

# HEALTH-RELATED QUALITY OF LIFE



## What is Health-Related Quality of Life (HRQoL)?

HRQoL is a construct that reflects an individual's perceptions of his or her well-being in health-related aspects of life, with the concept of health understood to encompass physical, mental and social dimensions.<sup>1,2</sup>



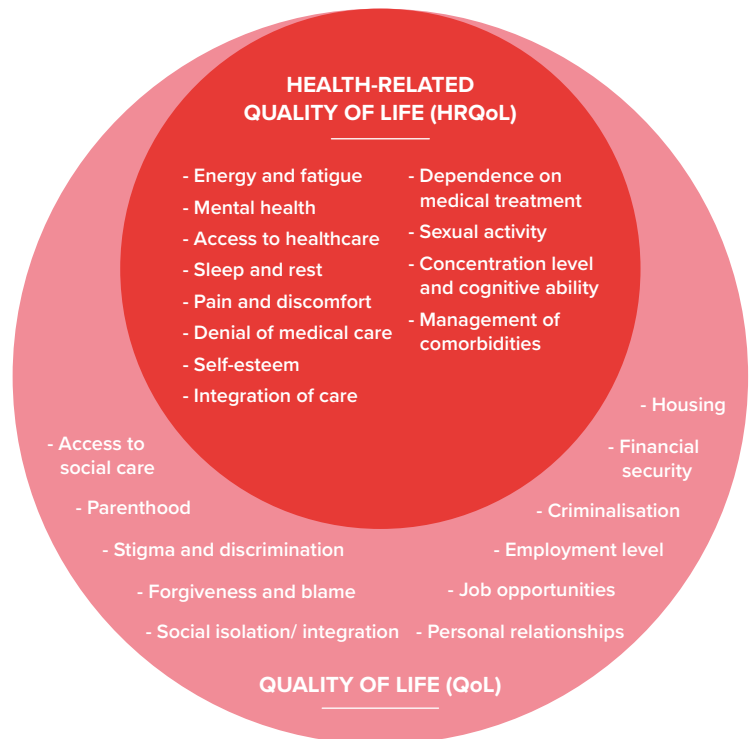
## What is the difference between HRQoL and quality of life?

The World Health Organization (WHO) defines quality of life (QoL) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns".<sup>3</sup> HRQoL can be thought of as the aspects of QoL that affect or are affected by one's health.<sup>4</sup>

## Why does HRQoL matter for people living with HIV?

Over the last decade, the widespread availability of highly effective antiretroviral therapy (ART) has meant that people living with HIV can live long and healthy lives. Care for them has largely evolved towards a model of long-term condition management. As a result, HRQoL has become central to addressing the long-term well-being of people living with HIV.

HRQoL is being increasingly considered in clinical settings through the use of validated tools to support patient-centred care. Because health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"<sup>5</sup>, policy-makers should also recognise the importance of HRQoL.

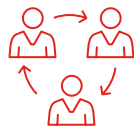


## What do we know about the HRQoL of people living with HIV?

In Europe, HRQoL has been reported to be lower among people living with HIV than among those without HIV.<sup>6-8</sup> **Setting**, such as the city or country, and **context**, such as being part of a marginalised community or being older, are important determinants of HRQoL.

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## Who uses HRQoL information and how do they use it?

HRQoL data are primarily collected as part of cohort or other academic studies. Yet, some of the existing HRQoL scales used in these studies can also be applied to routine HIV care. Patient-reported outcome measures (PROMs) assess people’s perceptions of their health and can be used to systematically quantify people’s HRQoL.

