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## Optimising quality of life –the fourth 90%: how to include quality of life in guidelines

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HIV Futures



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## Quality of Life and HIV Care

The interrelationship between quality of life, stigma and treatment adherence has been well established. (3-7)

- PLHIV with poor mental health and/or experiencing stigma are less likely to adhere to treatment [3-6].
- Improving health outcomes through viral suppression does not by itself ensure improved quality of life among people living with HIV [6].



## Some points from HIV Futures 8

Overall, most PLHIV reported good levels of physical health and general health overall.

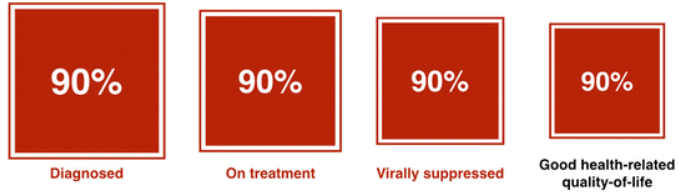
However this masks the diversity

- Varied considerably by age and other demographics
- Considerable prevalence of issues concerning mental health, isolation, co-morbidities, and impact of stigma and discrimination



[www.latrobe.edu.au/arcshs/projects/hiv-futures](http://www.latrobe.edu.au/arcshs/projects/hiv-futures)



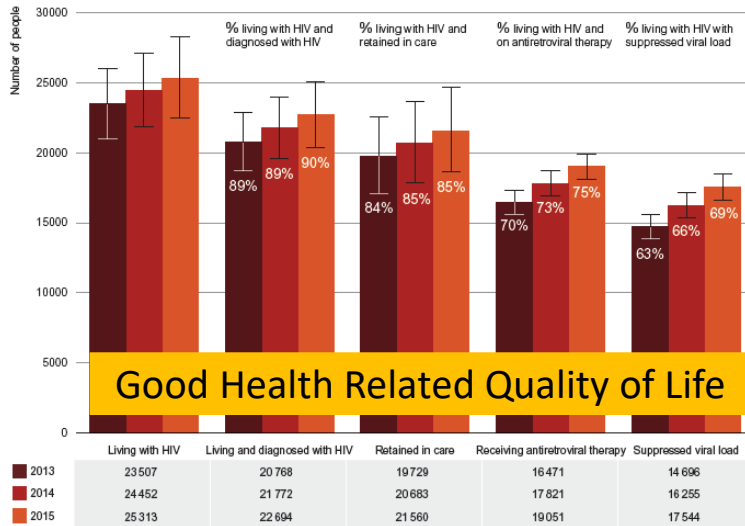


\*Adapted from: UNAIDS. 90-90-90: an ambitious treatment target to help end the AIDS epidemic. 2014. Available at [http://unaids.org/sites/default/files/media\\_asset/90-90-90\\_en\\_0.pdf](http://unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf). Accessed on 25 April 2016

Lazarus, Jeffrey V., et al. "Beyond viral suppression of HIV—the new quality of life frontier." *BMC medicine* 14.1 (2016): 94.



Figure 29 The HIV diagnosis and care cascade, 2013 – 2015



The Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2016. The Kirby Institute, UNSW Sydney, Sydney NSW 2052



## Some barriers with current scales

- Generic scales do not capture the unique social and stigma related elements key to HIV care
- Most current scales for PLHIV are large, restricted in their use, expensive, or developed prior to the current treatment era
- The more comprehensive scales are long, take a substantial amount of time to complete and not practical for most day to day service use. (5-7)
- HIV community, support, and healthcare services in Australia expressed a need for an empirically validated, short and practical way to measure quality of life of PLHIV accessing their programs.



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## How did we develop and validate PozQoL?

PozQoL study embedded in the GIPA/MIPA principles of a direct partnership with peer-led organisations representing people living with HIV.

- Involved in the conceptualisation and prioritisation of the domains, development of items, and decisions concerning the refinement of the final scale.
- The insights from consultations with PLHIV and other stakeholders supported the balancing of statistical rigour, conceptual accuracy, and practical use.



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## How did we develop and validate PozQoL?

Stage	Key tasks	Progress
<b>Stage 1</b> <b>Development of the draft instrument</b> <b>4 months</b>	<ul style="list-style-type: none"> <li>• Systematic review of literature, current scales</li> <li>• Identify domains</li> <li>• Generate a draft scale</li> </ul>	Completed
<b>Stage 2</b> <b>Pre-testing and Validation of scale</b> <b>8 Months</b>	<ul style="list-style-type: none"> <li>• Pre-test with key sector partners</li> <li>• Recruit 465 PLHIV to complete instrument alongside other longer scales</li> <li>• Data analysis to test validity of the instrument and identify the fewest and most effective items (13 items across 4 domains)</li> </ul>	Completed
<b>Stage 3</b> <b>Implementation Trial of the PozQoL Scale</b> <b>12 months</b>	<ul style="list-style-type: none"> <li>• <b>Usability and acceptability trial</b></li> <li>• <b>Sensitivity trial</b></li> </ul>	January to December 2018



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## How did we develop and validate PozQoL?

