



Introduction

Patient-Reported Outcomes (PROs)

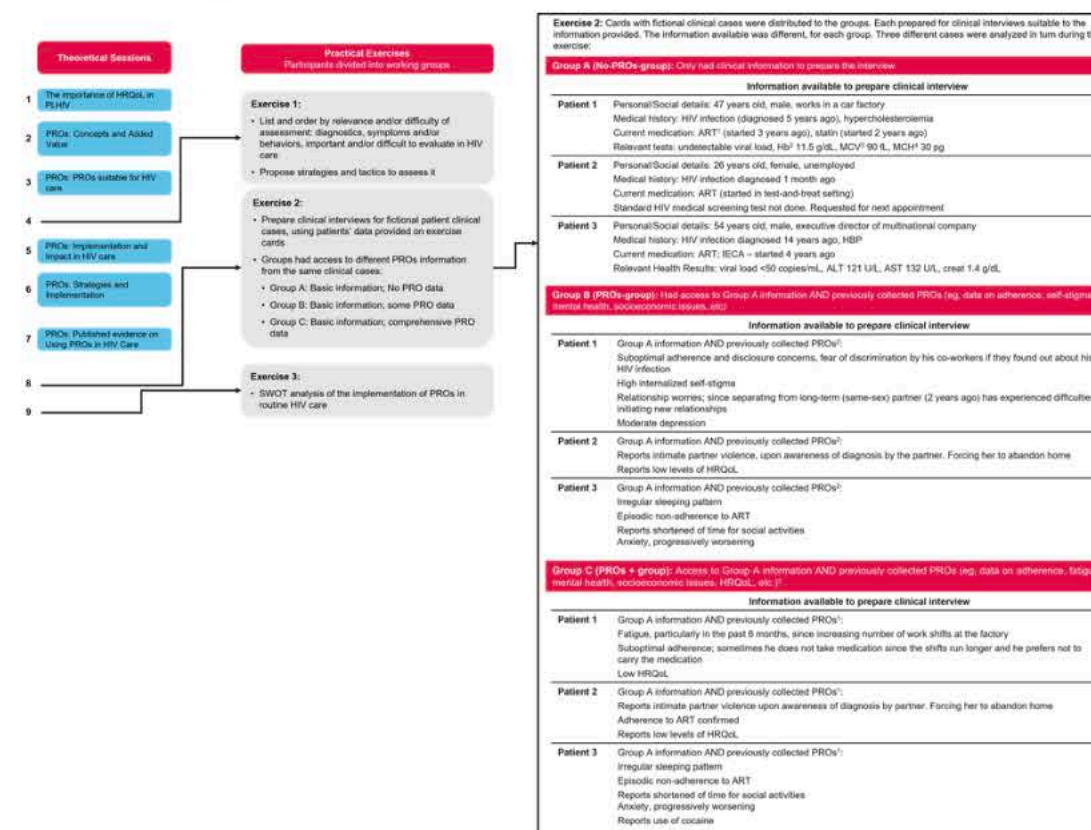
- Well-implemented PROs can add value to routine HIV care by facilitating improved patient-centered care:

OPEN

Methods

- The workshop consisted of **six brief theoretical presentations combined with three interactive practical exercises** (see Figure 1).

Figure 1. PRO-Act Workshop agenda: Brief theoretical presentations, combined with interactive practical cases with the intervention of all participants.



Theoretical and practical sessions

OPEN

Results

- Participants identified several common themes relating to assessment challenges where PROs can provide valuable insights.
- Following the practical sessions, **participants acknowledged the value of PROs in clinical interview preparation.**

OPEN

Objectives

- PROs are not commonly integrated in routine Portuguese HIV care**, mainly due to the absence of guidance on implementation and standardization [7,8].
- The «**PRO-Act**» project aims to **raise awareness on the added value of PROs integration in routine HIV care and provide a replicable framework to boost PRO implementation.** The first activity was a **master-workshop**, in which **Portuguese HCPs** (physicians, nurses, pharmacists) were **informed on**

OPEN

Conclusions

- All participants considered the **contents of the workshop pertinent or very pertinent** and 90% considered the information shared to be **impactful or very impactful, for clinical practice**, highlighting the workshop's real-world impact.
- Participants suggested the **inclusion of practical exercises using PRO scales/tools would be valuable.**

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Introduction

Patient-Reported Outcomes (PROs)

- Well-implemented PROs can add value to routine HIV care by facilitating improved patient-centered care:
- PROs can:
 - Provide the patient's perspective on the effect of HIV and its treatment [1].
 - Promote the prioritization of the discussion topics in the medical appointment, thus helping to align the healthcare providers' expectations with what matters most to the patient.

