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Understanding the 4th 90: quality of life (QoL) as patient-reported outcome (PROMs) to improve comprehensive HIV care

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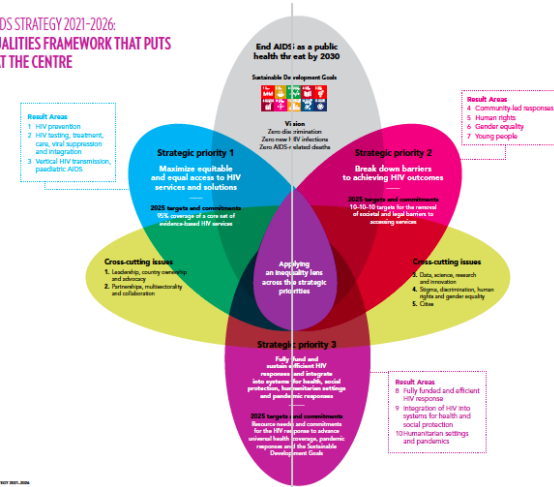
BREACH 23/11/2022



A focus on QoL – putting people at the center of the HIV response

- QoL is a central aspect of long-term health and well-being
- HIV stigma, mental and sexual health and structural issues affect HIV outcomes across the HIV continuum of care (CoC)
- QoL: potential to improve HIV outcomes, including adherence and clinical outcomes
 - patient-centered interventions
- Quality and effectiveness of HIV care should be assessed using more than biomedical outcomes

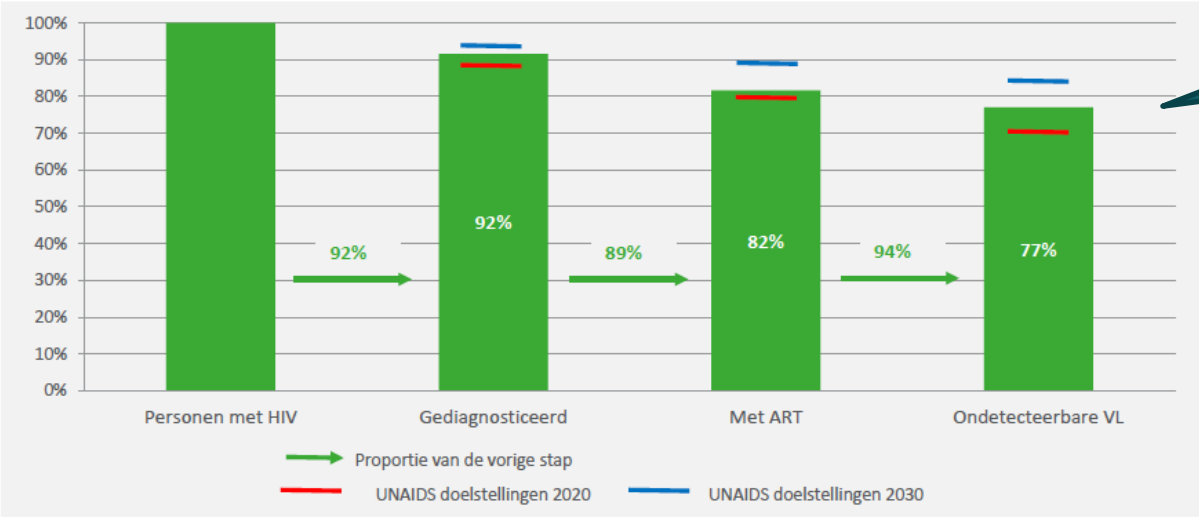
GLOBAL AIDS STRATEGY 2021-2026:
AN INEQUALITIES FRAMEWORK THAT PUTS
PEOPLE AT THE CENTRE



- Pillar in HIV plan
- Reporting requirement HRCs?
- Resource optimization?

HIV CoC in Belgium – fast track targets 95:95:95

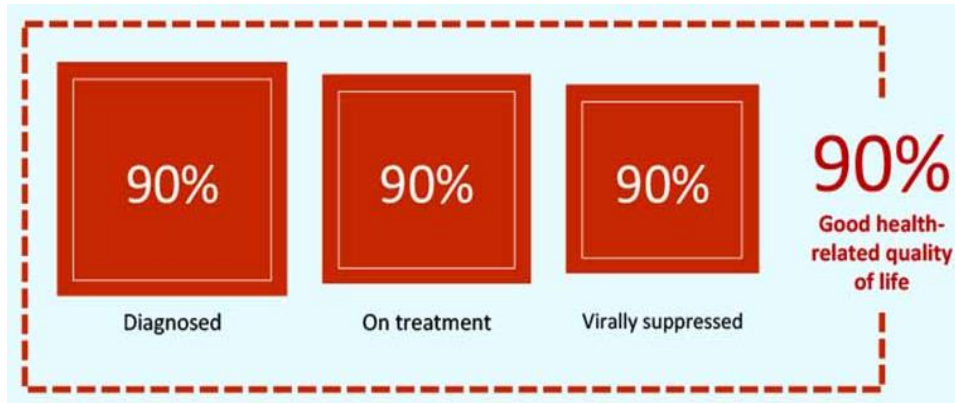
Continuüm van de zorg voor de mensen die met hiv leven in België en de vergelijking met de 2020 en 2030 doelstellingen van UNAIDS, 2020



