

# SPADIS

## Measuring the social participation of people living with chronic diseases in Belgium

*For people living with HIV in Belgium*

Maxim Van den broecke, Sarah de Jong, dr. Régine Kiasuwa Mbengi, prof dr.  
Christophe Vanroelen (VUB), prof dr. Aline Bingen (ULB)

BREACH Conference - 30th of november

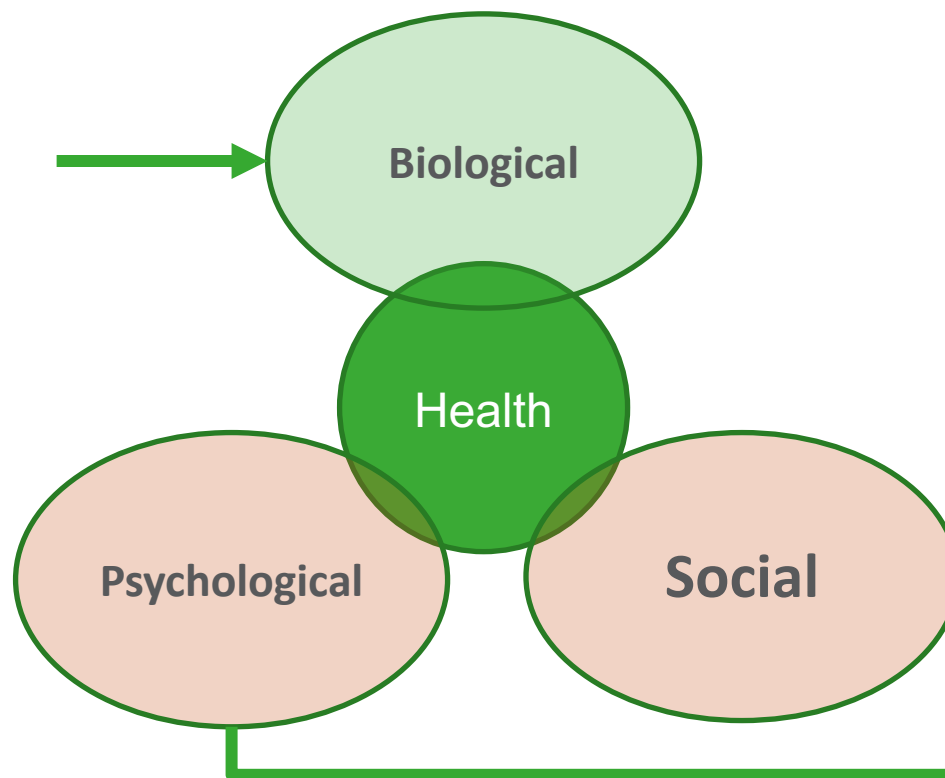
Department of Epidemiology  
and Public Health



Epidemiological monitoring  
Diagnoses | Risk factors | **Health status**

Diabetes – IQED registry  
Cystic Fibrosis – BCFR  
Neuromuscular diseases – BNMDR  
Rare diseases - CRRD  
People living with HIV – HIV Cohort

**The HIV cohort:**  
clinical, biological and  
therapeutic information



# What is social participation? How do we measure it?

**Social participation** refers to the *involvement of individuals in activities that allow for interactions with other in society or the community*<sup>1</sup>.

## SPADIS main goals

- Measuring the **impact of living with a chronic disease** in Belgium **on social well-being and participation**
- Identifying the **determinants of social participation** for people living with a chronic disease in Belgium
- Determining the **effect of environmental and contextual factors** on social participation and its determinants

