

A TOOLKIT TO SUPPORT THE IMPLEMENTATION OF PATIENT-REPORTED OUTCOME MEASURES IN ROUTINE HIV CARE

Duncan Short,¹ Rob J. Fredericksen,² Heidi M. Crane,² William Lober,² Justin McReynolds,² Sierramatice Karras,² Emma Fitzsimmons,² António Antunes^{3*}

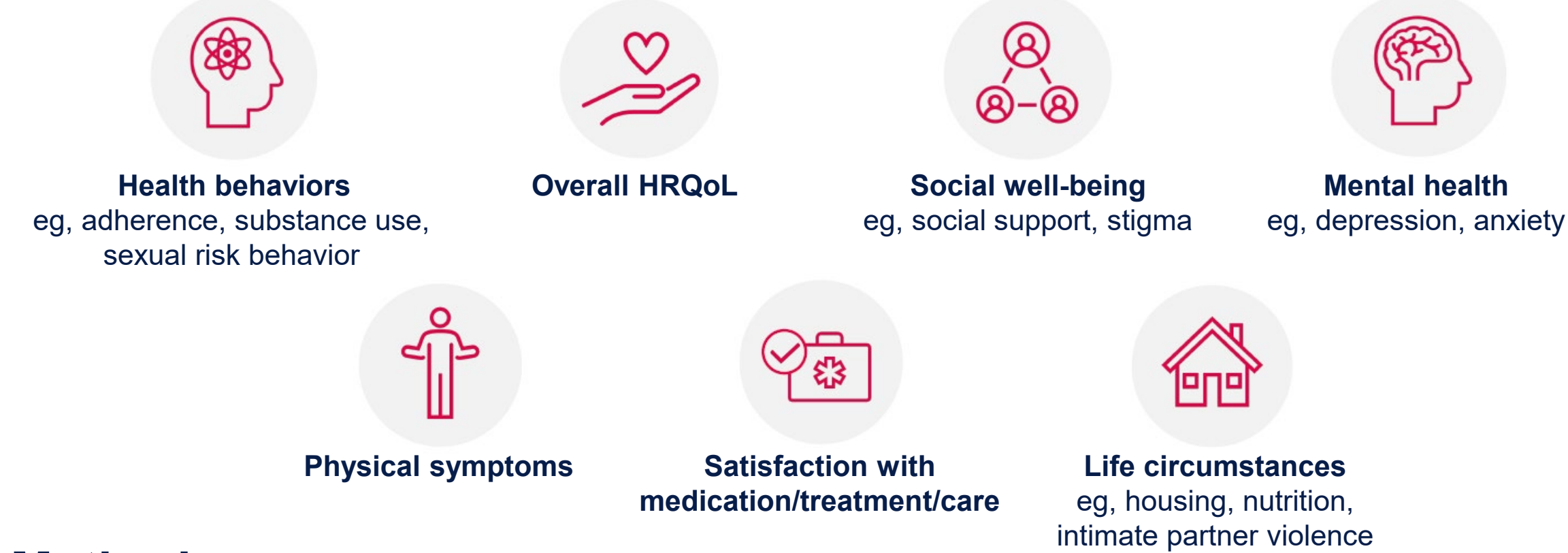
¹ViiV Healthcare, Brentford, UK; ²Center for AIDS Research, University of Washington, Seattle, WA, USA; ³ViiV Healthcare, Lisbon, Portugal

*Presenting on behalf of the authors.

Introduction

There Is Increasing Recognition for HIV Care and Management to Look Beyond Viral Suppression in Terms of Patient Outcomes

- Being virologically suppressed **does NOT mean** people living with HIV (PLHIV) are enjoying a good health-related quality of life (HRQoL)
- Many determinants of HRQoL are **difficult to directly identify** but are critical for optimal HIV care
- Patient-reported outcomes (PROs)** can help facilitate the identification of many determinants of HRQoL and may be especially relevant in HIV care because many issues are sensitive (eg, sexual risk behavior, alcohol/drug use)
- PROs may include one or more dimensions of care



Methods

Implementation of PROs in Routine HIV Care Is Challenging and Initiation May Seem Overwhelming

- The **PROgress Project** developed evidence, insights, and resources to support implementation of PROs in routine HIV care



Results

The Toolkit Provides Practical Advice to Support the Introduction of PRO Assessments Into Routine HIV Care

- The Toolkit includes information on
Chapter 1: Assessing and improving readiness to implement PROs in HIV clinical care
Chapter 2: Engage stakeholders
Chapter 3: Technical choices and infrastructure
Chapter 4: Create PRO assessment
Chapter 5: Outline workflow
Chapter 6: Train clinic personnel
Chapter 7: Monitor and evaluate
Appendix: Online PRO timing tool
Appendix: Sample stakeholder presentation

Chapter 1: Assessing and Improving Readiness to Implement PROs in HIV Clinical Care

- Are PROs right for my clinic right now? If not, how do we get there?
• Patient population
• Clinic leadership
• Provider support
• Logistical and clinic flow considerations
• Technical capacity
• Start-up and running costs
- Creating a business case for PRO implementation

Chapter 2: Engage Stakeholders

- Identify stakeholders
- Prepare demonstration of value
- Meet with stakeholders
- Provide an overview of the value of PROs
- Address common concerns
- Include providers in PRO selection process and output design
- Secure implementation champion
- Appendix: Sample stakeholder presentation

PRACTICAL TIP
Provide a clear justification for PRO data collection, as providers and staff are more likely to support PRO implementation if they understand the value.³ Short practical examples are more compelling.

