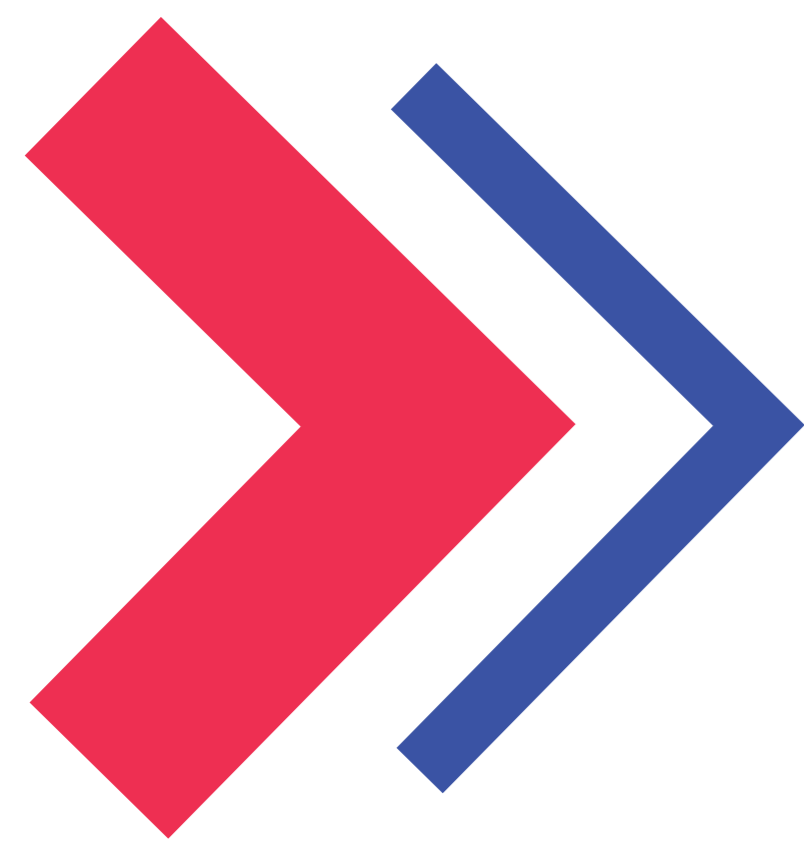
HCPs and PLHIV both have busy schedules, and therefore certain time challenges arise when implementing PROMs.

#### Solutions

As mentioned earlier, eHealth has the potential to reduce time constraints in the clinic for both HCPs and PLHIV. eHealth can enable PLHIV to download and complete PROMs remotely and feedback their results to HCPs real-time

In addition to resolving time issues in the traditional healthcare setting with the use of eHealth, community services, such as checkpoints, webcam consultations or nurses collecting information for GPs were all identified as potential solutions.

Even in clinics with no access to ePROMs, the use of PROMs may become a time-saving solution in the long run. The ability of PROMs to improve patient-HCP interaction and streamline consultations to concentrate on patients' most pressing concerns can facilitate the most efficient use of time and resources in the long-term.

