MOVING
FOURTH

Feedback & Discuss

Improving patient-healthcare professional dialogue and shared decision making in HIV care

PHARMACEUTICAL COMPANIES OF Johnson & Johnson

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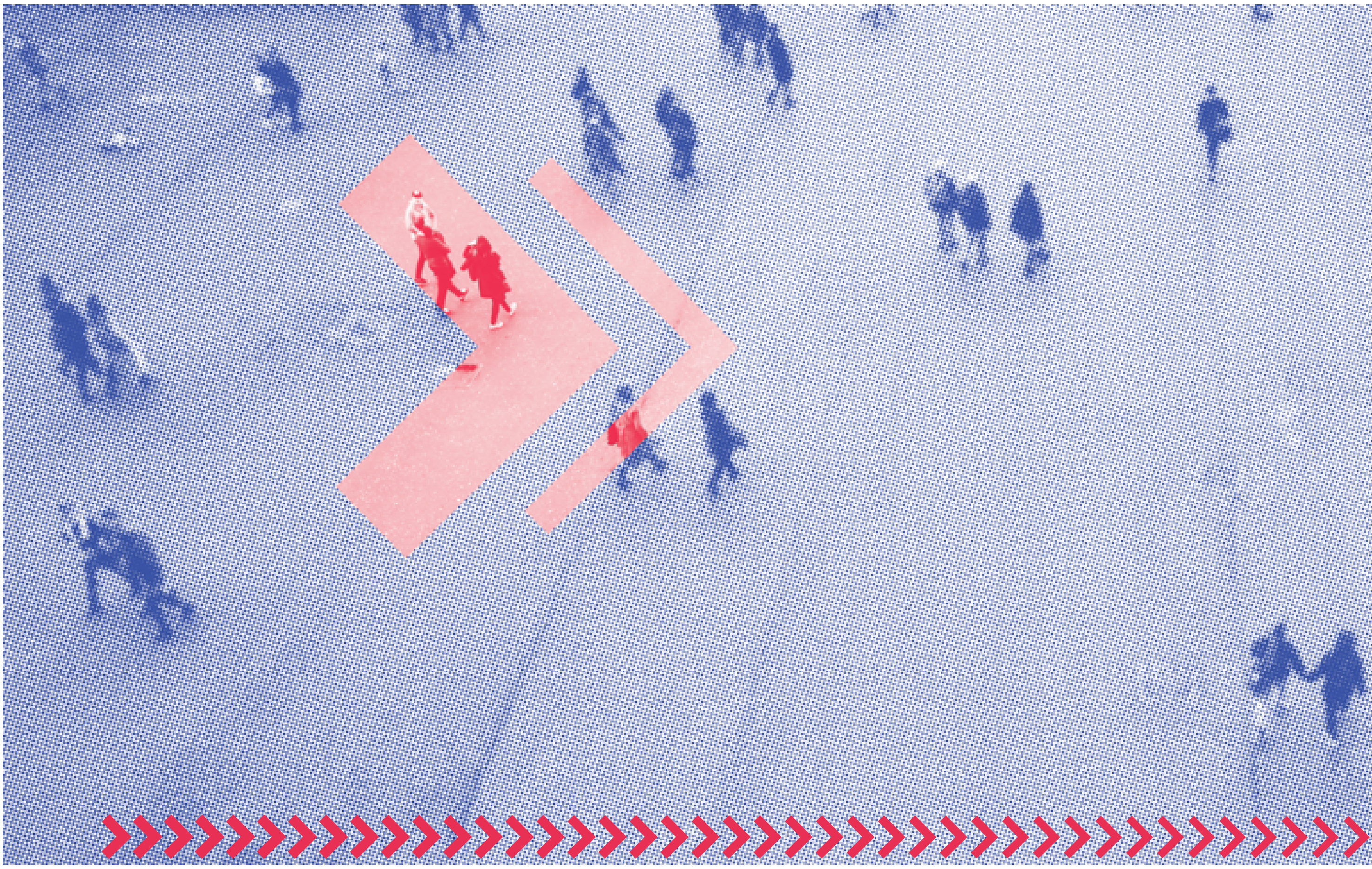
Executive summary

In the first chapter of Moving Fourth, the Steering Committee proposed the *Health Goals for Me* concept and supporting framework – a three-step plan with the vision of achieving long-term healthy living with HIV, through close collaboration and mutual decision making between healthcare professionals (HCPs) and people living with HIV (PLHIV).[1]