- Online survey with  $N = 465$  adult PLHIV in Australia
- The survey included the pilot PozQoL scale (64 items) and other validated measures of health and wellbeing.
  - SF-36: RAND Short Form 36 1.0<sup>(8)</sup>
  - FAHI: Functional Assessment of Human Immunodeficiency Virus Infection<sup>(9)</sup>
  - Psychological Distress: K6 Scale<sup>(10)</sup>
  - Wellbeing: The Short Warwick-Edinburgh Mental Well-being Scale<sup>(11)</sup>
  - Satisfaction with life: The Satisfaction with Life Scale<sup>(12)</sup>
  - Resilience: The Brief Resilience Scale<sup>(13)</sup>
  - Stigma: Internalised AIDS-Related Stigma Scale<sup>(14)</sup>
  - Social Support: Interpersonal Support Evaluation List<sup>(15)</sup> ISEL-12 version<sup>(16)</sup>



25 Years of partnership  
and collaboration



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## How did we develop and validate PozQoL?

- Thirteen items were selected
  - based on Exploratory Factor Analysis and conceptual considerations.
  - then subjected to Confirmatory Factor Analysis with excellent levels of fit
    - (model fit:  $\chi^2_{(61)} = 74.42, p = .116; CFI = .992, SRMR = .036, RMSEA = .034 [.000, .059]$ ).



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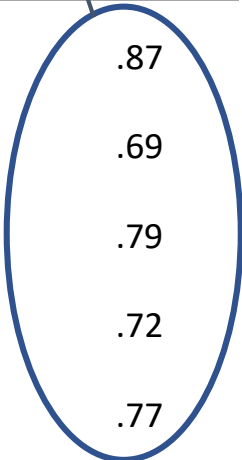
# What is the PozQoL Scale

13 items across 4 domains	
Health concerns	I worry about my health
	I worry about the impact of HIV on my health
	I fear the health effects of HIV as I get older
Psychological	I am enjoying life
	I feel in control of my life
	I am optimistic about my future
Social	I feel good about myself as a person
	I feel that HIV limits my personal relationships
	I lack a sense of belonging with people around me
Functional	I am afraid that people might reject me when they learn I have HIV
	I feel that HIV prevents me from doing as much as I would like
	Having HIV limits my opportunities in life
	Managing HIV wears me out



CONVERGENT VALIDITY			
	SF-36 PCS	SF-36 MCS	FAHI
PozQoL (total score)	.68	.77	.87
Health concerns	.54	.57	.69
Psychological	.65	.78	.79
Social	.45	.57	.72
Functional	.66	.69	.77

WOW!



MEAN SCORES AND RELIABILITIES					
Scale	# of items	Alpha	Test-retest reliability	Mean	SD
PozQoL (total score)	13	0.94	0.95	3.43	0.92
Health concerns	3	0.91	0.91	3.22	1.13
Psychological	4	0.90	0.85	3.38	0.97
Social	3	0.82	0.83	3.26	1.14
Functional	3	0.87	0.89	3.94	1.10

Awesome!

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## Implementation Trial of PozQoL

- PozQoL developed a short, reliable, and validated scale measuring HRQoL among PLHIV.
- The next step is an implementation trial
  - To assess the usability, acceptability, and usefulness of the PozQoL scale in the day to day work of different health and community services
  - To assess how sensitive the PozQoL scale is in measuring changes in health-related quality of life as a result of interventions or services
- An implementation trial is an important step in building the evidence for the practical use of the PozQoL scale.



## Implementation Trial of PozQoL

- Plan to trial across five types of service/programs
  - PLHIV peer workshops
  - One-to-one counselling or peer support services
  - General practice or specialist clinics
  - Online intervention
  - Informal online peer network



## Treatment Related Items

Best 11 so far....

treatment and QoL	<b>T7_11 Thanks to my treatment I feel that I have everything under control</b>
	T7_2 Having to take medication makes HIV too present in my life
	<b>T7_9 My treatment reminds me that I am sick</b>
	<b>T7_3 I worry about the impact of treatment on my health as I get older</b>
	T7_10 I fear the side effects of treatment as I get older
satisfaction with treatment	<b>T7_8 I worry about other people finding out I have HIV when I take my medicine</b>
	T7_1 Thanks to my treatment I feel that my HIV is under control
	T7_5 My treatment improves my life
	T7_6 My treatment makes me feel healthier
	T7_7 I am unhappy with the side effects of my treatment
	T7_12 I find my treatment convenient



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## In closing...

- Indicators of health related QoL may be useful as both an input to, and an outcome of, optimising care.
  - Input – such as guide care plans as well as referral to peer and other community/psyc etc services
  - Outcome – to monitor how the adaptations we are all making across our services are working across different groups.
- Incorporating a meaningful quality of life perspective into guidelines for optimising care will be essential to achieving sustained outcomes for PLHIV in in a rapidly changing context.
- Implementation trial of PozQoL scale will show if we have developed something short enough and meaningful enough to support this.



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- **465 PLHIV who completed a survey to create a survey!!!**



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