PROs in Modern HIV Care

- Significant improvements in HIV medication now mean that people living with HIV (PLHIV) have a life expectancy similar to those without HIV, but compared to the general population, PLHIV have lower HRQoL [2,3].

PLHIV experience higher rates of [2,4,5].

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PROs in Modern HIV Care

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- PLHIV experience higher rates of [2,4,5]:



Co-morbidities



Substance use



Depression



Violence in
intimate relationships



Stigma, discrimination,
psychosocial issues



Challenges in communication
and shared decision-making
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- PLHIV experience higher rates of [2,4,5]:



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Challenges in communication
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- Many of these aspects are not directly observable and often are undisclosed to HCPs.
- An effective way to assess PLHIV's needs is to collect PROs in routine HIV care [6].

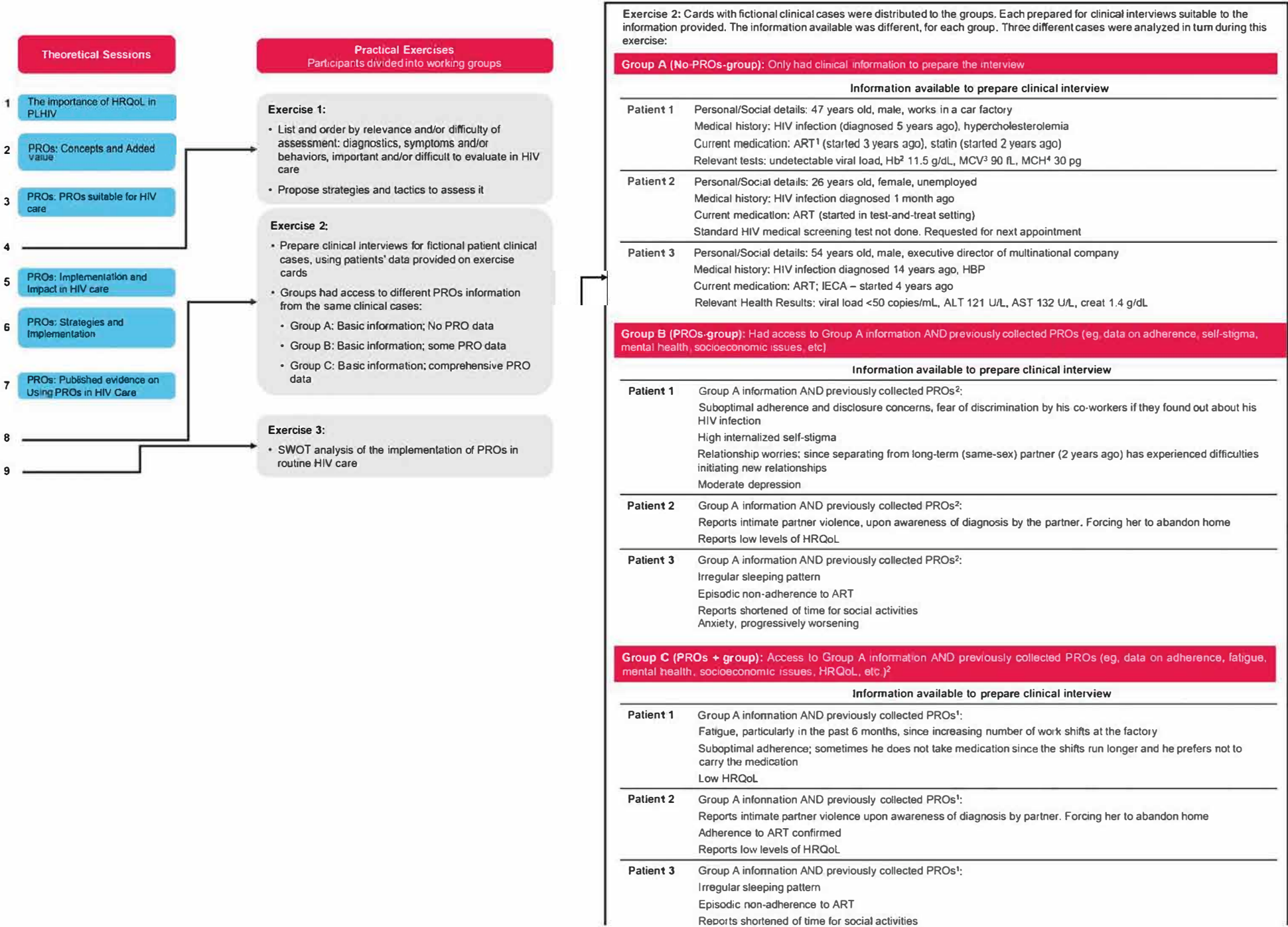
Objectives

- **PROs are not commonly integrated in routine Portuguese HIV care**, mainly due to the absence of guidance on implementation and standardization [7,8].
- The «**PRO-Act**» project **aims to raise awareness on the added value of PROs integration in routine HIV care and provide a replicable framework to boost PRO implementation**. The first activity was a **master-workshop**, in which **Portuguese HCPs** (physicians, nurses, pharmacists) were **informed on the relevance of PROs, available resources, and means of implementation in routine clinical HIV care**.