Following the proposal of the *Health Goals for Me* framework, the Steering Committee developed a set of recommendations around the first step *Ask & Measure*. The recommendations provide guidance on the use of patient-reported outcome measures (PROMs) to help assess each individual's quality of life (QoL) status.[2]

We now advance closer to implementing the *Health Goals for Me* framework in clinical practice by providing practical recommendations for the second step *Feedback & Discuss*. Focusing on improving dialogue and shared decision making (SDM) between HCPs and PLHIV, these recommendations address the barriers to effective communication and SDM, whilst considering the evolving landscape of HIV care. Not just as it adapts to the changing needs of PLHIV, but also considering the implications of the COVID-19 pandemic, which has contributed to the adoption of digital health and remote care.

This **Expert Opinion Piece** summarises the Steering Committee's recommendations for HCPs and PLHIV to support and improve collaboration, SDM and individualised goal setting.



Introduction

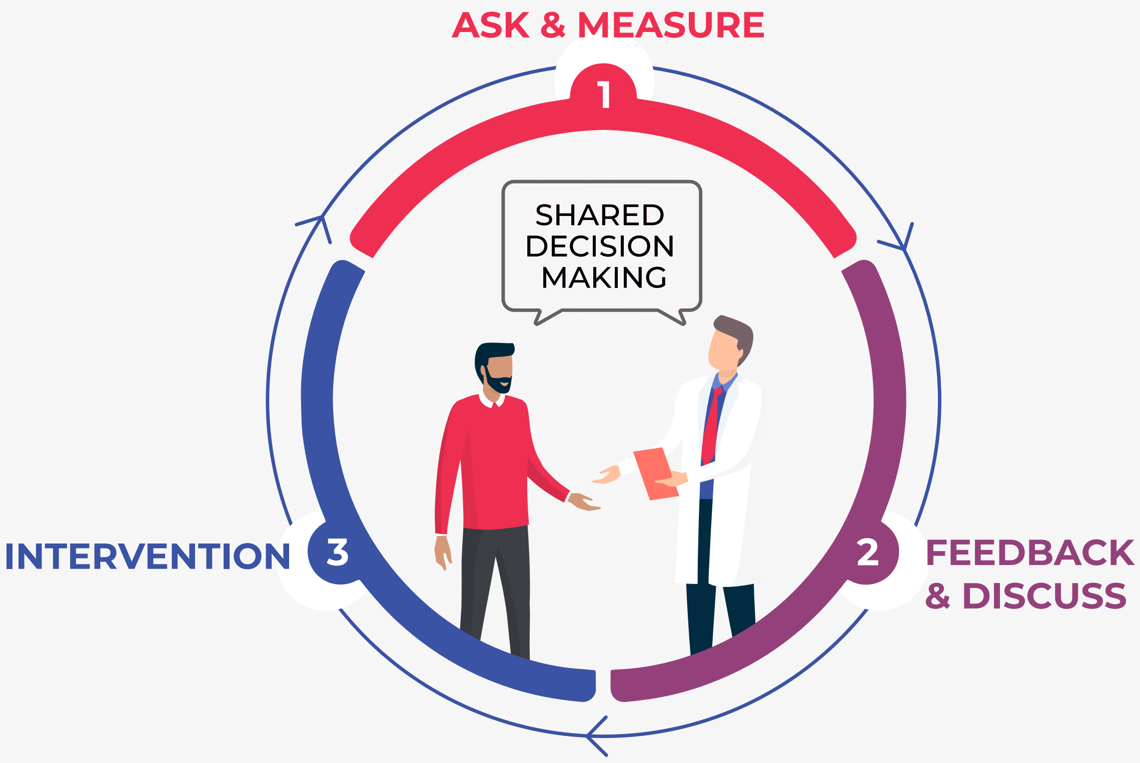
The Moving Fourth Steering Committee initiated the *Health Goals for Me* framework with the vision of achieving long-term healthy living with HIV beyond viral load.[1] This system was designed to facilitate HCPs and PLHIV working together to mutually agree on care objectives for each individual in a continuous cycle that follows three key steps:

ASK & MEASURE – Asking the right questions and measuring health data

FEEDBACK & DISCUSS – Sharing feedback and discussion of management options taking into consideration information obtained from the first step

INTERVENTION – Agreeing on individual objectives for care and a hierarchy of interventions

Figure 1. The collaborative *Health Goals for Me* framework developed by the Moving Fourth Steering Commitee