Source: Sciensano, 2021



QoL: a 4th - or a cross-cutting target?



90% of all people living with HIV (PLWH) have **good Health related Quality of Life**

(Source: Lazarus & Safreed-Harmon, 2019)

- Conceptualized as 4th 90
- Debate: QoL important for all PLHIV
- Cross-cutting
- Interventions at each step of the HIV CoC
- Consensus statement on the role of health systems in advancing the long-term well-being of PLHIV (Lazarus et al., 2021)
→ indicator development

Initiative at HRC Antwerp - current

- **ITM Clinic** monitors data on QoL of PLWH in follow-up ('MyLife')
 - Data of >1200 patients since 2018, ongoing
 - WHO-QOL HIV BREF: 6 domains
 - Health Monitor: control & acceptance
 - Used to guide clinical practice (counselling)
 - Longitudinal data collection
 - ⇒ insight into how QoL evolves



Initiative at HRC Antwerp – planned study

■ Objectives

- Analyze QoL of PLWH in ITM Clinic using MyLife database
 - What are the most frequent QoL areas of concern?
 - What are the determinants of QoL?
 - How does QoL evolve over time, and which factors influence it?
- Explore subjective experiences of QoL: in-depth interviews
 - Rich cases: low scores, high scores, major changes
 - Validity of findings: contextualized picture
- Develop and test an intervention to improve QoL among PLWH

Initiative at HRC Antwerp – planned study

■ Expected outcomes / impact

- Unique dataset (size + longitudinal) allows to answer pending research questions on QoL in PLWH
- Structural use of QoL data, by analyzing profile of PLWH at risk and developing targeted (group level) interventions
- Improve psychosocial care of PLWH in Belgium
 - Inspire other HRCs with results of this QoL tool and study
 - Collaborate with Sciensano to use PROMs in Belgian HIV Cohort

Towards harmonization of data: HRCs JESSA Hasselt, UZ Ghent, ITM/Antwerp

- Variety of QoL domains, health behavior and lifestyle questions, satisfaction with care, ...
- Different instruments: validated \leftrightarrow self-developed
- Different data collection modes \rightarrow electronic files?
- Representativeness? \rightarrow How to reach those “difficult to reach”?
- General questionnaire fatigue \leftrightarrow cultural sensitivity, digital (health literacy)



Towards harmonization of data: a core set of PROMs?

Domein/items	Jessa Hasselt	UZ Gent	HRC Antwerp
Instruments	PROM list of Kjaer et al., 2018(Aarhus)	own PROM/PREM developed	MyLife project WHO-HIV-QoL-BREF
Data collection			
General health	How can you describe your general health? (5 pt. scale)	How satisfied are you with your general health? (5 pt. scale)	How is your health? (5 pt. scale)
Depression	Did you feel depressed, sad or hopeless during the last month? yes/no	How often did you suffer from negative feelings such as gloom, despair, anxiety, depression (previous 4-6 months)? (5 pt. scale)	How often do you have negative feelings (blue mood, despair) (last two weeks)? (5 pt. scale)
Cognition	Do you regularly experience memory loss? Do you feel that you are slower in reasoning, planning, problem solving? Do you have difficulties maintaining your attention on something?	Do you regularly experience memory loss? Do you feel that you are slower in reasoning, planning, problem solving? Do you have difficulties maintaining your attention on something?	How well are you able to concentrate? (5 pt. scale)
Sexual satisfaction	5 items measuring sexual problems: desire/orgasm; (current and last month); perception of problem	Satisfaction with sex life (general) (5 pt. scale)	How satisfied are you with your sex life? (5 pt. scale)

Next steps

- Collaboration with interested HRCs, Sciensano?
- Working mode: working party HRC college
 - Core data set + additional items of interest per HRC (input PLHIV and their organizations)
 - Electronic data collection → consultable database (downstream activities)?
 - Approaches to reach those “difficult to reach”?
 - To inform intervention: inventory of existing interventions; collaboration with PLHIV
 - **All feedback welcome [cnoestlinger@itg.be; gscheerder@itg.be]**



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