



## Implementation of PROM in clinical practice Workgroup HRQoL HRCs

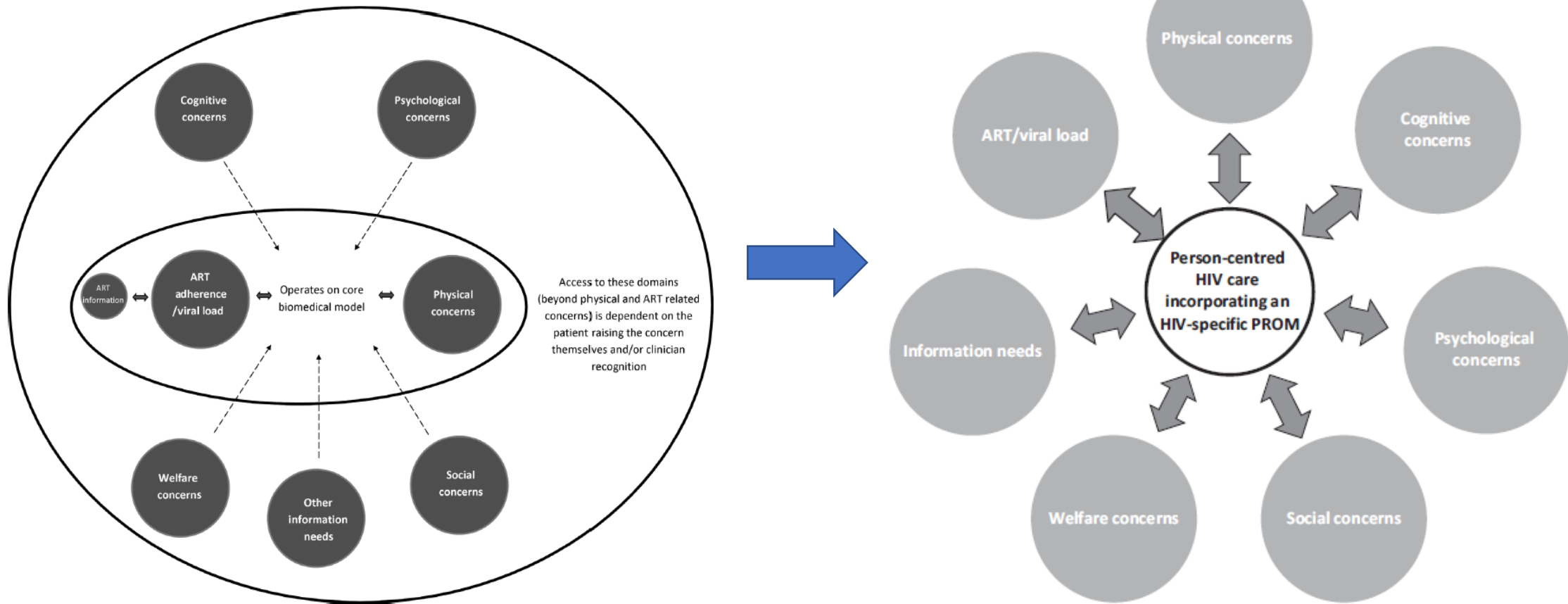
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# Context: Health-related Quality of Life