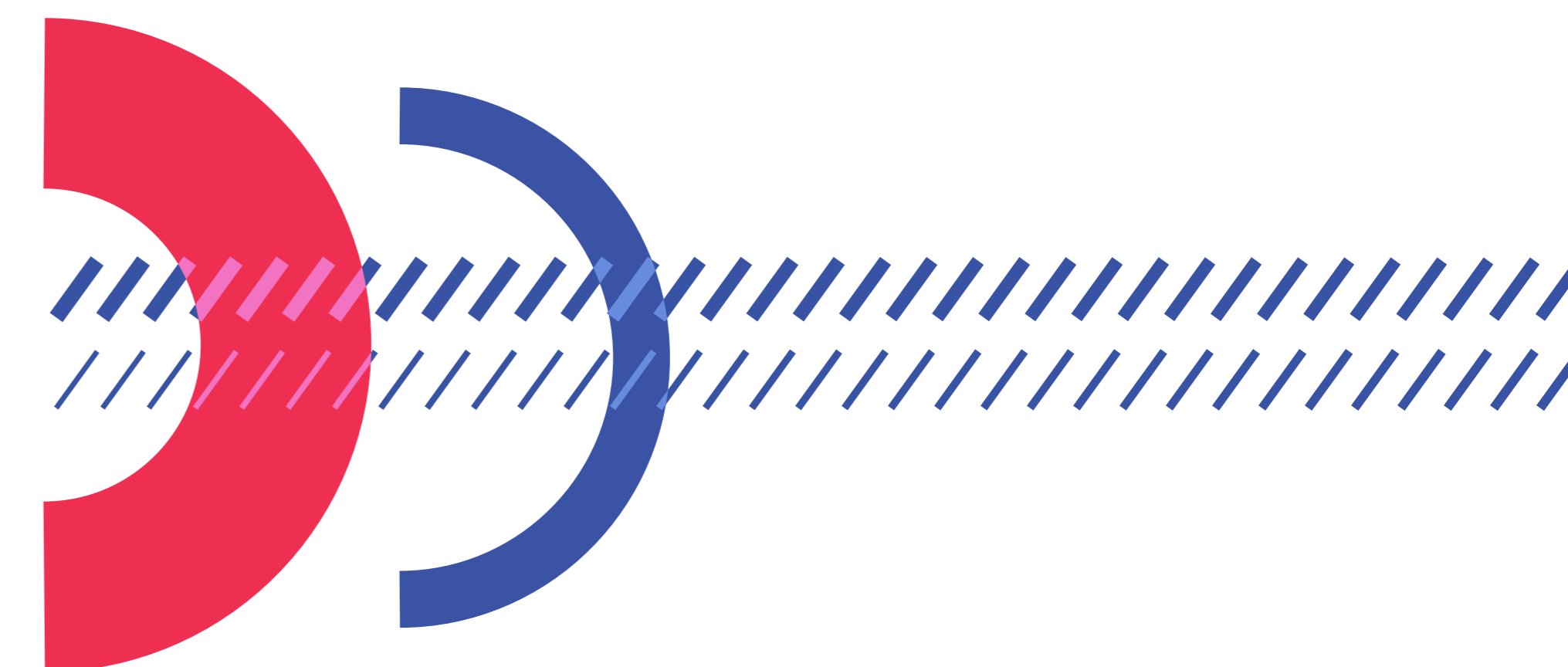


## Realistic assessment

HCP resistance	
<b>Barriers</b> <p>For many, QoL measurement is unfamiliar territory compared with objective measures. It has been found that HCPs may be afraid of uncovering problems for which they do not have a solution. It could also be perceived that consultation would become too 'mechanistic' and replace a trusting patient-HCP relationship.</p>	<b>Solutions</b> <p>It should be explained that PROMs are there to facilitate the conversation rather than replace it. By facilitating this information exchange between patient and HCP, trust between the two stakeholders can be enhanced. In many cases, the act of simply listening is sufficient.</p>
Integration with EHRs	
<b>Barriers</b> <p>GDPR concerns are a persistent issue in healthcare services, and things like data entry, storage, protection, sharing and tracking changes all rely upon third-party data systems. A lack of connectivity with Electronic Health Records (EHRs) was also highlighted.</p>	<b>Solutions</b> <p>Allowing PLHIV to link their device with their hospital EHR was identified as a potential solution. This would allow PLHIV to enter data directly into the EHR so that HCPs can see how their scores change. Using trusted eHealth platforms with emerging blockchain technology can effectively and safely facilitate remote data sharing.</p>
Patient concerns over disclosing and storing information	
<b>Barriers</b> <p>Some PLHIV have difficulty in disclosing their status or confidential information for many reasons.</p>	<b>Solutions</b> <p>ASK &amp; MEASURE aims to strengthen trust and communication through the regular exchange of health status information.</p>
Lack of understanding rationale for/goal of PROMs, and PROM completion fatigue	
<b>Barriers</b> <p>PLHIV and HCPs will not participate in initiatives if they do not see the overall benefit. Additionally, PLHIV may see PROMs as a 'box-ticking' exercise and not engage fully.</p>	<b>Solutions</b> <p>It must be clear (through education) that ASK &amp; MEASURE is as important to PLHIV as a blood test or an X-ray. While it requires input from the PLHIV, they will significantly benefit in the long-term.</p>

We also highlighted a number of other potential barriers to ASK & MEASURE that should be considered:

- » Health literacy
- » Cultural and language barriers
- » Lack of digital skills and resistance to technology usage
- » PLHIV not feeling empowered to engage in their healthcare
- » Resistance to using technology in practice
- » Patient aversion to 'being reminded of disease'
- » Difficulty to achieve tailored care
- » PLHIV not being able to afford trip to the clinic
- » Lack of evidence in favour of new technologies