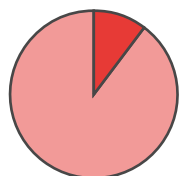
Integrating HRQoL monitoring into clinical HIV care can provide a person-centred perspective on the effectiveness of treatments and inform health-related decisionmaking for both patients and care providers. This provides insight into how well people respond to the challenges associated with complex long-term health conditions and allows for population HRQoL to be studied over time.<sup>9–11</sup>

**Hearing from patients about their everyday challenges gives me a fuller picture of their well-being**

**“ ”**

## Are there examples of how HRQoL has been used to improve treatment and care for people living with HIV?

Florence, an HIV care provider in a low-resource part of Europe, monitors the HRQoL of her patients using a simple set of PROMs. “They enable me to have a dialogue with my patients so that I can explore any symptoms that are bothering them. This sometimes helps me to diagnose new comorbidities that I wouldn’t have previously been aware of. It allows me to prioritise the patients’ concerns. Collecting this information gives me a fuller picture of my patients’ well-being and helps me and other health researchers to spot any emerging trends between self-reported HRQoL and clinical outcomes. Also, it is gratifying because the quality of my relationship with the patients has improved.”



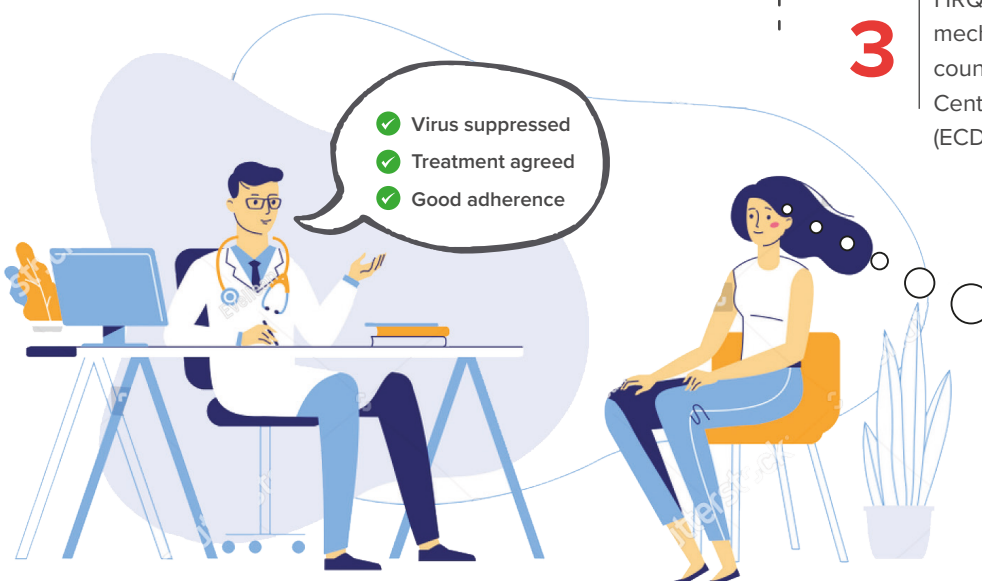
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COUNTRIES

## How many countries currently monitor HRQoL?

In 2018, only five of 48 countries in Europe who responded to the monitoring of the Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia reported that they included HRQoL in their HIV monitoring.<sup>12</sup> Monitoring HRQoL provides value to policy-makers and care providers aiming to improve health and social services.

## What are the next steps for the use of HRQoL for people living with HIV?

- 1 The role of HRQoL in clinical and policy settings should be highlighted and its potential value assessed.
- 2 Consideration should be given as to the use of existing patient-reported HRQoL scales in clinical care to set broader targets and monitor progress.
- 3 HRQoL monitoring is lacking and as such mechanisms need to be improved at the country and European (eg national, European Centre for Disease Prevention and Control (ECDC), UNAIDS and WHO) levels.



9. O'Brien, K. K. et al. Research priorities for rehabilitation and aging with HIV: A framework from the Canada-International HIV and Rehabilitation Research Collaborative (CIHRRC). *AIDS Res. Ther.* 17, 21 (2020).  
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12. Safreed-Harmon, K. et al. Ability to Monitor National Responses to the HIV Epidemic "Beyond Viral Suppression": Findings From Six European Countries. *Front. Public Heal.* 8, 36 (2020).