Whilst building this framework, we recognised the importance of providing appropriate guidance to help HCPs and PLHIV apply each step in everyday clinical practice. With this in mind, we developed a system of recommendations for *Ask & Measure*.[2]

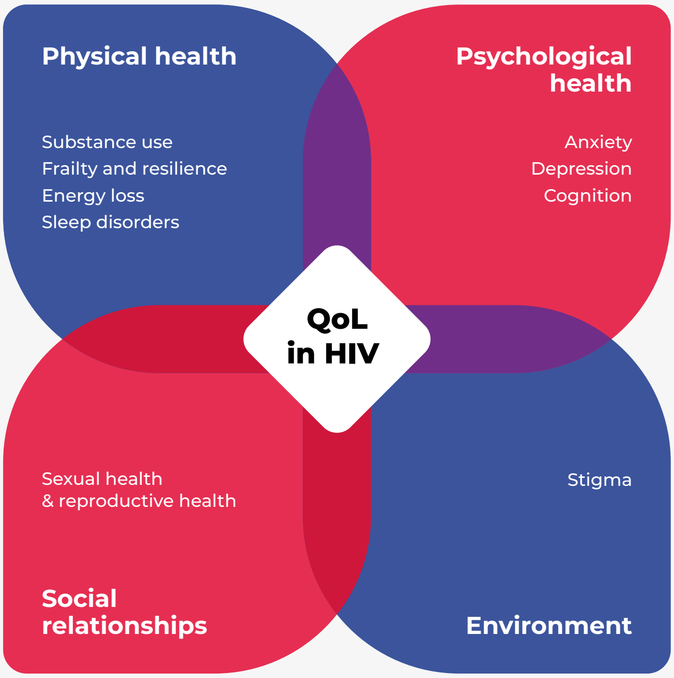
Focus has now turned toward the next step of the framework, *Feedback & Discuss*. In this **Expert Opinion Piece,** the Steering Committee consider the important drivers of these key elements and present a set of practical recommendations toward this step.

Moving Fourth Step 2:

Feedback & Discuss

The first step of the Moving Fourth *Health Goals for Me* framework, *Ask & Measure,* uses PROMs in HIV to help HCPs and PLHIV identify the relevant issues, ask the right questions and measure nine factors across four key domains (physical health, psychological health, social relationships and environment) that may affect the QoL of an individual (Figure 2).

Figure 2. The four key domains and nine factors that impact QoL in PLHIV, as proposed by the Steering Committee based on the World Health Organisation Quality of Life Instruments (WHOQoL-BREF)[3]



Once the health status is measured, the next step, *Feedback & Discuss,* is to feedback information to the PLHIV and discuss priorities and potential interventions. This step can be broken down into two key components:

FEEDBACK – Provide the health status information in a format that the PLHIV can easily interpret

DISCUSS – Continually support PLHIV to share their information and discuss its relevance to the choice of appropriate intervention in partnership with their HCP

Identifying relevant issues, asking the right questions, measuring the individual's health status and then feeding this information back to the PLHIV should be continuous throughout long-term HIV care. As PLHIV build greater awareness of their own health status and information and see the impact it may have on their well-being and QoL, they are more likely to participate in SDM and make meaningful changes to their lives. Moreover, the issues related to care that are perceived as important to a PLHIV can change over time. As such, effective ongoing communication and collaboration between both stakeholders is crucial to set individual goals for care and select interventions to achieve them. Understanding and providing guidance on how to improve communication and SDM between HCPs and PLHIV, will help continue progressing toward healthy living with HIV beyond viral suppression.

The current consultation scenario

Existing guidelines

Although there are several existing tools and guidelines that encourage and improve HCP-PLHIV dialogue, these are either too specific or too general. For example, a tool published by the International Association of Providers of AIDS Care is useful in supporting meaningful discussions between HCPs and PLHIV but is only targeted to women with HIV.[4] On the other hand, a set of United States guidelines provides practical tips for PLHIV on how to prepare for their next HCP consultation, but does not seem to be anchored on any one validated model.[5] Thus, there is a pressing need for updated guidance that broadly addresses the wider HIV patient community, while specifically focusing on the gaps and barriers faced by both HCPs and PLHIV around communication and SDM.

Barriers and challenges

A long-term, trusting HCP-PLHIV relationship is an essential part of HIV care.[6] The Steering Committee recognise the progress made in this regard thus far; it has become apparent that HIV management has pioneered a unique approach to care more broadly, where both parties of the care relationship often have balanced roles and responsibilities. Despite this, there are still several organisation and cultural barriers to optimal communication and SDM between the two stakeholders which can hinder effective HIV care (Figure 3).

