

Optimising HIV care using information obtained from PROMs: Protocol for an observational study.

Supplement

Appendix 1: Numbers of patients, doctors, and nurses per site

Site	Patients	Doctors	Nurses
AMC	2255	13 plus 1 to 3 fellows	6
VUMC	598	4 plus 2 fellows	3

Appendix 2: PROMs used in the outpatient clinics

Six PROMIS CAT domains were chosen for anxiety, depression, fatigue, physical functioning, sleep disturbances and social isolation. In the DC Klinieken site, we used the PROMIS social isolation 8-item short because the CAT version was not available for its electronic patient portal.

The five-item Medication Adherence Report Scale (MARS) was selected to assess adherence. We chose two subscales of the short Berger HIV Stigma to assess disclosure concerns and negative self-image, along with two screening questions added by community partners the Dutch HIV Association and Shiva: “HIV is a punishment” and “HIV can happen to anybody”. We introduced a screening process for the Alcohol Use Disorders Identification Test (AUDIT) to allow patients who never drink alcohol and those who drink less than 7 units per week? when they do drink to skip the rest of the instrument. We adapted the Drug Use Disorders Identification Test (DUDIT) with input from Mainline, the Dutch harm reduction organisation, to be less confrontational for our patients and further adapted it to reflect the types of drugs that our patients are most likely to use. We chose the Primary Care PTSD Screen for DSM-5 (PC-PTSD-5) to screen for post-traumatic stress disorder. Internal and external stakeholders developed extra questions for our clinics’ populations to screen for social status, including finances, housing and immigration status, and sexuality.

Appendix 2 - Table: PROMs used in the outpatient clinics

PROM	Domain(s)	Number of Items	Scales	Frequency
PROMIS Adult	Anxiety(v1.0), depression(v1.0), fatigue(v1.0), physical functioning(v1.2), sleep disturbances(v1.1), social isolation(v1.0)	See Appendix 3 Table: PROMIS Adult versions used in the outpatient clinics for details	T-score 10-90; higher is worse, except for physical functioning where higher is better	Once yearly
Medication Adherence Report Scale-5 (MARS-5) ⁱⁱ	Treatment adherence	5	Total score 5-25; higher is better	On demand for treatment switches, temporary increases in viral load (blips), and pregnancies
Berger HIV Stigma Stigma Scale (12-item) ⁱⁱⁱ adapted	HIV Stigma	8	Subscale 1, Disclosure: 3-12 Subscale 2, Self-stigma: 3-12 Subscale 3: n/a No total score	Every three years
Adapted AUDIT ^{iv}	Problematic alcohol use	1 screening question 1 question with to determine problematic alcohol use 10 questions from AUDIT	Total score 0-40, higher is worse.	Once yearly
Drug use (adapted from DUDIT) ^v	Drug use	1 screening question 1 question with list of drugs patient has had experience with 10 questions based on DUDIT	Score 0-6 per question, higher is worse. No total score	Once yearly
Social status ^{vi}	Finances, housing, migration status	1	N/A	Once yearly
Sexuality screening ^{vii}	Sexuality	4	N/A	Once yearly
PC-PTSD-5 ^{viii}	Post-traumatic stress disorder	1 screening question, followed by 5 if screening is positive	Total score 0-5, higher is worse, 3 is an indication of PTSD	Every three years
Patient Assessment Chronic Illness Care, Short Form (PACIC-S) ^{ix}	Patient perception of quality of care and patient engagement	11	Total score 11-55	Once yearly

i Hanmer, J., Jensen, R.E. & Rothrock, N. A reporting checklist for HealthMeasures' patient-reported outcomes: ASCQ-Me, Neuro-QoL, NIH Toolbox, and PROMIS. *J Patient Rep Outcomes* 4, 21 (2020). <https://doi.org/10.1186/s41687-020-0176-4>

ii Chan AHY, Horne R, Hankins M, Chisari C. The Medication Adherence Report Scale: A measurement tool for eliciting patients' reports of nonadherence. *Br J Clin Pharmacol.* 2020;86(7):1281-1288. doi:10.1111/bcp.14193.

iii Reinius, M., Wettergren, L., Wiklander, M. et al. Development of a 12-item short version of the HIV stigma scale. *Health Qual Life Outcomes.* 2027;15:115. doi:10.1186/s12955-017-0691-z

iv Saunders JB, Aasland OG, Babor TF, de la Fuente JR, Grant M. Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption--II. *Addiction.* 1993;88(6):791-804. doi:10.1111/j.1360-0443.1993.tb02093.x. See appendix 4 for our adaptations.

v Dudit available: <https://www.emcdda.europa.eu/system/files/attachments/12173/DUDIT-English-version.pdf>. Accessed 20 Feb 2023. See appendix 5 for our adaptations.

vi Screening question developed by the PROMs Kerngroep, along with a full questionnaire that healthcare workers complete if the screening is positive. See Appendix 6.

vii Questions developed by the PROMs Kerngroep and Champions. See appendix 6.

viii Prins A, Bovin MJ, Smolenski DJ, Marx BP, Kimerling R, Jenkins-Guarneri MA, Kaloupek DG, Schnurr PP, Kaiser AP, Leyva YE, Tiet QQ. The Primary Care PTSD Screen for DSM-5 (PC-PTSD-5): Development and Evaluation Within a Veteran Primary Care Sample. *J Gen Intern Med.* 2016 Oct;31(10):1206-11. doi: 10.1007/s11606-016-3703-5.