## Right mindset

# Implementing 'ASK & MEASURE' with the right mindset

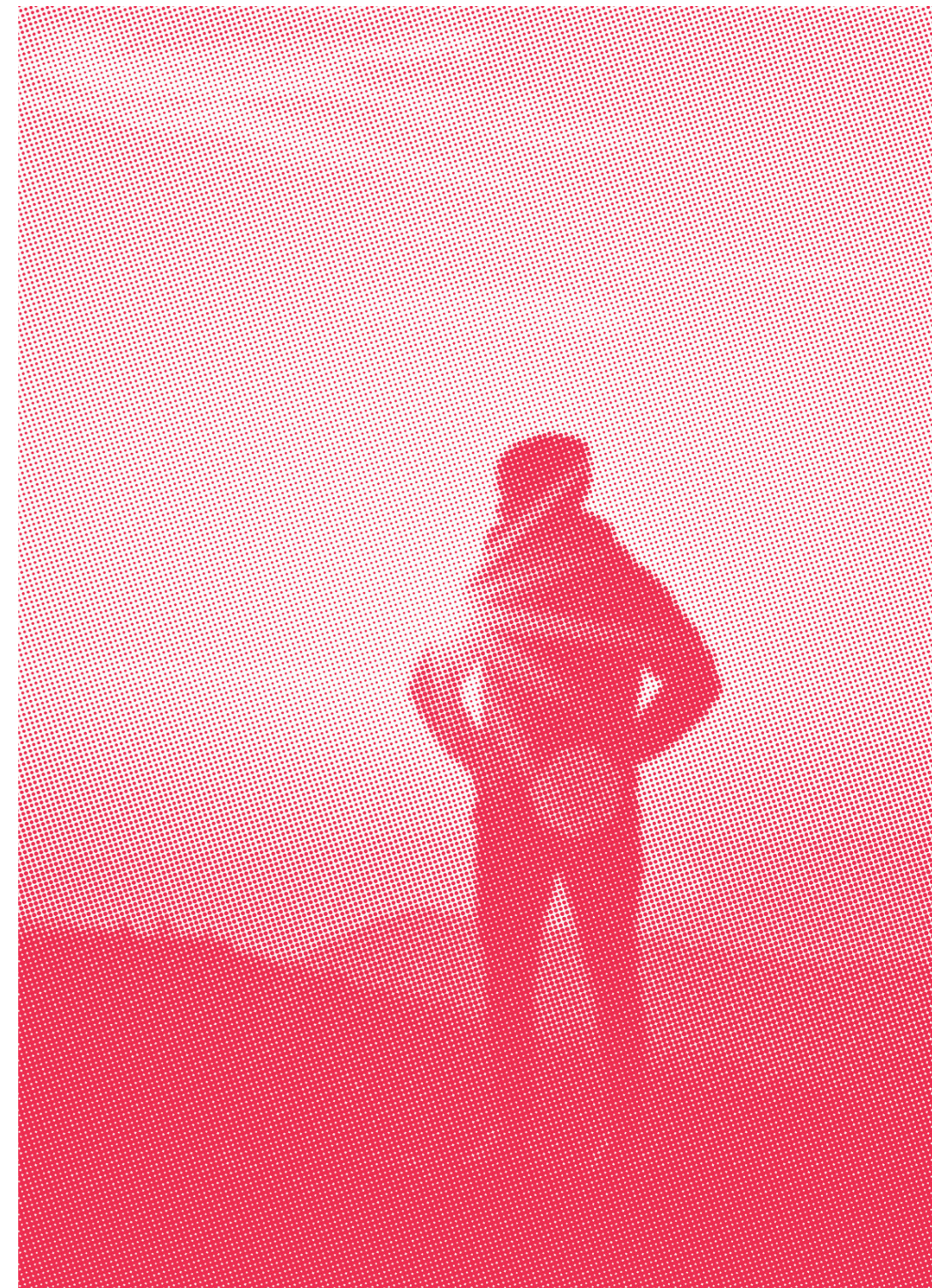
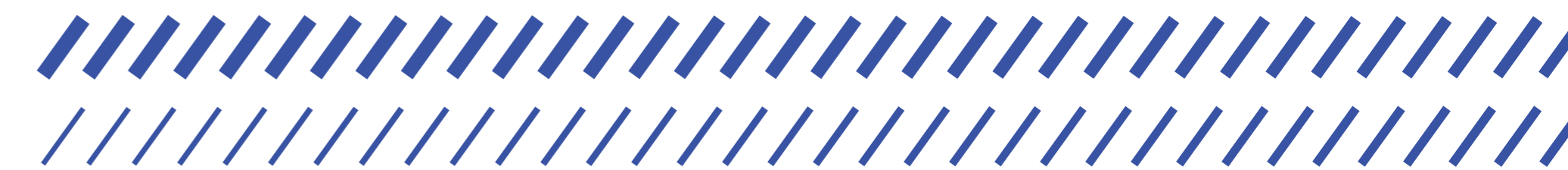
Perhaps the most critical consideration when administering ASK & MEASURE is to ensure that both HCPs and PLHIV are in the right mindset.