Organisation barriers

Every PLHIV should be granted access to effective HIV diagnostics and treatment. However, despite scientific advancements in HIV care, several countries are far from achieving the UNAIDs 90-90-90 targets.[*7] As a result, a significant number of people still do not have access to effective HIV prevention, diagnosis, treatment and care.[8,9,10] At the end of 2020, 10.2 million people were still waiting for access to anti-retroviral treatment (ART) globally.[8] This is partly due to organisational and policy barriers.[9,10] Moreover, inequality in healthcare services means people living in certain regions, such as rural areas, may face greater barriers in accessing HIV care.[10]

As HIV care starts with diagnosing HIV, the first 90 – diagnosing 90% of people living with HIV – is a critical component in the global health community effort to end the AIDS epidemic.[7] However, substantial gaps in HIV testing coverage mean many countries with the most devastating HIV epidemics have been the slowest in achieving the first 90.[7,10]

One organisational barrier that can impede effective communication and SDM is an inconsistent healthcare team. For a chronic condition such as HIV, the HCP-PLHIV relationship throughout the continuum of care must stay consistent. However, there is often a continuous rotation of HCPs that care for PLHIV, which can result in a lack of trust and reduced SDM. For this reason, it is important PLHIV are able to visit the same HCP, where possible.[11,12]

Moreover, time constraints due to competing priorities, poorly timed appointments, interruptions during visits and noise and distractions in the consultation environment are commonly experienced and are major organisation barriers among some PLHIV when initiating discussions.[13,14,15,16] As such, making better use of time during consultations, while ensuring a quiet and private environment, is necessary to resolve existing communication barriers.

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*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 Steering Committee 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.

Cultural barriers

Cultural factors can complicate and inhibit HIV treatment and care. For example, findings from a survey around patient experiences and views on ART show that, whilst the majority of people are very comfortable with raising issues of concern with their main HIV doctor, feelings of guilt and a need for secrecy still remain.[17] The anticipated stigma may have implications on the PLHIV-HCP relationship and, thus, care.[13] Additionally, difficulties in engaging in conversations around sensitive topics (e.g., sexual health) can impede effective dialogue between an individual and their HCP.[15]

Another important barrier to effective communication is differences between HCPs and PLHIV in terms of identity and culture. Non-inclusion of cultural norms and values can often hinder effective communication and lead to misinterpretation or reinterpretation of key HIV messages.[13,15,16,18] Indeed, a disparity often exists between HCPs and PLHIV around care priorities and concerns that should be addressed together.[10]

Other barriers

Outside of organisational and cultural barriers, there are several factors that can impede effective communication. These include HCPs use of medical jargon and overloading people with information.[15]

Figure 3. Summary of key communication and SDM barriers faced by PLHIV and HCPs that can hinder effective HIV care[9–18]

Organisation barriers	Cultural barriers
· Limited access to HIV prevention, treatment and care · Inconsistent healthcare team · Time constraints · Environmental issues	· Anticipated stigma · Difficulties in engaging in sensitive conversation topics · Different cultural values and beliefs

Evolution of HIV care

Another challenge associated with HIV care is that, as a chronic condition, it requires long-term management. As a result, the health needs of individuals will likely change as they progress through the different stages of life.[19] Consequently, the approach to care also needs to adapt. For example, the Steering Committee acknowledges that promotion of health literacy and a disease-focus may be required at the beginning of the journey, whereas QoL and PROMs become more important at later stages. Additionally, PLHIV may be less engaged at different stages of their care journey, which presents additional challenges.[20] Utilising different tools and communication to personalise care and adapt to the evolving needs of PLHIV is considered key to overcome these setbacks.

In addition, it is becoming apparent that digital health is transforming care. The use of digital health technologies, such as electronic and mobile health, to make health systems and services more efficient was widely recognised even prior to the COVID-19 pandemic.[21] The pandemic, however, has seen healthcare systems and patients momentarily embrace a shift to online and virtual consultations.[21,22,23] Although this brings certain benefits, PLHIV and HCPs may face challenges as a consequence of remote care.[22] For example, people who traditionally experienced barriers to accessing face-to-face care, like people with mobility issues or those who fear stigma when attending clinic visits, may find remote care beneficial.[22,23] The convenience of remote care can also result in a number of benefits, including decreased travel time, expenses or time away from work.[22] However, many people who are unfamiliar with technology may lack the digital skills required to access digital healthcare services. This can prevent people getting help if their only choice is a remote consultation.[22] Moreover, PLHIV report concerns about privacy, data breaches, billing and insurance challenges associated with remote care.[23]

Steering Committee recommendations:

Feedback & Discuss

To overcome some of the identified barriers and considerations, the Steering Committee propose a set of practical recommendations designed to improve HCP-PLHIV dialogue and promote SDM. These recommendations were also developed keeping in mind the benefits and challenges associated with digital and remote HIV care.