Methods

- The workshop consisted of **six brief theoretical presentations combined with three interactive practical exercises** (see Figure 1).

Figure 1. PRO-Act Workshop agenda: Brief theoretical presentations, combined with interactive practical cases with the intervention of all participants.



Methods

Reports low levels of HRQoL	
Patient 3	Group A information AND previously collected PROs ² : Irregular sleeping pattern Episodic non-adherence to ART Reports shortened of time for social activities Anxiety, progressively worsening
Group C (PROs + group): Access to Group A information AND previously collected PROs (eg, data on adherence, fatigue, mental health, socioeconomic issues, HRQoL, etc.) ²	
Information available to prepare clinical interview	
Patient 1	Group A information AND previously collected PROs ¹ : Fatigue, particularly in the past 6 months, since increasing number of work shifts at the factory Suboptimal adherence; sometimes he does not take medication since the shifts run longer and he prefers not to carry the medication Low HRQoL
Patient 2	Group A information AND previously collected PROs ¹ : Reports intimate partner violence upon awareness of diagnosis by partner. Forcing her to abandon home Adherence to ART confirmed Reports low levels of HRQoL
Patient 3	Group A information AND previously collected PROs ¹ : Irregular sleeping pattern Episodic non-adherence to ART Reports shortened of time for social activities Anxiety, progressively worsening Reports use of cocaine

- Theoretical and practical **sessions provided an overview of PROs and their added value in HIV care from implementation studies.**
- The groups sequentially presented their thinking on clinical interviews based upon their increasing availability of data.
- **Practical exercises using PLHIV examples with both the presence and absence of previously collected PROs** showed the impact of successfully addressing patient-specific issues and how to conduct clinical interviews more efficiently.

Results

- Participants identified several common themes relating to assessment challenges where PROs can provide valuable insights.
- Following the practical sessions, **participants acknowledged the value of PROs in clinical interview preparation.**
- **The PROs-groups would be much more likely to successfully address important patient-specific issues than the non-PROs-group.**

Table 1. Results from exercise 1

Exercise 1		
Aspects of HIV		
Considered of greatest relevance in Clinical Practice, by participants	Deemed as most difficult to assess in HIV Clinical Practice, by the participants	Potential strategies to overcome assessment challenges in Clinical Practice, proposed by participants
<ul style="list-style-type: none">• Neuropsychiatric symptoms• Socioeconomic conditions• Patient–HCP communication• Depression• Alcohol consumption• Self-stigma• Neurocognitive changes (memory, sleep quality)• Sexuality (maternity, breastfeeding, contraception, relationships)• Substance abuse• Adherence to therapy	<ul style="list-style-type: none">• Neuropsychiatric symptoms• Sexual risk behavior• Addictive behaviors (alcohol, drugs)• Changes in memory• Substance abuse (drugs)• Stigma• Adherence to therapy• Domestic/Work violence, discrimination	<ul style="list-style-type: none">• Anonymous questionnaires• Strategy adaptation to individual cultural context and literacy level• Multidisciplinary teams• Promotion of simultaneous direct contact with HCPs from different medical specialties• Collaboration with community-based non-governmental organizations (NGOs)• Communication improvement between patients, physicians, nurse, NGOs, and healthcare administrators• Improvement of patients and general population (eg, in schools) health literacy• Better communication skills of HCPs: focusing on sensitivity and empathy• Training HCPs to correctly interpret and act accordingly to PROs' findings

Results

Table 2. Results from exercise 2

Exercise 2

Groups effectively identified several issues relevant to clinical practice.

The no-PRO-group was unable to identify important issues that are difficult to observe, for example, the need for social support and the presence of depression in clinical case #1

Table 3. Results from exercise 3

Exercise 3

Participants' Analysis of the implementation of PROs in routine HIV care in Portugal			
Strengths		Challenges	
<ul style="list-style-type: none">Improved communication between patients and HCPsEnhanced problem identificationTime optimizationCreation of interdisciplinary channelsIncreased HIV care team motivationImproved patient satisfactionAutonomy to develop local PRO pilot projects		<ul style="list-style-type: none">Difficulty in connecting already existing patient information to new PRO dataLogistical issues for the patients to fill out the questionnaires (ie, who would oversee and explain, how to get the information to HCPs)	
Opportunities		Threats	
<ul style="list-style-type: none">Even the smallest action would add value (compared to the absolute lack of PROs)Useful availability of this new kind of data for lobbying activities		<ul style="list-style-type: none">Lack of quick and useful reactions (ie, concrete actions by HCPs) considering the pre-workshop situationLack of community-based responses	

