

# PozQoL:

Assessing PLHIV quality of life  
in Melbourne, Australia

Assoc Prof Graham Brown

# LONDON

## FAST-TRACK CITIES 2019

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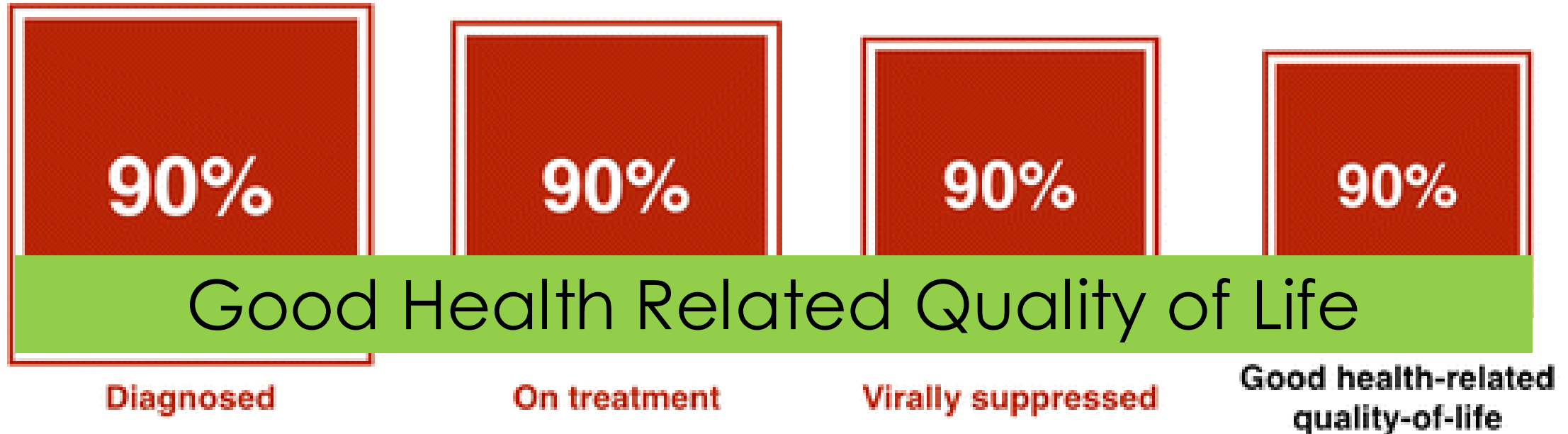
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# PLHIV IN RESEARCH

*Thank you to the people living with HIV who have generously shared their time, experience, and body for the purposes of research.*

*Much of the fight against HIV and AIDS relies upon people living with HIV continuing to put themselves forward and the PozQoL study and our pursuit of the end of HIV is indebted to those past and present.*



\*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

PozQoL Project was an alignment of priorities of

- peer organisations,
- research, and
- industry

# POZQOL

## VALUING QUALITY OF LIFE AMONG PLHIV



# HOW DID WE DEVELOP AND VALIDATE POZQOL?

Stage	Key tasks
<b>Stage 1 (2015/16)</b> <b>Development</b> <b>4 months</b>	<ul style="list-style-type: none"> <li>• Systematic review of literature, current scales</li> <li>• Identify domains with sector partners</li> <li>• Generate a draft scale</li> </ul>
<b>Stage 2 (2016/17)</b> <b>Pre-testing and Validation</b> <b>8 Months</b>	<ul style="list-style-type: none"> <li>• Pre-test with 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> <li>• Assess convergence with 8 other larger validated scales</li> </ul>
<b>Stage 3 (2018/19)</b> <b>Implementation Trial</b> <b>12 months</b>	<ul style="list-style-type: none"> <li>• Usability and acceptability trial</li> <li>• Sensitivity trial</li> </ul>



# 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  
I feel good about myself as a person

### Social

I feel that HIV limits my personal relationships  
I lack a sense of belonging with people around me  
I am afraid that people might reject me when they learn I have HIV