More specifically, the guidance includes recommended actions that HCPs and PLHIV can carry out before, during and after consultations, to actively stimulate effective communication, SDM and mutual responsibility of care – towards the ultimate goal of improving QoL. Central to this is effective listening and building knowledge – ensuring that both individuals are understood and have the information they need, from themselves and each other, to make well-informed and collaborative health decisions.

Recommendations for HCPs

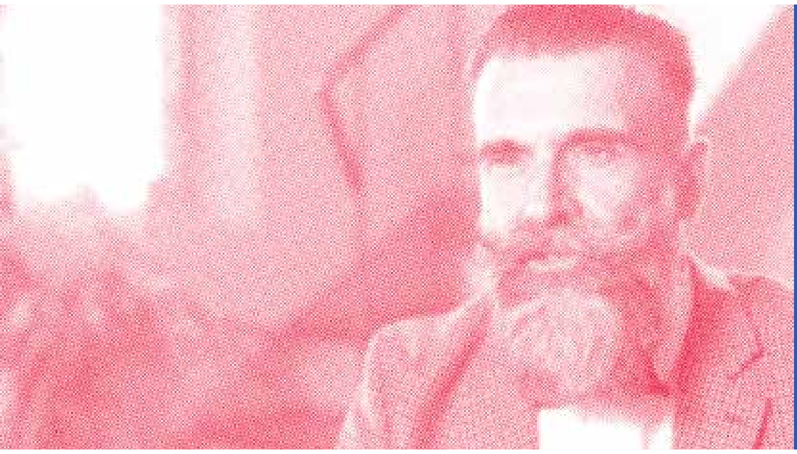
Preparation is key

As time was highlighted as a major barrier to effective communication and SDM, pre-consultation preparation may be required in complex cases to ensure efficiency during visits. The Committee therefore recommends HCPs collect key information, where possible, prior to the consultation to help save time and personalise care. This could include fundamental health information such as the individual's medical history, PROMs and previous consultation notes, or obtaining a greater understanding of individual needs. The latter can be achieved by identifying which health goals need improving, to better understand what decisions need to be made in order to drive SDM. In the future, digital solutions may help facilitate more extensive pre-visit preparation for more cases, as it allows for better information sharing between HCPs and PLHIV.

Accounting for PLHIV preferences and implementing the correct approach

During consultations, the Committee recommends that HCPs frame discussions with PLHIV to produce informative and actionable outcomes, for example, by considering the key questions that he/she may have when interventions have been identified. It is also important to assess the level of SDM that PLHIV are willing to contribute and commit to, both at the beginning and throughout the care journey. The Committee identified that establishing clear care plans and goals with PLHIV is an effective driver of communication; not only stimulating for open discussions, but also for identifying priorities and giving individuals the opportunity to focus on specific issues relevant to them.

Careful consideration of the appropriate communication style during consultations is essential to encourage PLHIV to be involved in conversations. This style can be summarised into a so-called 'counselling approach' – using a non-judgemental attitude and listening actively to the individual can support and empower them to reach a decision around interventions themselves.