All stages of the Health Goals for Me framework depend on a collaborative relationship and mutual responsibility; both stakeholders should be engaged and invested in the process. The following shifts in mindset, therefore, are important to address:

- » ASK & MEASURE must be viewed as an integral part of HIV care, if the fourth 90 and a better QoL for PLHIV is to be achieved
- » PLHIV must be made aware that they are not taking part in the framework for the HCP or anyone else, they are engaging for themselves and to improve their own QoL
  - Many PLHIV understand that blood tests and x-rays are critical components of a general health examination. They require

time and effort from the patient, but the outcome is in the best interests of the individual. Using ASK & MEASURE and the wider framework should hold a similar position in the lives of PLHIV

- PLHIV and HCPs should frequently investigate aspects of their daily life that affect QoL, for both good and bad. Being aware of what factors can change QoL empowers the patient, and encourages action to take place
- PLHIV and HCPs should remain disciplined to ASK & MEASURE. The framework does not promise instant benefits; it will take time and dedication. Getting the first step right and maintaining a positive attitude is critical to improving health and wellbeing in PLHIV





## Looking towards next steps

# HEALTH GOALS FOR ME: Next steps

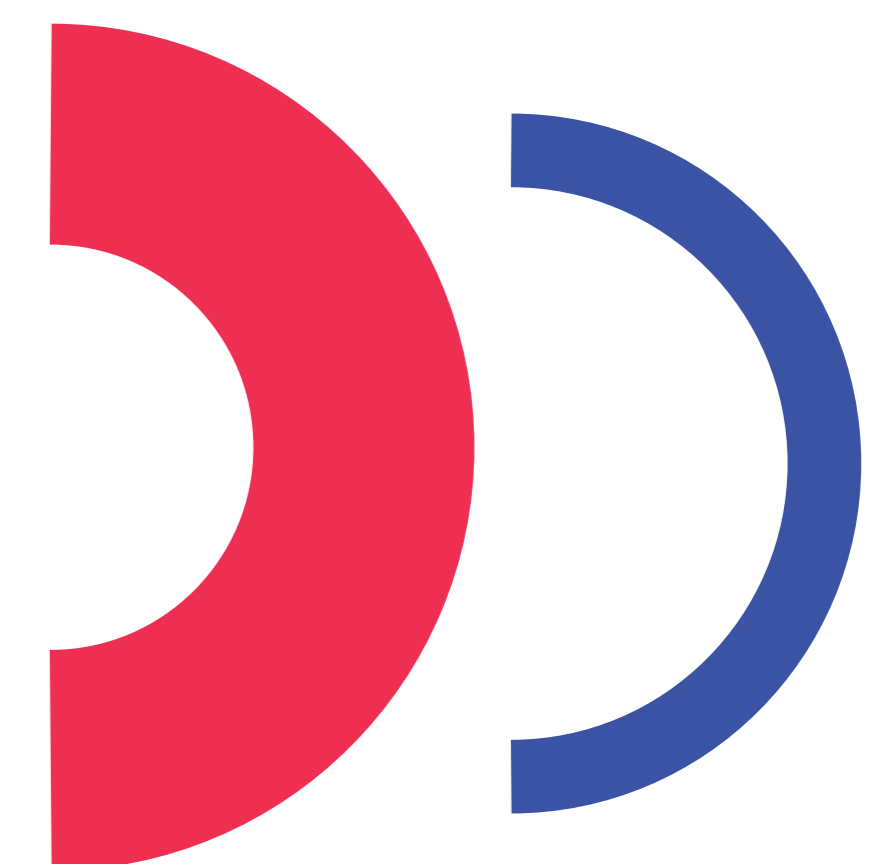


We acknowledge several limitations and open questions around our first set of practical recommendations for the Health Goals for Me framework::

- » While PROMs are a beneficial tool to collect information on the health status of PLHIV, more work is needed to develop PROMs that cover other factors that can impact an individual's QoL but have not been covered in the ASK & MEASURE system due to certain limitations (e.g. lack of available PROMs for other specific QoL factors in HIV). However, it is important to remember that ASK & MEASURE is the first of its kind in Europe to collate practically feasible PROMS and will pave the way for further work on implementing PROMs in HIV practice
- » While ASK & MEASURE is the critical first step of the wider Health Goals for Me Framework, it operates only to identify specific problems faced by PLHIV

- In order to achieve the common goal of the fourth 90 – healthy living with HIV – the framework needs to be implemented as a whole, including the other two components: FEEDBACK & DISCUSS and INTERVENTION

However, while some questions as above still remain, by providing HCPs and patients with practical recommendations around the ASK & MEASURE system, we tackle the first step of the Health Goals for Me framework and move closer to our goal of improving QoL for PLHIV.