Sample stakeholder presentation



Chapter 3: Technical Choices and Infrastructure

- Understanding PRO choices
- Identify issues to guide choices
• Gathering information from the patient
• Presenting information to the provider
• Storing information into the medical record
• Reuse of information for population health
- Consider system features
- Consider data quality
- Resources

Key considerations

Key consideration	Definition
EHR infrastructure	Existence and type of EHR system. Important to consider because of both degrees of data integration and feature comparisons, between EHR vendor PRO tools, PRO tools that can be integrated with the existing EHR, and standalone PRO tools
Data standards	Methods, protocols, terminologies, and specifications for the collection, exchange, storage, and retrieval of information associated with PROs
Dashboard design and alerting	Frequency and scheduling of alerts, the data displayed in the dashboard to monitor system performance and usage, the number of clicks or steps required to access information, whether there should be capabilities to temporarily mute or turn off certain features, and the types of icons and graphics that are recognized most easily

Resources

- Guidance on infrastructure**
• Snyder C and Wu AW, eds. Users' guide to integrating patient-reported outcomes in electronic health records. Baltimore, MD: Johns Hopkins University; 2017. Funded by Patient-Centered Outcomes Research Institute (PCORI). JHU Contract No. 10.01.14 TO2 08.01.15. Available from: <http://www.pcori.org/document/users-guide-integrating-patient-reported-outcomes-electronic-health-records>. Accessed October 2020.

First Name	Last Name	MRN: 000000	DOB: 1/1/1900	3/29/2020	5/29/2019
Depression (PHQ-9)					
Moderate depression (10-16)			0	0	2
No depression (0-4)			0	0	0
Not at all			0	0	0
Suicide ideation (PHQ-9)					
No suicidal thoughts			0	0	0
Not at all			0	0	0
Concern for HIV test result					
Felt respected/controlled			0 Yes	No	No
Frustrated of time			0 Yes	No	No
Sexual violence			No	No	No
No			No	No	No
Interactive time estimate tool - Estimate Tool (Display)					
HIV Symptom Index-1		Average completion time			
Depression (PHQ-9)-2.3		0:00:53			
Anxiety (PHQ-15)-1.3		0:00:52			
Tobacco Use-4		0:00:36			
Alcohol Use (AUDIT-C)-5.6		0:00:34			
Substance Use (ASSIST)-7.8		0:01:27			
Drug Treatment (past year) (1 item)-9		0:00:09			
Adherence (SRQ)-10.12		0:00:08			
Sexual Risk Behavior (SRB)-13		0:00:51			
Intimate Partner Violence (IPV)-13.4		0:00:26			
Social Support (MAAP)-15.15		0:00:15			
Quality of Life (QoL)-10.18		0:00:52			
Housing Status-17		0:00:41			
Physical Activity-18		0:01:17			
Gender Identity (1 item)-19		0:00:06			
Sexual Orientation (1 item)-19		0:00:12			
Estimated Time Needed to Administer:		0:08:21			

Online time-budget tool

Acknowledgments: This study was funded by ViiV Healthcare. Data included in this poster have previously been presented in full at ISOQOL 28th Annual Conference; October 12-28, 2021; Virtual; Slides 103.2.

In HIV Care, PROs May Improve Patient-Provider Communication and Detection of Otherwise Hidden Needs

- PROs have the potential to improve several aspects of HIV care



Chapter 5: Outline Workflow

- Select workflow: when, where, and how to administer PROs
- Define staff roles and centralize responsibility
- Create protocol: when not to administer PROs
• Patient-based factors
• Flow-related factors
- How to introduce PROs to patients
- Define emergency and high-risk protocols
- Pilot
- Launch tips
- Resources

Sample script

"Hi, I'm <name>. Your provider <name> is interested in finding out a little bit more about how you're doing before your appointment starts. This questionnaire gives us a better idea of your general health, like your health behaviors and any symptoms you might have. It takes about <x> minutes to complete. All questions are optional. Are you willing to do this today? (if yes) Great. Let us know if you get stuck and need help."