# What is social participation? How do we measure it?

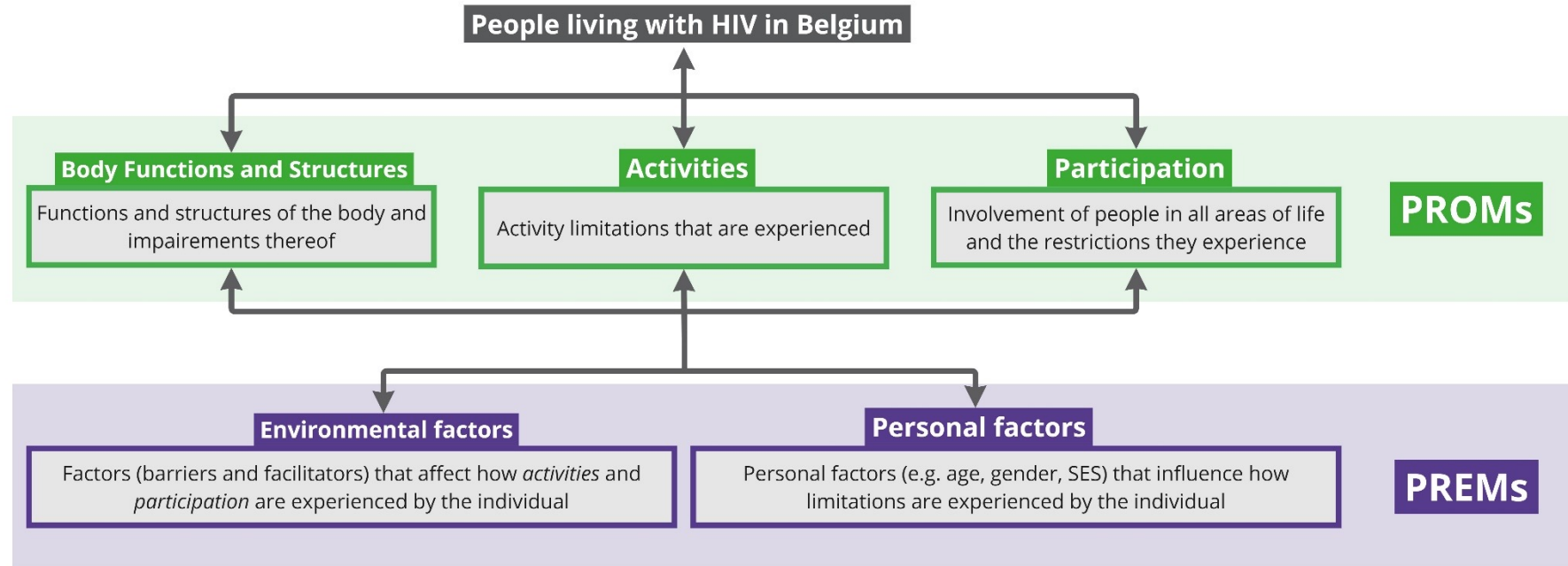
## How do we measure social participation and its determinants?

In SPADIS-WP3: based on **patient-reported information**, collected with **relevant** and **validated disease-specific questionnaires**

- Questionnaires are not always disease-specific
- No patient involvement in the development
- Questionnaires do not address aspects specific to the Belgian context
- No transparent or standardized methodology
- Questionnaires are often too long