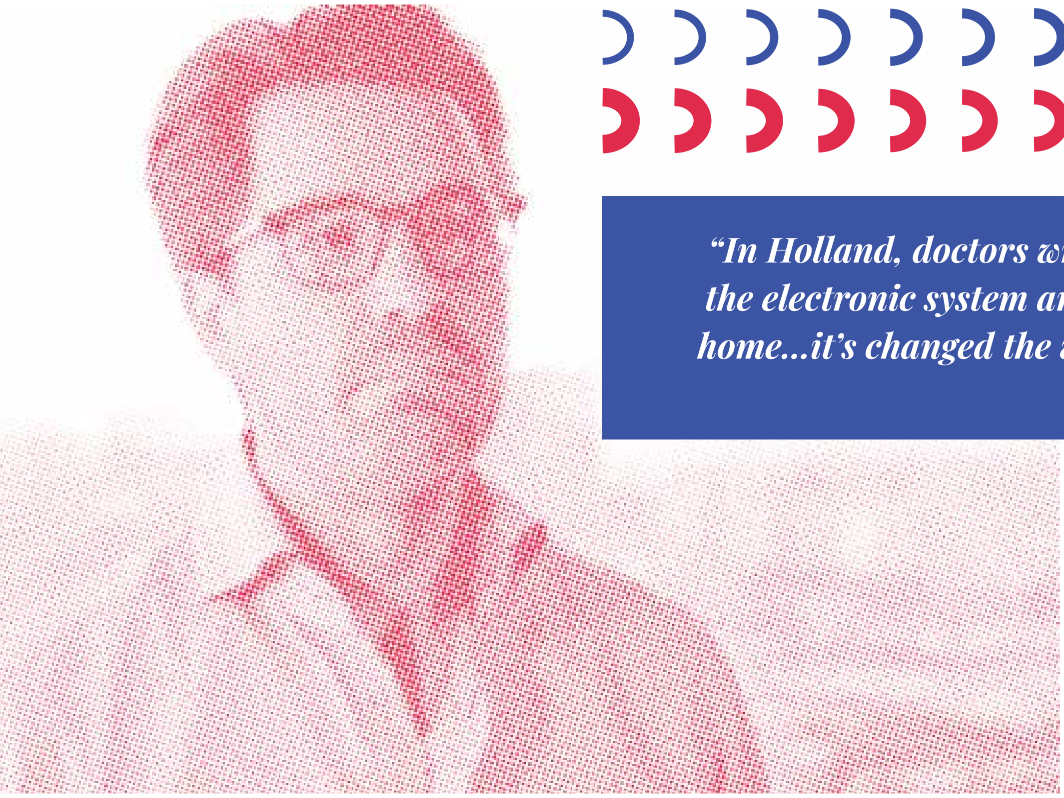
> *"A counselling approach – it means that we do not necessarily have the solution, but rather we try to make the PLHIV understand which are the resources that he/she can review in order to find the solution."*
>
> *– Dr Giovanni Guaraldi*

As part of this attitude, HCPs should be respectful and prudent when communicating with PLHIV and, importantly, be conscious of cultural beliefs and values they hold, even if they differ to their own – a key barrier to communication and SDM. Another communication consideration is ensuring the style is adapted depending on the format of the consultation, particularly as HIV care becomes increasingly digital and remote. It is recommended that HCPs use direct, closed questions during virtual formats and open questions during face-to-face format.

In terms of time-saving recommendations, a problem-solving approach can help prioritise which issues to focus on during the consultation. Whilst, managing expectations in terms of which issues can be realistically discussed with an infectious disease specialist can help avoid disappointment and help focus discussions. However, it is vital that adequate time is allocated to address both disease and general health during the consultation.

›› ***Knowledge is power***

Finally, the Committee recommends that HCPs allow PLHIV to make an audio or written recording during consultations if they would find it useful. Additionally, as some countries now enable remote access to electronic health records, providing an electronic record or summary of the consultation after the visit is also recommended if applicable. This will ensure the individual has the knowledge and tools they need to inform SDM. In this situation, HCPs should be aware that, when writing consultation notes, the messages and tone are appropriate for a patient audience. It is also important that the information provided to PLHIV is delivered traditionally (i.e., written format) as well as digitally, to ensure individuals that are unable to use digital technologies do not feel excluded, as discussed earlier. HCPs should also take care when storing and disseminating patient information to address any privacy concerns.



> *"In Holland, doctors write down a medical note in the electronic system and the PLHIV can view it at home…it's changed the way doctors are reporting."*
>
> *– Dr Joop Arends*

Figure 4. Summary of the Steering Committee recommendations for HCPs to drive effective communication and SDM in HIV care

Pre-consultation

Where possible, collect sufficient information/data on the medical history and PROMS for the PLHIV to save time and ensure the approach is personalised

Identify which health goals need to be improved to understand what decisions need to be made

During consultation

Consider the key questions that PLHIV may have once interventions have been identified

Set a clear care plan for the PLHIV with specific goals tailored to the individual

Assess the level of SDM PLHIV wish to contribute and commit to

Use a counselling approach through non-judgemental communication, active listening and supporting PLHIV to reach intervention decisions themselves

Be respectful and prudent when communicating with PLHIV, considering any differences in cultural beliefs and values

Use a problem-solving approach by prioritising which issues to focus on during the consultation

Adapt communication style depending on the format of the consultation – use direct, closed questions during virtual formats and open questions during face-to-face format

Ensure adequate time to address both disease and general health during the consultation