need for a shift in “treatment paradigm” towards new model of care



Bristowe K, HIV Med 2019

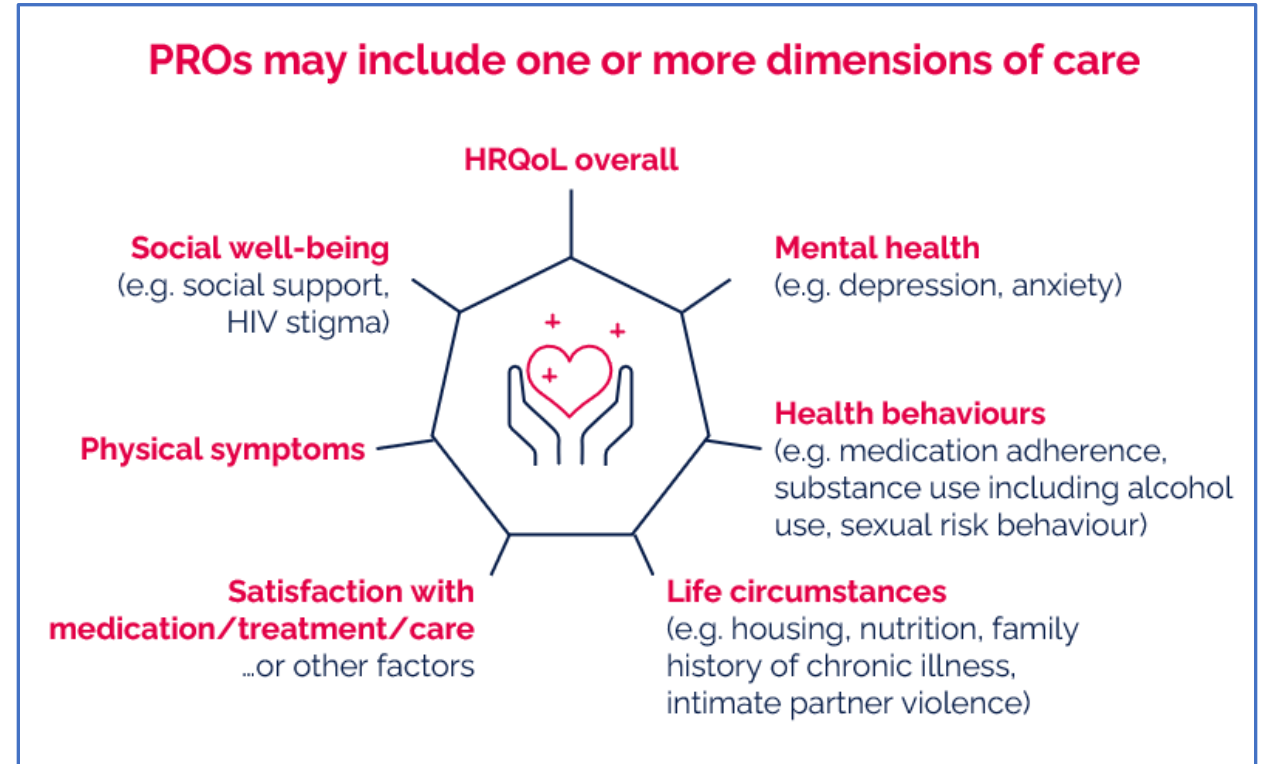
Our focus needs to extend beyond viral suppression and other clinical markers, to include **symptom burden and HRQoL**

# What are PROs?

➤ **Patient-reported outcomes** are outcomes, behaviours, needs or preferences directly reported by the people who experience them

➤ **Not directly observable!**

➤ **Patient's unmet needs**



➤ **PROMs**: tools used to capture information about PRO's, mostly questionnaires and survey's

➤ **Patient reported experience measures (PREMs)** measure patients' perceptions of their experience of the process -rather than outcome- of care

# PROM in the ideal world



# Use of Patient Reported Outcome Measures (PROMs) in HIV Clinical Care

## The use of Patient Reported Outcome Measures (PROMs) in HIV Clinical Care

Patient reported outcome measures (PROMs) are being increasingly used in clinical care to directly measure patient symptomatology and quality of life. EACS guidelines recommend utilization of PROM tools annually in every individual to facilitate the dialogue between care providers and the patient, improve patient and physicians' awareness of their own health, introduce patient-centered care and to empower patients in this conversation.

## What to collect?

PROMs pertain multidimensional domains including (but not limited to): physical, mental and sexual health, pain, stigma, family/community support, social isolation, loneliness, food security, housing, financial and migration status.

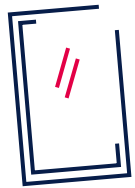
Domains should be chosen according to local and regional requirements, age, socio-economic background and environmental characteristics in consultation with local patient representatives.

## How to assess PROs in clinical care...

?

There are different ways of integrating PROs within care

- / Which PROs are used
- / How and when PRO information is gathered in advance of the consultation, for example:



An iPad in the clinic while waiting for an appointment



URL link to questionnaire emailed and completed before an appointment



Through a mobile phone app



Via a patient portal



Interviewer-based assessment

# Workgroup of HRC college HRQoL

**Multidisciplinary WG**, incorporating of 3 existing PROM pilot projects (ITG, UZGent, Jessa)

## Tasks:

1. Consensus/convergence on PROM/PREM methodology: **basic set** of PROM questions
2. Toolbox for nationwide implementation
3. Accessible database/website for “downstream” actions and initiatives






