

The PozQoL Scale

AN EXPLANATION GUIDE



Advances in HIV care, including antiretroviral therapies, have enabled people with HIV to lead longer lives than ever before.^{1,2} Health-related quality of life (HRQoL) is an increasingly important aspect of holistic care for people with HIV.^{3,4}

In Australia, the Positive Perspectives Wave 2 study confirmed the importance of a holistic approach to HIV care and identified substantial unmet needs among people with HIV.⁵ Although 96.7% (116/120) of respondents reported being virally suppressed, 35% (42/120) reported suboptimal mental health.⁵

The PozQoL Scale was developed in response to community and healthcare organisations' needs for a reliable way to measure quality of life among people with HIV. PozQoL was designed and validated in Australia in collaboration with peer-led HIV organisations.⁶



HOW POZQOL CAN HELP PEOPLE WITH HIV

Patient-reported outcome measures (PROMs) of HRQoL, such as the PozQoL scale, provide a patient-centred approach to quantifying responses to care.⁴

PozQoL is a short, easy-to-use quality of life scale that has the potential to help:^{4,6}



Better understand the needs of people with HIV, including concerns about sensitive problems.



Improve the quality of HIV care and services provided to people with HIV.



Inform decisions to improve health outcomes and quality of life for people with HIV.

POZQOL DOMAINS OF WELLBEING^{6,7}

Domains of wellbeing were developed in consultation with peer HIV organisations according to their relevance and usefulness in HIV care. Notably, the domains of wellbeing align with World Health Organization's definition of QoL.⁶

- **Health concerns** – Including perception of one's health, health-related concerns, energy, and HIV management.
- **Psychological** – including mood, coping, hope and fear of the future, and self-worth.
- **Social** – including personal and social life, belonging, support, and social stigma
- **Functional** – including the ability to live a "normal" life, independence, meaningful occupation, and satisfactory standard of living

WHEN AND HOW TO USE POZQOL⁷

The PozQoL Scale should ideally be administered at an early appointment or before starting a new intervention or program. It may be beneficial to administer PozQoL in person for the first time.

The timing of subsequent administration of PozQoL may be tailored according to how frequently individuals or groups of people with HIV will tolerate completing the scale.



The PozQoL authors recommend the following timings for administering PozQoL:⁷

- **At an early appointment or before starting a new workshop or program.**
- **Wait at least 2 months before re-administering.**
- **Repeat quarterly (every 4 months) for targeted programs or workshops.**
- **Repeat every 3–6 months in ongoing care and support services.**

CALCULATING POZQOL SCORES

The first step in calculating a PozQoL score is to attribute a value to each response. There are 4 positively worded items (all in the psychological domain) and 9 negatively worded items within the PozQoL Scale. Positively worded items are coded in proportion to response numbers; negatively worded items are coded in reverse to the response numbers.

This coding ensures that for all items, higher scores indicate higher quality of life.

Positive item scores	Response	Negative item scores
1	Not at all	5
2	Slightly	4
3	Moderately	3
4	Very	2
5	Extremely	1

PozQoL items with score coding example⁷

Item	Not at all	Slightly	Moderately	Very	Extremely
1. I am enjoying life.*				4	
2. I worry about my health.			3		
3. I lack a sense of belonging with people around me.	5				
4. I feel that HIV prevents me from doing as much as I would like.			3		
5. I feel good about myself as a person.*					5
6. Having HIV limits my opportunities in life.			3		
7. I worry about the impact of HIV on my health.		4			
8. I feel in control of my life.*				4	
9. I am afraid that people may reject me when they learn I have HIV.			3		
10. Managing HIV wears me out.	5				
11. I feel that HIV limits my personal relationships.		4			
12. I fear the health effects of HIV as I get older.				2	
13. I am optimistic about my future.*			3		