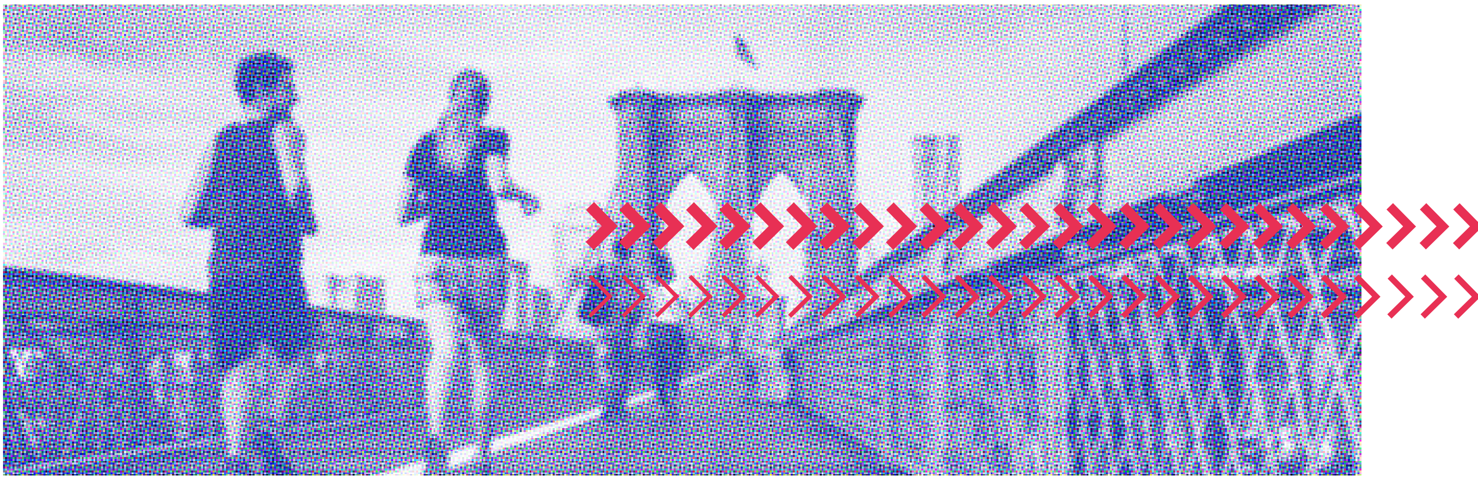
Manage expectations in terms of which issues can be realistically discussed with an infectious disease specialist

Allow PLHIV to make an audio recording or written notes of consultations to help inform SDM should they find this useful

Post-consultation

Provide PLHIV with the knowledge and information they need to make informed decisions, through electronic health records and/or consultation summaries

Ensure post-visit communication via electronic health records is suitable for PLHIV



Recommendations for PLHIV

Preparing for consultations and addressing the right questions

In terms of pre-consultation preparation, PLHIV should identify one to three key questions or concerns that should be the focus of a consultation. Such questions can be identified by the individual or pre-defined by the HCP, depending on preferences. Importantly, PLHIV should be reminded that questions or concerns can be important to discuss, even if he/she does not perceive them to be. As such, even the factors that may or may not seem meaningful should always be kept into consideration, particularly if they impact QoL.

Identifying PROMs should also be considered as a crucial component of pre-consultation preparation. PROMs can help facilitate the flow of communication and focus discussions on critical aspects emerging from the questionnaire. As such, PLHIV should recognise the importance of these measures and must be encouraged to take the time to fill out PROM questionnaires out prior to health visits.

Importantly, this collected information and data should be easily accessible in both a digital format and a written format to ensure inclusivity and that *"no one is left behind"* – an important consideration when adapting to a digital world. Digital tools, like smartphone application or websites can play an important role when sharing information with HCPs, for example PROM questionnaires, to help make visits more efficient and allowing both stakeholders to focus on the issues that really matter for the PLHIV.

Being truthful and open

Facilitating open and honest discussions both at the beginning and over the course of the PLHIV-HCP relationship, is crucial for effective communication and SDM. PLHIV should recognise that being open and sincere to their HCP about health concerns and personal issues during consultations can be beneficial to their care, as they are not always aware of the advantages. This could be an effective means of optimising communication between the PLHIV and HCP, but also making HCP aware of certain aspects like stigma, mental health, loneliness and social isolation or economic issues, which are not always captured during consultations. As part of this, PLHIV should communicate what HIV means to them personally to their HCP at the start and throughout their care journey. This will help ensure care is personalised depending on the evolving circumstances and needs of the individual.