# Basic set of PROM: 18 questions every 6-12 months

BIOMEDICAL HEALTH/ QoL		
Physical health (general)	How much are you bothered by physical problems related to your HIV infection?	1-5
Cognition	Do you regularly experience memory loss (e.g. forget special events, recent events, appointments, et.)?	1-5
	Do you feel that you are slower at reasoning, planning activities or solving problems?	1-5
	Do you have difficulty maintaining your attention on something (e.g. a conversation, a book, a movie)?	1-5
Depression	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1-5
	In the past month, have you lost interest/joy in certain activities that normally brought you joy?	1-5
Sleep	How satisfied are you with your sleep?	1-5
Sexual satisfaction/ dysfunction	How satisfied are you with your sex life?	1-5
PSYCHOSOCIAL HEALTH/QoL		
Well-being	How would you rate your quality of life?	1-5
Subjective health	How would you rate your own health over the past month?	1-5
Adherence to therapy	How often do you find it difficult to take your HIV medication properly?	1-5
Stigma/ self-stigma/ guilt	How often do you experience HIV stigma (discrimination, stereotypes, negative attitudes)	1-5
	Have you ever withheld yourself from important matters, because of potential reactions to your HIV-status (starting an intimate relationship, applying for a job, social activities, ...)	1-5
Support	How satisfied are you with the support you receive from your friends and/or family?	1-5
Coping	I've been able to accept my HIV status and integrate it into my life	1-5
BEHAVIOUR		
Smoking/alcohol	How often do you smoke?	1-5
	How often do you drink alcohol?	1-5
Drug use	How often do you use narcotics or stimulants (cannabis, XTC, crystal meth,...)?	1-5
SEXUAL ACTIVITY	OPTIONAL: once every year or 2 years	




# Example of implementation of PROM: KWS based

Depressie




*Laatst bewaard 13-9-2022 15:13*

Heeft u zich in de afgelopen maand depressief, droevig of hopeloos gevoeld? 


☒ Ja

☐ Nee

Heeft u in de afgelopen maand de interesse/vreugde verloren in bepaalde activiteiten die u normaal wel vreugde brachten? 

☒ Ja

☐ Nee

Bent u de laatste maand veel gewicht verloren of hebt u een verlies van eetlust? 

☐ Ja

☐ Nee

# Example of implementation of PROM: KWS based

Report: Matrix (inverted) (HTML) ▼		
Hoe vaak gebeurt het dat je je HIV-medicatie niet inneemt?	Zelden of nooit (5)	R_Medicatie_1
Ervaar jij het als een probleem als je je pillen niet neemt?		R_Medicatie_2
Globaal gezien, hoe goed denkt u zelf de medicatie in te nemen?	Heel goed (5)	R_Medicatie_3
Heeft u zich in de afgelopen maand depressief, droevig of hopeloos gevoeld?	Ja (1)	R_Depressie_2
Heeft u in de afgelopen maand de interesse/vreugde verloren in bepaalde activiteiten die u normaal wel vreugde brachten?	Ja (1)	R_Depressie_3
Bent u de laatste maand veel gewicht verloren of hebt u een verlies van eetlust?	Nee (0)	R_Depressie_4
Heeft u last van slapeloosheid of extreme vermoeidheid?	Nee (0)	R_Depressie_5
Heeft u het gevoel dat u vertraagd bent in het oplossen van problemen, plannen van activiteiten?	Nee (0)	R_Depressie_6
Bent u de laatste tijd erg vermoeid?	Nee (0)	R_Depressie_7
Heeft u moeilijkheden om uw aandacht erbij te houden?	Ja (1)	R_Depressie_8
Heeft u er al eens aan gedacht om er liever niet meer te zijn?	Nee (0)	R_Depressie_9
<b>Score angststoornis</b>	1	CF_Depressie
Depressie	/	CF_Angst_besluit
Hoe kan u uw algemene gezondheid het best beschrijven?	Goed (3)	R_Lifestyle_1
Bewaren Afdrukken FXBrowser		

# Example of implementation of PROM: 2022 & 2023

## DETERMINANTS AND EVOLUTION OF QUALITY OF LIFE IN PEOPLE LIVING WITH HIV



INSTITUTE  
OF TROPICAL  
MEDICINE  
ANTWERP

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<sup>1</sup> Institute of Tropical Medicine, Department of Public Health, Sexual Health and HIV Research Unit

<sup>2</sup> Institute of Tropical Medicine, Department of Clinical Sciences, HIV and STI Clinic

### BACKGROUND

With HIV evolving into a chronic disease, attention is shifting to the '4<sup>th</sup> 90': improving quality of life (QoL) beyond viral load suppression. In Belgium, most people living with HIV (PLWH) who are in care had an undetectable viral load in 2021 (81%; < 200 copies/ml), but still face challenges in achieving a good QoL. Little is known, however, about how QoL evolves over time and its determinants.

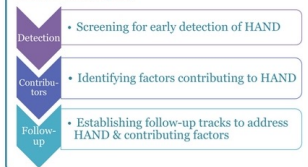
## Screening for neurocognitive impairment in people living with HIV (PLHIV) through patient-reported outcomes (PROMS) and cognitive assessment

Marie-Angélique DE SCHEERDER<sup>1</sup>, Els TOBBACK<sup>1</sup>, Charlotte VANDEN BULCKE<sup>1</sup>, Christina JOOSTEN<sup>1</sup>, Jolanda PELGROM<sup>1</sup>, Filip VAN WANZEELE<sup>1</sup>, Maja KISELINOVA<sup>1</sup>, Elise VAN CAELENBERG<sup>2</sup>

<sup>1</sup>General Internal Medicine, <sup>2</sup>Ghent University Hospital, Ghent, Belgium

### Objectives

To identify the current burden of HIV-associated neurocognitive disorder (HAND) in PLHIV followed in the HIV Reference Center of Ghent (Belgium)



### Methods

EACS screening questions as part of bigger PROM iPad questionnaire.