*Positively worded items

■ Psychological
 ■ Social
 ■ Health Concerns
 ■ Functional

Visit pozqol.org/using-pozqol/ for more about using PozQoL Scores

CALCULATING OVERALL QUALITY OF LIFE AND DOMAIN SCORES⁷

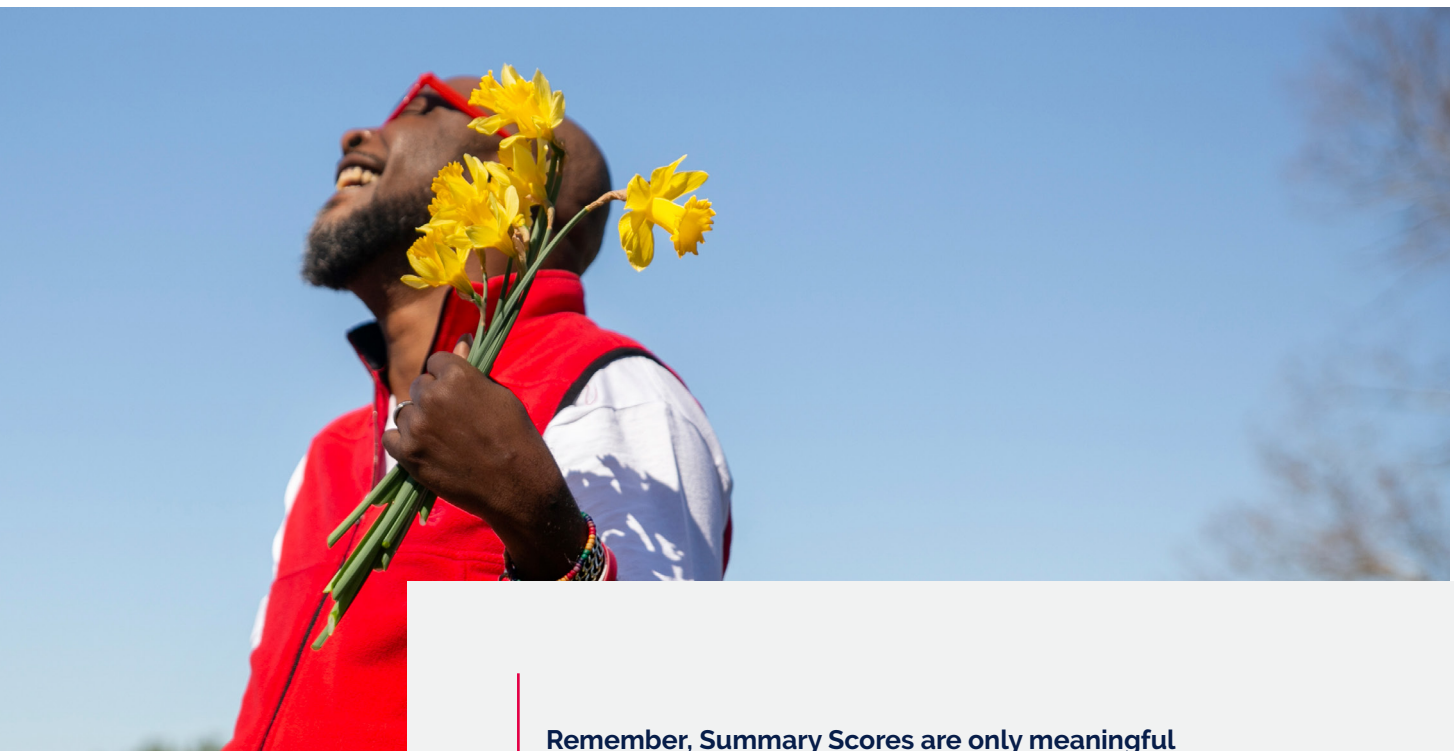
Scores can be calculated for overall quality of life (PozQoL Score) and for each domain (PozQoL Domain Scores).

The PozQoL and Domain Scores can be calculated as an average or as a sum.

Average Scores are preferable and range from 1 to 5 for the PozQoL score and each Domain Score. The PozQoL authors do not recommend calculating average Domain Scores if more than one item from a domain is left blank.

Summary Scores are only valid if all items are completed. Higher Summary Scores indicate the respondent is experiencing better quality of life overall or within a particular domain.

- **Overall PozQoL Score** – ranges from 13 to 65.
- **Psychological Domain Score** – ranges from 4 to 20.
- **All other Domain Scores** – range from 3 to 15.



Remember, Summary Scores are only meaningful when all of the relevant items have been answered.

INTERPRETING POZQOL AND DOMAIN SCORES

The next step after calculating scores is to interpret what level of quality of life each score represents. This will help to guide conversations about respondents' HRQoL and health goals.

The PozQoL authors have constructed threshold tables for Average and Summary Scores, based on empirical trials of the Scale for PLHIV in Australia.⁷

Thresholds for Average and Summary PozQoL Scores⁷

Score Range	Low QoL	Moderate QoL	High QoL	Very High QoL
PozQoL (Overall QoL)	≤2.84	2.85-3.53	3.54-4.14	≥4.15
	≤36	37-45	46-53	≥54
Psychological domain	≤2.74	2.75-3.49	3.50-3.99	≥4.00
	≤10	11-13	14-16	≥17
Social domain	≤2.32	2.33-3.32	3.33-3.99	≥4.00
	≤6	7-9	10-12	≥13
Health Concerns domain	≤2.32	2.33-3.32	3.33-3.99	≥4.00
	≤6	7-9	10-12	≥13
Functional domain	≤3.32	3.33-4.32	4.33-4.66	≥4.67
	≤9	10-11	12-14	≥15

Average scores Summary scores



For more information about how to use PozQoL and interpret PozQoL Scores, visit: Pozqol.org/using-pozqol or scan the QR code directly



USING POZQOL TO GUIDE CONVERSATIONS AND ACHIEVE IMPROVED OUTCOMES

One of the key benefits the PozQoL Scale provides is a better understanding of the needs of people with HIV. Interpreting PozQoL and Domain Scores provides an indication of HRQoL, which can be used to inform healthcare decisions and may reveal barriers that prevent desired clinical outcomes. Importantly, insights gained may help healthcare providers and people living with HIV make better decisions to meet shared goals. They may also foster discussion about overall HRQoL and help target conversations around individual domains.