> ***"It should be an open discussion with your doctor, let him/her know right from the beginning, and in the course of the relationship, what HIV means for yourself."***
>
> – *Mario Cascio*

Taking responsibility for their own health

Ensuring PLHIV are empowered and well-informed is important to drive dialogue and SDM. PLHIV should be aware of their role within the care relationship. They should understand which aspects they have the right to ask or challenge during consultations. Conversely, they should be aware of their duties in their own care, including their responsibilities when preparing for consultations (e.g., PROM questionnaires).

Additionally, once a specific intervention has been identified, PLHIV should actively ask themselves, or their HCP, three key questions: 'What are the possibilities with the intervention?'; what are the advantages and disadvantages of the intervention?'; and 'what does that intervention mean personally for me given my situation

> ***"PLHIV should be aware of their rights and role within the therapeutic relationship – they should be aware of their right to ask and challenge."***
> *– Mario Cascio*

Increased knowledge for informed decisions

As mentioned previously, empowering PLHIV and equipping them with the information they may need can help them make care decisions in collaboration with their HCPs. It is therefore recommended that they have the option to make audio recordings or written notes during consultations and have access to electronic health records or consultation summaries provided by their HCP.

Figure 5. Summary of the Steering Committee recommendations for PLHIV to drive effective communication and SDM in HIV care

Pre-consultation
Prepare 1–3 key questions to focus during each consultation, either defined by you or provided by your HCP
Complete PROM questionnaires prior to consultations to identify priorities
During consultation
Do not assume an issue is insignificant – any factor that impacts your QoL should be shared with your HCP
Recognise that being open and sincere to your HCP about personal issues can be beneficial to your care and well-being
Try to understand what HIV means for you and communicate this to your HCP at the beginning and throughout your care journey
Provide adequate and correct information to your HCP according to your set care plan
Be aware of your role and responsibility within the care relationship and what aspects you have the right to ask or challenge during consultations
Once an intervention has been identified, ask yourself and/or your HCP three key questions (e.g. what are the possibilities with the intervention? What are the advantages and disadvantages of the intervention? What does that intervention mean personally for me given my situation?)
Make an audio recording or written notes of consultations if desired to help inform decision making
Post-consultation
Utilise electronic health records and/or consultation summaries provided by your HCP to inform your care decisions

Conclusion

The Moving Fourth Steering Committee recommendations highlight the critical importance of a consistent, personalised and evolving approach to HIV care, where education, non-judgmental listening and open communication are key. Such a system should support all PLHIV in collaborating with their HCP and making informed care decisions that are consistent with their needs, values and preferences.

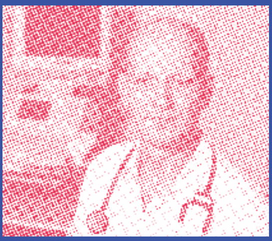
Following establishment of recommendations for Feedback & Discuss, the next important consideration is to identify how they can be implemented in parallel with any existing guidelines. Finally, to complete the third chapter of Moving Fourth, we will develop a practical system for the next and final step of the framework, Intervention. To do this, we will examine case studies which illustrate the implementation of interventions that support overall health and well-being in the clinic, based on joint priority setting and shared decision making.

Here, we take a great stride towards long-term healthy living with HIV, by providing a set of practical recommendations for enhanced dialogue and SDM, which can stimulate collaboration and PLHIV empowerment, to, ultimately, achieve the second step of the *Health Goals for Me* framework.

Conflict of interests

Dr Joop Arends
reports advisory board fees from Janssen and ViiV Healthcare.

Dr Guido van den Berk
has nothing to disclose.



Dr Thomas Buhk
reports advisory board fees and/or personal fees from Galapagos, Gilead, Janssen and ViiV.

Mario Cascio:
reports personal fees from Janssen and ViiV Healthcare.

Dr Adrian Curran
reports personal fees from Janssen.

Dr Giovanni Guaraldi
reports personal fees and grants from Janssen, ViiV Healthcare, Gilead and Merck.

Dr Eugenio Teofilo
reports advisory board fees from Gilead, Janssen, ViiV Healthcare and MSD and consultancy fees from ViiV and MSD.

All information listed on this page regarding the members of the Moving Fourth Steering Committee is correct as of August 2021.

Christian Verger contributed to the First Chapter of Moving Fourth (2019), however discontinued his efforts with the Steering Committee thereafter and in the subsequent Chapters (2020, 2021).

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