Testimonials from case managers

"... we did a graduated approach, ... we definitely had a lot of reluctant providers, ... I think having the gradual approach was good because it got other people interested, ... once you're on this system you no longer have to hand out specific PRO health questionnaires, like the PHQ9 for depression to the patient, collect that and then enter that in. All of it would happen automatically through our PRO system. So, that actually increased buy-in... and had a lot of people interested and eager to join the program."

Sample training agenda

Clinic staff training (all levels, group meeting)
PROs: purpose and general orientation
<ul style="list-style-type: none"> PROs introduction, definition Value of PROs: known clinical/research value, reduces social desirability bias, prioritizes needs PRO domains-examples Paid demo of PROs what patients see Results: what providers see Silent group activity: all staff members self-administer PRO assessment on separate devices (if possible), as if at risk for all categories Discussion of PRO assessment experience of answering PROs Discussion regarding improving, adding, or modifying content
Integration of PROs into clinic
<ul style="list-style-type: none"> How PROs will fit into clinic flow: overview Who follows up with patients at each step during their visit How patient will move through the appointment post-PRO integration Discussion of concerns, solicit feedback, refine protocol How to schedule PROs (if applicable) How to introduce PROs to patients Protocol for late patients or patients that are too ill/impaired to complete PROs Protocol for emergency (suicide/PIV) and other alerts Results: scoring and interpretation Results: delivery protocol Communication protocols between staff regarding PROs Care and storage of tablets Using the PRO platform: scheduling, patient lookup, data sets, etc.

Chapter 6: Train Clinic Personnel

- Initial training
- Ongoing training
- Resources

Chapter 7: Monitor and Evaluate

- Identify indicators of success
- Determine process and timing
- Implement a process of continuous quality improvement
- Resources

Example process indicators

Examples of process indicators based on PRO data	Examples of performance indicators based on PRO data
Percentage of patients refusing/starting/completing the PRO process	Percentage of patients with depression who receive antidepressant medications or receive a referral
Number of screenings for improvement in symptoms	Number of patients who indicate suicidal ideation who are provided with an intervention, including a formal risk assessment
Number of screenings to identify adverse events	Patient satisfaction scores

Testimonials from HIV physicians

"It helped in our setting to assign one domain to an HIV doctor and an HIV nurse. Once per month during an hour, a certain outcome indicator and related process indicators are being discussed during the weekly clinical HIV meeting. Not just one champion but making everybody partly responsible."

Example performance indicators

How Can You Access the Toolkit?

ViiV Healthcare | PROGRESS PROJECT | FOR HIV PROVIDERS | FOR PATIENTS | CLINICAL TOPICS | TRAINING | RESOURCES | PROGRESS STUDY | REFERENCES

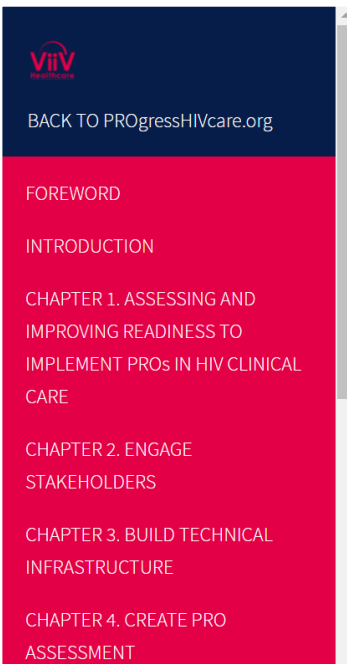
The PROgress Project: Implementing Patient Reported Outcomes Within Routine HIV Care.

- Helping patients share information with their doctor about their health, situation, needs and preferences that may otherwise not be discussed
- Improving patient-provider discussions and relationships to facilitate better-informed care and improve clinical efficiency



PROgress Implementation Toolkit

<https://progresshivcare.org/toolkit.html>



PROgress Project

<https://progresshivcare.org/>

PROgress Implementation Toolkit

This website was made possible by funding from ViiV Healthcare, a global specialist in company established in 2006, majority owned by GSK, with Pfizer and Shionogi as shareholders.

Authors

Rob J. Fredericksen, PhD, MPH – University of Washington, Medicine, Seattle, USA
Duncan Short, PhD – ViiV Healthcare, Global Implementation Science, UK
Emma Fitzsimmons, BA – University of Washington, Medicine, Seattle, USA
Justin McReynolds, MS – University of Washington, Health Informatics, Seattle, USA
Sierramatice Karras, BS – University of Washington, Health Informatics, Seattle, USA
William Lober, MD – University of Washington, Health Informatics, Seattle, USA
Heidi M. Crane, MD, MPH – University of Washington, Medicine, Seattle, USA

Conclusions

- Implementing PROs provides an opportunity for clinics to improve clinical care for PLHIV, yet PRO implementation can be perceived as a difficult and overwhelming step
- The PROgress Implementation Toolkit provides a practical resource to support the integration of PROs within routine HIV care
- This Toolkit is a novel resource that can be useful for different types of clinics and offers flexibility to adapt implementation processes