Using existing questionnaires can be problematic

# PROMs, PREMs and the ICF model

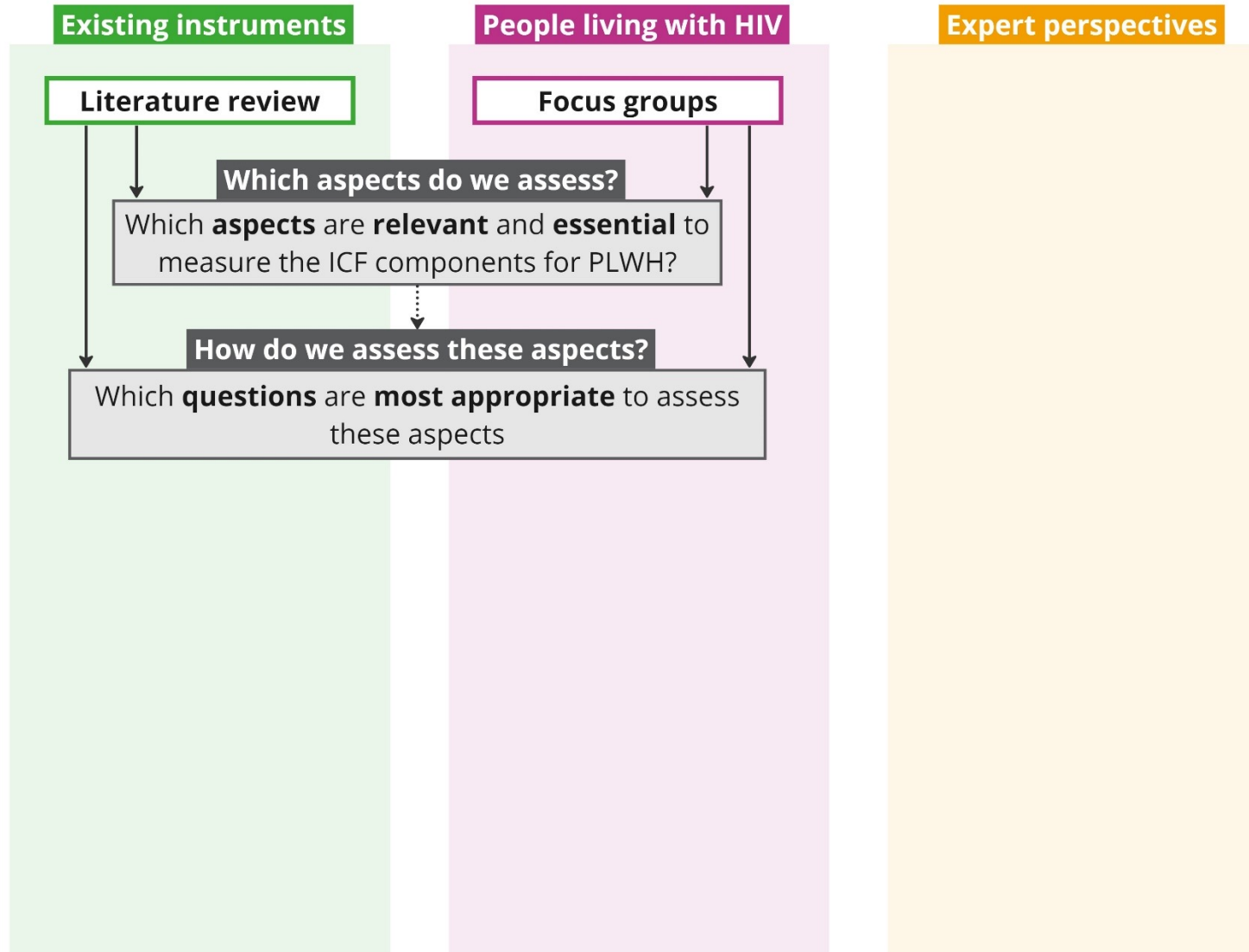


**Goal** Develop and validate *patient-reported measures (PROMs and PREMs)* to measure the ICF components, for people living with HIV in Belgium

**How?** In a **transparent** and **standardized** way. Based on

- (1) Perspectives of people living with HIV in Belgium (**patients**)
- (2) Existing patient reported measurement instruments (**literature**)
- (3) Perspectives of experts in the field (**experts**)

