

Quality of Life in HIV Care: PROM data and implementation stories from three HRC


Breach Symposium – 27 November 2025

Presented by the Breach QoL Prom Working Group

Overview presentation

- Exploration of PROM data : first insights from ITM and UZ Ghent
- Implementation stories from 3 HRCs :
 - HRC Ghent University hospital
 - HRC Jessa Hospital Hasselt
 - HRC ITM Antwerp
- Take-home messages

Exploration of QoL prom data

- : Measure quality of life in people living with HIV to complement clinical care
- QoL PROM tool : 20 item list developed by the working group covering different domains (e.g. mental health, stigma, sleep)
- PROM data in this presentation :
 - Data from ITM and UZ Ghent
 - Data analysis at this stage is explorative, not representative
 - Results are preliminary but highlight key disparities

PROM participant characteristics

Total sample: N=877
Period: February-October 2025

HRC	Ghent	665 (75,8%)
	Antwerp	212 (24,2%)
Language	Dutch	88,7%
	French	5,1%
	English	6,2%
Age group	20-39	16,4%
	40-59	54,1%
	60plus	29,5%
Ethnicity	white	83,5%
	black	10,0%
	other	6,5%

Gender	Male	84,6%
	Female	15,4%
Sexual orientation	Homosexual	63,3%
	Bisexual	6,7%
	Heterosexual	28,2%
	Other	1,8%
Year of HIV diagnosis	≤1996 (LTS)	9,0%
	1997-2010	39,3%
	2011-2022	40,3%
	2023-2025 (recent diagnosis)	11,4%

PROM item scores

Subjective QoL	(very) good	83,9%
Subjective health	(very) good	76,6%
Physical health problems (related to HIV)	moderately - very much	14,1%
Cognition (sum score)	≥2 symptoms	22,8%
Depressive symptoms (sum score)	quite often - always	18,3%
Satisfaction sleep	(very) dissatisfied	22,9%
Satisfaction sex life	(very) dissatisfied	25,6%
Acceptance hiv status	(very) poor	9,0%
ART adherence problems	sometimes - always	10,4%
Stigma, self-stigma, discrimination (sum score)	sometimes - always	12,2%
Social support	(very) dissatisfied	7,2%
Financial situation (enough to meet needs)	not at all – a little	12,5%
Health behaviour: smoking, alcohol, drugs (sum score)	occassionally - daily	22,8%

Associations with PROM total score

Mean score: 68/85

		% low score (≤ 60)
HRC	Ghent	15,0%
	Antwerp	16,6%
Language	Dutch	13,6%
	French	25,0%**
	English	29,4%**
Age group	20-39	22,6%**
	40-59	14,9%
	60plus	11,6%
Ethnicity	white	13,0%
	black	22,2%**
	Hispanic	33,3%

		% low score (≤ 60)
Gender	Male	14,7%
	Female	19,1%
Sexual orientation	homo/bisexual	14,6%
	heterosexual	16,1%
	other	44,4%**
Year HIV diagnosis	≤ 1996 (LTS)	21,1%
	1997-2010	15,7%
	2011-2022	20,0%
	recent diagnosis	20,8%
Financial situation	difficult	60,2%**
	comfortable	11,1%


** $p < .05$

QoL PROM: Our journey so far

Jessa Hasselt

 : June 2025



Current Status:

-  50% response rate
- Automation in progress
- No data extraction yet

UZ Ghent

 : February 18, 2025



Current Status:

-  **707 enrolled**
-  52% response rate

ITM Antwerp

 : May 19, 2025

Current Status:

-  **307 enrolled**
-  72% completed

UZ Ghent



Tools:

- Integrated into consultations/EPD via QuestManager

Process:

- Mail and/or sms to complete survey 1 month before consultation
- Reminder 1 week before consultation
- Each year automatic reminder
- If missed, option to complete survey via QRtoken or on ipad with the help of (social)nurses
- NDL/FR/ENG
- EPD: results are easily accessible, with red flags displayed at the top
- Evaluation after 1 year: 'missed' population

Jessa Hasselt



Tools:

- Integrated into consultation/EPD via KWS/Nexuzhealth app

Process:

- Mail and/or sms to complete survey 14 days before consultation, automatic reminder
- Completion @ home: PC or smartphone
- Rescue: tablet in waiting room: QR code
- Part of SoC: results in EPD
- Manual invitation as for now; 12/2025: automated invitation anticipated
- No team reminders (yet..)

ITM Antwerp



Tools :

- Completion via REDCap (EPD external system hosted by ITM)

Process:

- Invitation during consultation (recruitment document with link/qr)
- Patient can complete at home, sometimes with the help of the team
- Yearly automated reminder
- Team reminders and workflow optimization
- NL/ENG/FR, other languages will follow
- Linkage with EPD, results can be consulted
- Ongoing evaluation by internal working group

Turning Challenges into Solutions

Barriers:

- Patients : willingness, ease of use, language, culture, literacy
- Technical link with EPD
- Missing identifiers (RR number, admin issues)
- Extra task for supporting staff
- Limited time during consultations
- Resources: staff; financial

Solutions:

- Close collaboration with IT and clinical teams
- Multiple ways to complete
- Clear workflow + reminders
- Continuous effort: Inclusive communication and cultural sensitivity checks

Impact and Benefits

For Patients:

- PROM prioritize patient-reported experiences, ensuring that care reflects real needs and contexts
- Future: Self-help & psycho-education tools to be provided

For Clinicians:

- Conversation starter in consultations
- Alerts for risk scores (e.g., depression, substance use)
- Future: Basis for personalized care pathways/clinical guidelines

Impact and Benefits

For **HRC**:

- Easy integration via EPD, REDCap,...
- Synergy between HRC within Breach PROM working group
- Provides a framework for stepped care, triage and allocation of resources

For **research-surveillance activities/public health**:

- PROM offer a broader perspective on the lived experiences of people with HIV, beyond clinical indicators
- Already used for recruitment into a sleep intervention study at ITM
- Intersectionality matters: PROM can help capture overlapping identities and their combined impact

Roadmap



- The questionnaires/tools have already been developed
- Think from the patient's perspective: ease of use, reminders, actionable items
- Secure leadership buy-in (maybe there's another department implementing PROM?)
- Sit together with ICT: what is realistic? costs? time? data extraction?
- Run a pilot
- Assign dedicated staff to follow-up on the project
- Be patient and persevere

Take-home messages

Take-Home Messages

- PROM implementation is feasible and valuable in HIV care though resource and equity challenges must be addressed
- PROM enhance patient engagement and inform personalized care
- Implementation requires planning, ICT collaboration, and persistence

Call to Action

- Join the Breach QoL PROM Working Group:
 - Share your experience
 - Access practical tools and protocols
 - Collaborate on research and data analysis

Thank you!

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