# References

1. Jeffrey V Lazarus, *et al.* Beyond viral suppression of HIV – the new quality of life frontier. *BMC Med.* 2016; 14:94. Available at: <https://doi.org/10.1186/s12916-016-0640-4> (accessed September 2022).
2. Giovanni Guaraldi, *et al.* “Moving Fourth”: A Vision Toward Achieving Healthy Living with HIV Beyond Viral Suppression. *AIDS Rev.* 2019; 21(3): 135-142. Available at: <https://www.aidsreviews.com/resumen.php?id=1495&indice=2019213&u=unp> (accessed September 2022).
3. WHO. Health Statistics and information systems. *WHOQOL: Measuring Quality of life.* Available at: <https://www.who.int/tools/whoqol> (accessed September 2022).
4. Annemiek Schadé, *et al.* HIV-infected mental health patients: characteristics and comparison with HIV-infected patients from the general population and non-infected mental health patients. *BMC Psychiatry.* 2013; 13:35. Available at: <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/1471-244X-13-35> (accessed September 2022).
5. Maria Giulia Nanni, *et al.* Depression in HIV infected PLHIV: a Review. *Curr Psychiatry Rep.* 2015; 17:530. Available at: <https://link.springer.com/article/10.1007/s11920-014-0530-4> (accessed September 2022).
6. Noe Garin, *et al.* Recreational drug use among individuals living with HIV in Europe: review of the prevalence, comparison with the general population and HIV guidelines recommendations. *Front Microbiol.* 2015; 6:690. Available at: <https://www.frontiersin.org/articles/10.3389/fmicb.2015.00690/full> (accessed September 2022).
7. Christiana Nöstlinger, *et al.* HIV-Related discrimination in European health care settings. *AIDS Patient Care STDS.* 2014; 28(3): 155-61. Available at: <https://www.liebertpub.com/doi/abs/10.1089/apc.2013.0247> (accessed September 2022).
8. Vanessa Cooper, *et al.* Measuring quality of life among people living with HIV: a systematic review of reviews. *Health and Quality of Life Outcomes.* 2017; 15:220. Available at: <https://hqlo.biomedcentral.com/articles/10.1186/s12955-017-0778-6> (accessed September 2022).
9. Meaghan Kall, *et al.* Patient-reported outcomes to enhance person-centred HIV care. *Lancet HIV.* 2020; 7(1): e59-e68. Available at: [https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018\(19\)30345-5/fulltext](https://www.thelancet.com/journals/lanhiv/article/PIIS2352-3018(19)30345-5/fulltext) (accessed September 2022).
10. Ethan Basch, *et al.* Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. 2015; 34(6): 557-65. Available at: <https://ascopubs.org/doi/10.1200/JCO.2015.63.0830> (accessed September 2022).
11. Melanie Calvert, *et al.* Reporting of Patient-Reported Outcomes in Randomized Trials. *JAMA.* 2013; 309(8): 814-822. Available at: <https://jamanetwork.com/journals/jama/fullarticle/1656259> (accessed September 2022).
12. Kimberly A Koester, *et al.* The influence of the ‘good’ patient ideal on engagement in HIV care. *PLoS ONE.* 2019; 14(3): e0214636. Available at: <https://pubmed.ncbi.nlm.nih.gov/30921440/> (accessed September 2022).
13. E. Jeniffer Edelman, *et al.* Patient and Provider-Reported Symptoms in the Post-cART Era. *AIDS Behav.* 2011; 15(4): 853-861. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3118476/> (accessed September 2022).
14. Célyne H Bastien, *et al.* Validation of the Insomnia Severity Index as an Outcome Measure for Insomnia Research. *Sleep Med.* 2001; 2(4): 297-307. Available at: <https://www.sciencedirect.com/science/article/abs/pii/S1389945700000654> (accessed September 2022).
15. WHO. eHealth. 2018. Available at: [https://www.who.int/health-topics/digital-health#tab=tab\\_1](https://www.who.int/health-topics/digital-health#tab=tab_1) (accessed September 2022).
16. Guido E L van den Berk, *et al.* Improving HIV-related care through eHealth. *National Library of Medicine.* 2020; 7(1): e8-e10. Available at: <https://pubmed.ncbi.nlm.nih.gov/31776102/> (accessed September 2022).
17. Farmalarm. Available at: <https://www.vallhebron.com/farmalarm/> (accessed September 2022).