# A comprehensive methodology that involves PLWH

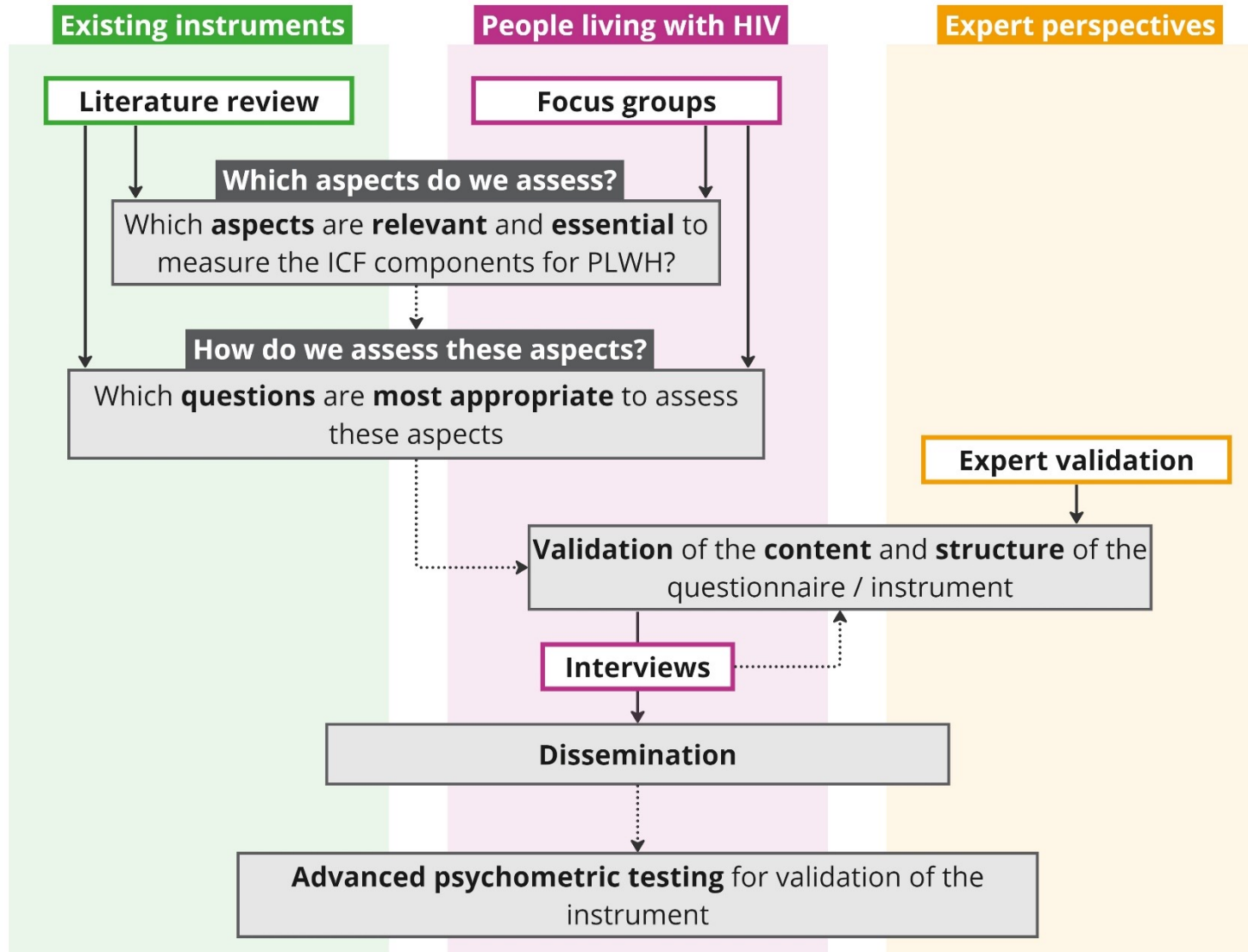


## Focus groups with PLWH

- preliminary results

- Relationships with family members
- Mental and physical fatigue
- “Feeling useful”
- Loneliness
- Relationship with physician
- Multidisciplinary of care
- ...