Insights from PozQoL scores can be used to inform referrals to medical, community or counselling services, among others, with the goal of improving overall HIV care plans and health outcomes. The PozQoL authors have created a set of suggestions to inform score interpretation and next steps:⁷

	Someone with a low score in this domain could be:	Actions that may benefit them:	Referrals to consider:
Psychological*	<ul style="list-style-type: none"> Experiencing poor mental health, such as: <ul style="list-style-type: none"> Low mood Negative outlook about themselves, their life, or their future 	<ul style="list-style-type: none"> Further discussion about their mental health. Assessment using diagnostic mental health tools. 	<ul style="list-style-type: none"> Counselling services. Community rehabilitation and support services. Care and support.
Social	<ul style="list-style-type: none"> Experiencing some difficulties in relationships with other people. Experiencing HIV-related discrimination. Lacking a sense of belonging and support. 	<ul style="list-style-type: none"> Meeting PLHIV peers, who can assist in: <ul style="list-style-type: none"> Overcoming isolation due to fear of stigma. Managing disclosure and confidence. 	<ul style="list-style-type: none"> Peer support. Peer navigation. Care and support.
Health concerns	<ul style="list-style-type: none"> Currently experiencing some difficulties managing their health. Concerned that their health will deteriorate due to HIV – even if they are enjoying good health at the moment 	<ul style="list-style-type: none"> Discussing treatment options or revisions. Speaking with PLHIV peers about managing HIV. Information about maintaining good health with HIV. 	<ul style="list-style-type: none"> Medical services. Health promotion. Peer education. Care and support. Counselling services.
Functional	<ul style="list-style-type: none"> Experiencing some difficulties with incorporating HIV into their everyday life. Lacking functional independence. Experiencing some financial distress. 	<ul style="list-style-type: none"> Meeting PLHIV peers. Community or financial support or advice. 	<ul style="list-style-type: none"> Community support. Financial and housing assistance. Personal development.

*PozQoL is not a diagnostic tool. If you are not a mental health worker but you are concerned about your patient or client's mental health, it is important to refer them to a mental health service to support individuals with HIV.

For example, low HRQoL in the Functional Domain could help identify poor functional independence through open and active discussion, and a referral for community support may help benefit the person with HIV.

View more PROM and PozQoL resources at <https://viivhealthcare.com/en-au/HCP>

Visit pozqol.org/using-pozqol/ for more about using PozQoL Scores

Learn more about patient-reported outcome measures and find more PozQoL resources at:

<https://viiivhealthcare.com/en-au/hiv-thrive/assessing-quality-of-life>

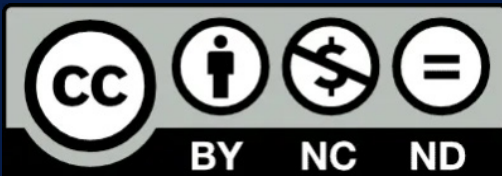
Or scan the QR code directly:



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Brown, G, Mikołajczak, G, Lyons, A, Power, J, Drummond, F, Cogle, A, Allan, B, Cooper, C & O'Connor, S 2018, 'Development and validation of PozQoL: A scale to assess quality of life of PLHIV', *BMC Public Health*, vol. 18, p. 527.

HRQoL: health-related quality of life. **PROM:** patient-reported outcome measure.

References: **1.** Wandeler G *et al. Curr Opin HIV AIDS.* 2016; 11(5): 492–500. **2.** Althoff KN *et al. Curr Opin HIV AIDS.* 2016; 11(5): 527–36. **3.** Lazarus JV *et al. BMC Med.* 2016; 14(1): 94. **4.** Lazarus JV *et al. Nat Commun.* 2021; 12(1): 4450. **5.** Allan B *et al. Popul Med.* 2021; 31: 1–14. **6.** Brown G *et al. BMC Public Health.* 2018; 18(1): 527. **7.** PozQoL. Using PozQoL. Available at: <https://www.pozqol.org/using-pozqol/> Accessed February 2022.

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The PozQoL Scale was developed by the Australian Research Centre in Sex Health and Society (ARCSHS) in partnership with, National Association of People with HIV Australia (NAPWHA), Living Positive Victoria, Positive Life NSW, Queensland Positive People (QPP), and ViiV Healthcare.