ix Cramm JM, Nieboer AP. Factorial validation of the Patient Assessment of Chronic Illness Care (PACIC) and PACIC short version (PACIC-S) among cardiovascular disease patients in the Netherlands. *Health Qual Life Outcomes.* 2012;10:104. Published 2012 Aug 31. doi:10.1186/1477-7525-10-104

Appendix 3

Table: PROMIS Adult versions used in the outpatient clinics

Location	Type	Domain	Version
AMC/VUMC	English and Dutch CAT	Anxiety ⁱ	1.0
		Depression ⁱ	1.0
		Fatigue ⁱⁱ	1.0
		Physical functioning ⁱⁱⁱ	1.2
		Sleep disturbances ^{iv}	1.0
		Social isolation ^v	2.0

i. Pilkonis PA, Choi SW, Reise SP, Stover AM, Riley WT, Cella D, et al. Item banks for measuring emotional distress from the Patient-Reported Outcomes Measurement Information System (PROMIS®): depression, anxiety, and anger. *Assessment*. 2011;18(3):263-283. doi:10.1177/1073191111411667

ii. Lai JS, Cella D, Choi S, Junghaenel DU, Christodoulou C, Gershon R, et al. How item banks and their application can influence measurement practice in rehabilitation medicine: a PROMIS fatigue item bank example. *Arch Phys Med Rehabil*. 2011 Oct;92(10 Suppl):S20-7. doi:10.1016/j.apmr.2010.08.033.

iii. Rose M, Bjorner JB, Gandek B, Bruce B, Fries JF, Ware JE Jr. The PROMIS Physical Function item bank was calibrated to a standardized metric and shown to improve measurement efficiency. *J Clin Epidemiol*. 2014 May;67(5):516-26. doi: 10.1016/j.jclinepi.2013.10.024.

iv. Buysse DJ, Yu L, Moul DE, Germain A, Stover A, Dodds NE, et al. Development and validation of patient-reported outcome measures for sleep disturbance and sleep-related impairments. *Sleep*. 2010 Jun;33(6):781-92. doi: 10.1093/sleep/33.6.781.

v. Hahn EA, DeWalt DA, Bode RK, Garcia SF, DeVellis RF, Correia H, et al. New English and Spanish social health measures will facilitate evaluating health determinants. *Health Psychol*. 2014 May;33(5):490-9. doi: 10.1037/hea0000055.

Appendix 4 – Adapted 12-item Berger HIV Stigma Scale

We used 2 subscales from the 12-item Berger HIV Stigma Scale: disclosure concerns and negative self-image. We then added 2 additional questions based on input from community partners to form a third subscale.

Answers for all questions:	Scores
Strongly agree	4
Agree	3
Disagree	2
Strongly disagree	1

Subscale 1: Disclosure concerns:

1. Telling someone I have HIV is risky
2. I work hard to keep my HIV a secret
3. I am very careful who I tell that I have HIV

Subscale 2: Negative self-image

4. I feel guilty because I have HIV
5. People's attitudes about HIV make me feel worse about myself
6. I feel I'm not as good a person as others because I have HIV

Subscale 3: Added questions

7. HIV is a punishment.
8. HIV can happen to anyone.

Appendix 5 – Adapted AUDIT

We adapted the AUDIT to allow for non-drinkers and those who drink less than 7 units per week to skip the entire questionnaire.

The first question offered to the patient is:

Do you drink alcohol?

If the answer is never, the questionnaire stops.

If the answer is one of the possible responses (monthly or less, two to four times a month, two to three times a week, four or more times a week), the patient is offered the second question:

How many units of alcohol do you drink per week?"

The responses "1 or 2", "3 or 4", and "5 or 6" stop the questionnaire. If the patient responds "7 to 9" or "10 or more", the patient is offered the rest of the questions in the AUDIT, as described in:

Saunders JB, Aasland OG, Babor TF, de la Fuente JR, Grant M. Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption--II. *Addiction*. 1993;88(6):791-804. doi:10.1111/j.1360-0443.1993.tb02093.x

Appendix 6– Drug use (Adapted from DUDIT)

Patients are offered the first question of the DUDIT “How often do you use drugs other than alcohol?”. If the answer is “never”, the questionnaire stops. All other answers trigger the rest of the questionnaire, which can be found at <https://www.emcdda.europa.eu/system/files/attachments/12173/DUDIT-English-version.pdf>.

A list of drugs is offered to the patient with the question “What drugs have you ever tried?”. This list is based on feedback from community partners:

Cannabis
Poppers
Laughing gas
XTC MDMA
GHB
GBL
Ketamine
Snort cocaine
Speed
Crystal meth (Tina, T, glass, ice)
4-MEC
4-FA (4-FMP)
3-MEC
3-MMC
2C-B
MXE
LSD
mushrooms
Crack/ base coke
Heroin
other:

Appendix 7– Social status screening questions

We developed a question to screen for problems related to housing, financial status, and migration status:

Do you experience any problems regarding housing, income and/or legal status? Yes/No

A positive answer triggers the HCP to fill in a form that can be used by nurses and the medical social worker to address patients' needs.

Appendix 8 – Sexuality

The following questions were developed by nurses to ask about sexuality and relationships:

Sexual health

1. Are you content about your sexual health in the past year? Yes/No/ NA
2. Do you experience any problems related to your sexuality or your sexual health at the moment? Yes/No/NA
3. Do you want to talk about your sexuality or sexual health at your next appointment? Yes/No/NA

Relationships

1. Does living with HIV influence you in getting into intimate relationships? Yes/ No/NA