# Involving experts & performing advanced psychometric testing

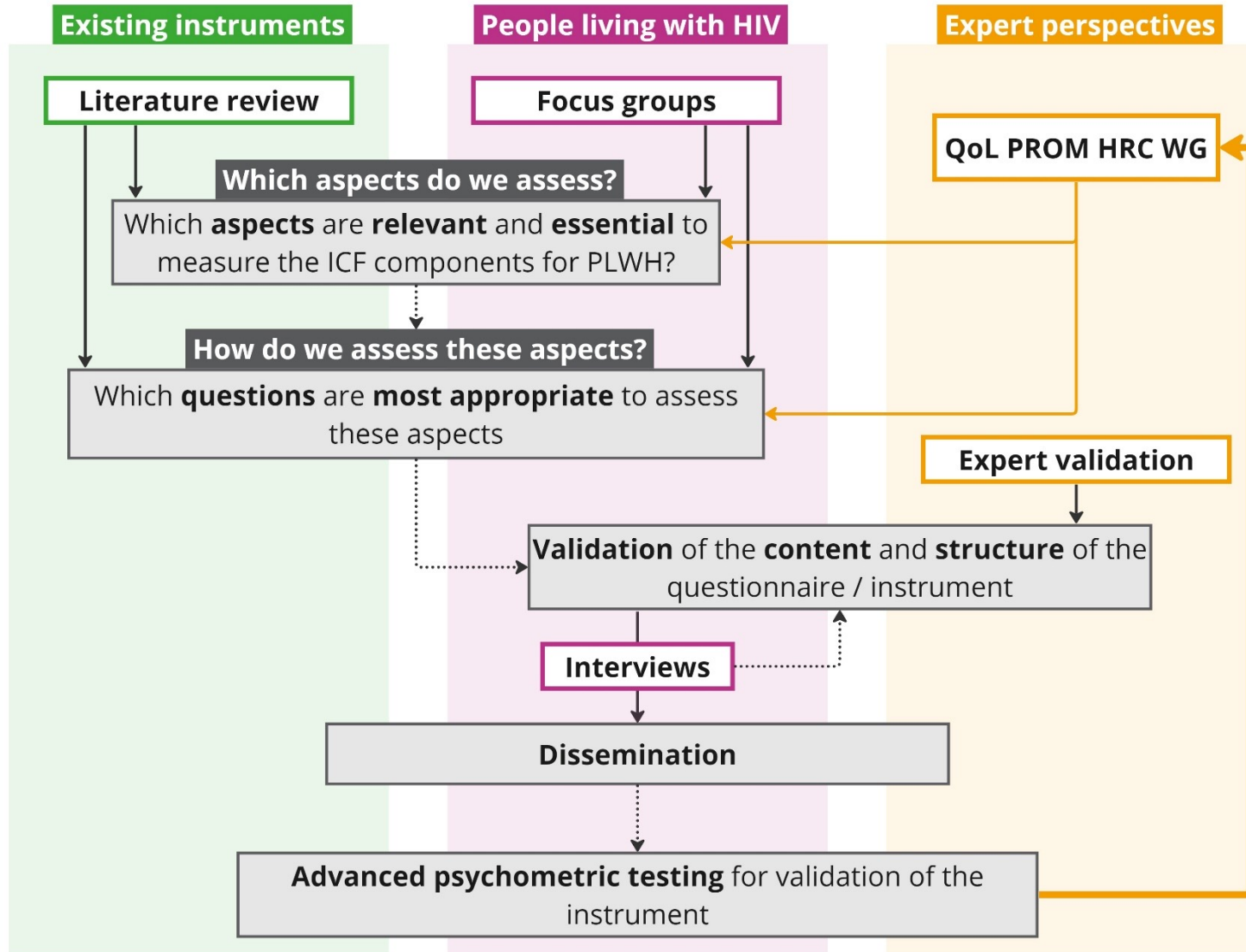


*“ Which questions are most relevant or appropriate for which sociodemographic and – economic profiles?”*

- High added value !
- Very detailed information at the level of the item / question

*(Advanced psychometric testing based on Item Response Theory)*

# A synergy between both exercises



## Synergy between SPADIS and the QoL PROM from the HRC WG

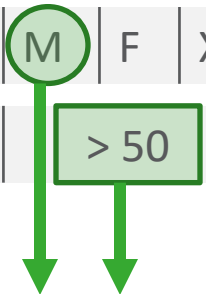
- SPADIS questions address essential aspects of (health-related) quality of life
- Expert perspectives as a starting point for the SPADIS HIV instrument (*face validity*)
- SPADIS to test which questions of the HRC QoL PROM are relevant for which specific sociodemographic and economic profiles



# A new golden standard for administering PROMs and PREMs?

What is your gender? ☒ M ☐ F ☐ X

What is your age?



<i>How satisfied are you with your <b>personal relationships</b>?</i>	Very dissatisfied	<i>How satisfied are you with your ability to <b>perform your daily living activities</b>?</i>	Very diss.
	Dissatisfied		Diss.
	Neither		Neither
	Satisfied		Sat.
	Very satisfied		Very sat.
<i>How satisfied are you with the <b>support</b> you get from your <b>friends</b>?</i>	Very dissatisfied	<i>How satisfied are you with your <b>ability to work</b>?</i>	Very dis.
	Dissatisfied		Diss.
	Neither		Neither
	Satisfied		Sat.
	Very satisfied		Very sat.

## Computerized Adaptive Testing (CAT)

- Questions are selected based on previous responses
- PLWH get less, yet more relevant questions (shortened and tailored questionnaires)
- Better measurement properties than traditional questionnaires (“Golden standard of the future”)

SPADIS prepares the introduction of CAT in Belgium for PLWH

# Outputs

## Answers to the SPADIS research questions

- How well do people living with HIV participate in activities that allow for interaction with other in society?
- What factors determine the extent to which they participate?
  - Physical – psychological factors vs. personal factors vs. environmental factors vs. ...
- How do these results compare to people living with other chronic diseases in Belgium? (Cancer, Diabetes)

## Additional SPADIS output

- Validated instruments to measure social participation and determinants (ICF model and components)

## SPADIS – HRC WG: outputs

**For SPADIS:** Enhanced validity SPADIS – HIV instrument.  
Valorization of SPADIS work at level of HRCs

**For HRC WG QoL PROM:** Enhanced validity QoL PROM

# Want to contribute?

Open invitation to help us reach our targets:



## Contact

Spadis@sciensano.be

Régine Kiasuwa Mbengi • [Régine.kiasuwambengi@sciensano.be](mailto:Régine.kiasuwambengi@sciensano.be) (Project Coordinator)

Maxim Van den broecke • [Maxim.vandenbroecke@sciensano.be](mailto:Maxim.vandenbroecke@sciensano.be) (PhD candidate)