- Following the workshop, the participants were asked to (optionally and anonymously) share their input:
- Overall workshop relevance - 20 participants (100%) found it relevant or very relevant
- Workshop's foreseen impact of PRO usage in clinical

Results

- Workshop's foreseen impact of PRO usage in clinical practice - 2 participants found it to be neutral and 18 participants (90%) found it to have some or high impact.
- Likelihood of recommending the workshop to other colleagues: 20 participants (100%) found it likely or highly likely
- Positive highlights mentioned by participants:
 - Addressing innovative approaches in HIV patient management;
 - Singular forum to collectively think about new strategies amongst peers;
 - Opportunity to share heterogeneous regional/local experiences, in small groups;
 - Content and quality of practical exercises implemented;
 - Workshop structure and facilitation methods implemented.

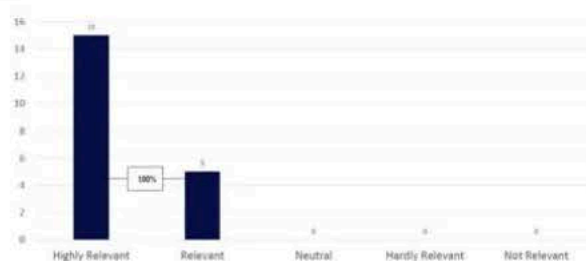
Results

- Workshop structure and facilitation methods implemented;
- Quality of speakers/presentations and speakers' interaction;
- Impact on clinical practice of operational strategies addressed;
- Usefulness and 'real impact' on everyday clinical practice with HIV patients.

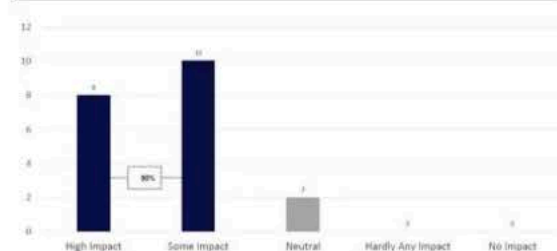


Feedback Report

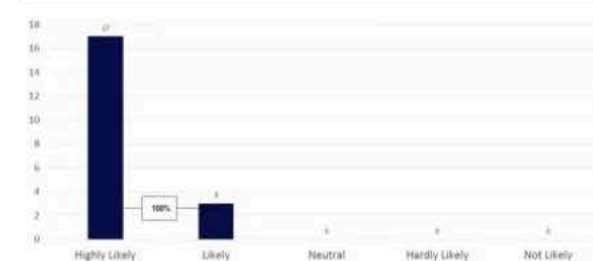
Overall Relevance



Foreseen Impact on PROs' Usage in Clinical Practice



Recommendation to Colleagues



- Participants' suggestions to inform and/or improve subsequent events:

Results

subsequent events:

- Presenting real-world evidence from studies including PROs;
- Presenting operational details regarding some PRO tools;
- Implementing further exercises addressing real-world usage of selected PRO tools;
- Sharing real-world strategies and results of PRO implementation in Portugal;
- Addressing Portuguese model-examples of PRO integration in clinical practice;
- Tackling team work (physicians/nurses) strategies in PRO implementation;
- Promoting further sharing moments amongst experts working in heterogenous contexts;
- Ensuring the consistent establishment of similar workshops.

Conclusions

- All participants considered the **contents of the workshop pertinent or very pertinent** and 90% considered the information shared to be **impactful or very impactful, for clinical practice**, highlighting the workshop's real-world impact.
- Participants suggested the **inclusion of practical exercises using PRO scales/tools would be valuable.**
- Participants experienced the **importance of collecting PROs** to help structure clinical appointments and to prioritize specific and personal issues of PLHIV.
- This workshop highlighted the **value of structured and routine PRO collection, to support holistic and individualized care**, a paramount pillar in **patient-centered care in HIV** – a strategy in which PROs play a key role.
- Our methods and strategy **demonstrated to HCPs how PROs go beyond clinical data**, helping to fully and multidimensionally **understand and act on PLHIV's**

Conclusions

- This workshop highlighted the **value of structured and routine PRO collection, to support holistic and individualized care**, a paramount pillar in **patient-centered care in HIV** – a strategy in which PROs play a key role.
- Our methods and strategy **demonstrated to HCPs how PROs go beyond clinical data**, helping to fully and multidimensionally **understand and act on PLHIV's needs**, resulting in **better health outcomes and better HRQoL in HIV care**.

References:

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- [2] Bing et al. *Arch Gen Psychiatry*. 2001;58:721-728.
- [3] Lazarus et al. *BMC Med*. 2016;14:94.
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