EACS screening questions  
When 2/3 affirmative answers → further assessment:

MOCA (Montreal Cognitive Assessment Test)  
HDS (HIV Dementia Scale)

Lifestyle factors through extra questionnaire

### Results

548 respondents

Mean age = 49 (±12) years, 76.3% male

44.7% reported neurocognitive complaints (≥1 affirmative question)

more than half of the cognitive issues (52.7%) were unknown by clinician

Click to view

• Sleep quality  
• Sexual satisfaction  
• Practicing chemsex  
• Feelings of guilt  
• Stigma

76 (13.8%) reported severe neurocognitive complaints (3 affirmative questions)

31 agreed to further assessment

45 did not agree

MOCA: 16 scored below cut-off (<26/30)  
HDS: 23 scored below the cut-off (<10/12)

### Conclusions & future perspectives

Although neurocognitive symptoms are frequent in our population, they often remain unnoticed by the clinicians. Screening revealed important gaps in the psychosocial care model that should be tackled in order to prevent and slow down progression of HAND.

## PROM to identify gaps in the management of people living with HIV

Marie-Angélique DE SCHEERDER<sup>1</sup>, Els TOBBACK<sup>1</sup>, Sophie DEGROOTE<sup>1</sup>, Charlotte VANDEN BULCKE<sup>1</sup>, Linos VANDEKERCKHOVE<sup>1</sup>, Els MERCKX<sup>1</sup>, Ruth DE MUYNCK<sup>1</sup> and Caroline MATTHYS<sup>1</sup>

<sup>1</sup>General Internal Medicine, Ghent University Hospital, Ghent, Belgium

### Purpose

The fourth 90



Patient-reported outcome measures (PROMs) are tools that help health providers to address health-related quality of life of persons living with HIV

The present study describes the results of the PROMs questionnaire that was introduced in the Ghent HIV reference center

### Methods

#### MEASURES

Behaviour questionnaire on iPad during routine follow-up: questions on mental, physical and sexual health, sleep, alcohol- and substance use, social support, stigma and neurocognitive complaints

#### PERIOD

Between 24th November 2021 and 30th August 2023

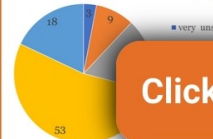


### Results

#### PROFILE OF THE RESPONDENTS (N=855)

Mean age ± SD = 49,2 ± 11,5 years, 77% male

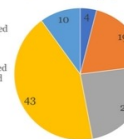
#### MENTAL health (%)



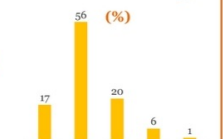
#### SEXUAL health (%)



#### SLEEP (%)

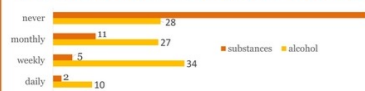


#### NEGATIVE feelings (%)

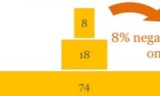


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#### ALCOHOL and SUBSTANCE USE (%)



#### CHEMSEX (%)



#### STIGMA

Respectively 14% and 10% experience at least often to be stigmatized in their personal and professional life, whereas 33% feel guilty or ashamed related to their HIV status

### Conclusions

- Important gaps in management of PLHIV were identified especially regarding mental and sexual health, sleep and stigma
- We should further identify potential subgroups suffering from unmet needs and develop integrated care paths, including referral to paramedical services, to address these issues individually

# Future perspectives



- Roll out of at least basic PROM in all HRCs
  - Timeline: Q1Q2 2024
  - Meeting with HRC representatives in the near future: help with practicalities
  - Evaluation of PROM implementation Q3 2024 + patient representatives
  - Possibility to start national project on the PROM data: BREACH (tbc)
- Questionnaire to HRCs and community-based organizations to gather data on existing “downstream” initiatives (i.e. psychosocial interventions): 12/2023
  - Consultable database for all stakeholders
- SPADIS project Sciensano
- Last but not least: many thanks to the members of the WG: Christiana Nöstlinger, Gert Scheerder, Charlotte Vandenbulcke, Marie-Angelique De Scheerder, Wim Vanden Berghe, Jessika Deblonde





**JESSA**  
ZIEKENHUIS

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THANK YOU FOR THE ATTENTION – ANY QUESTIONS?