### Functional

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

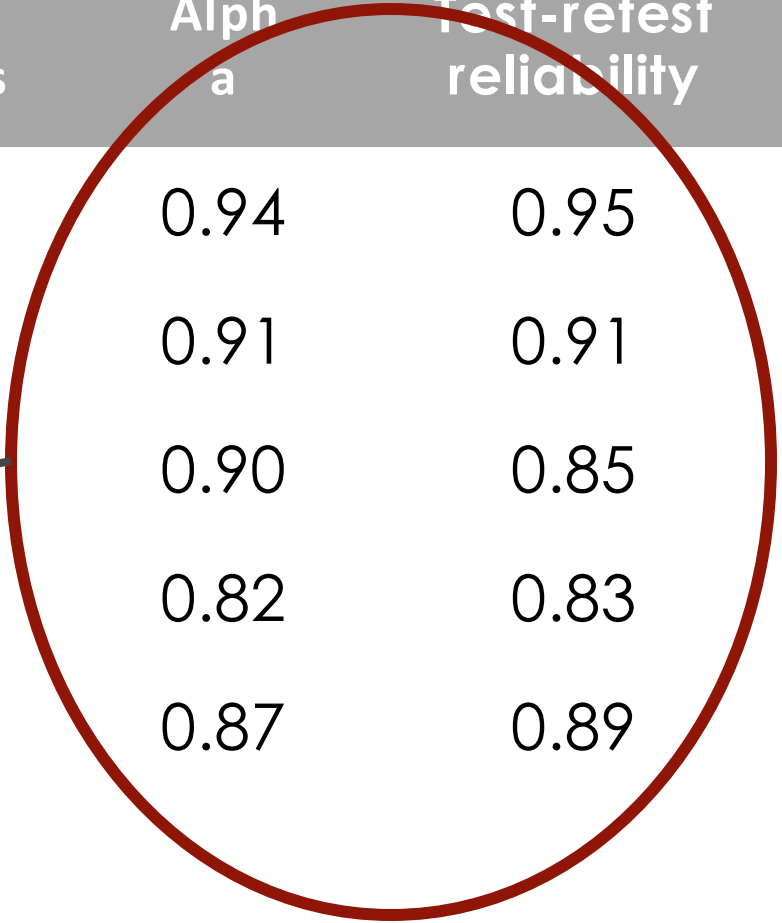
	SF-36 MCS (general com)	FAHI (HIV Specific)
<b>PozQoL (total score)</b>	<b>.77</b>	<b>.87</b>
Health concerns	.57	.69
Psychological	.78	.79
Social	.57	.72
Functional	.69	.77

Wow!

## MEAN SCORES AND RELIABILITIES

Scale	# of items	Alpha	Test-retest reliability	Mean	SD
<b>PozQoL (total score)</b>	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!





# IMPLEMENTATION TRIAL OF POZQOL

The next step was 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

**Where:** clinical services, PLHIV peer programs, community/welfare services, (7)

**Uses:** Evaluation of programs, monitor clients, enhance the client/provider discussion

# IMPLEMENTATION TRIAL OF POZQOL

Usability Feedback (online survey n=19, interviews n=9, from 7 orgs)

## **Benefits**

- supported understanding of the client group accessing the program/service
- influenced communication or topics discussed with the clients
- supported efforts to increase a focus on quality of life alongside quality of care

This was in addition to most respondents (n=15) reporting that PozQol was easy for staff to use.

# IMPLEMENTATION TRIAL OF POZQOL

## Challenges

- Time – particularly in clinical services – for any PROM
- Capacity/readiness of organisation's record management systems
- English only (at that time)

## Suggestions

- Digital solutions for collection and analysis
- Enhancing the implementation kit and online resources

# IMPLEMENTATION TRIAL OF POZQOL

## Sensitivity of PozQoL – Community and peer services

	Post – Pre (change)	95% CI	p value	N
<b>PozQoL Total Score</b>	0.291	( 0.178, 0.404)	<b>0.000*</b>	95
<b>PozQoL Health Concerns</b>	0.286	( 0.080, 0.492)	<b>0.006*</b>	95
<b>PozQoL Psychological</b>	0.272	( 0.096, 0.448)	<b>0.002*</b>	95
<b>PozQoL Social</b>	0.364	( 0.206, 0.522)	<b>0.000*</b>	95
<b>PozQoL Functional</b>	0.168	(-0.014, 0.351)	<b>0.070</b>	95

- PozQoL showed statistically significant changes across the community programs – demonstrating sensitive enough to measure changes in QoL over a two month period

# IMPLEMENTATION TRIAL OF POZQOL

## Sensitivity of PozQoL – Community and peer services

Intervention	Scale	Post – Pre (change)	95% CI	p value	N
<b>Newly Diagnosed PLHIV workshops</b>	PozQoL Total Score	0.520	( 0.297, 0.744)	<b>0.000*</b>	23
	PozQoL Health Concerns	0.732	( 0.332, 1.132)	<b>0.001*</b>	23
	PozQoL Social	0.526	( 0.269, 0.782)	<b>0.000*</b>	23
<b>Welfare/Community Services Combined</b>	PozQoL Total Score	0.212	( 0.057, 0.368)	<b>0.008*</b>	55
	PozQoL Psychological	0.306	( 0.051, 0.561)	<b>0.020*</b>	55

Major changes within the PozQoL domains (Health concerns, social, functional and psychological) corresponded with the aims of the programs

# So how did we achieve such a strong PozQoL?



PozQoL study was embedded in partnership and the GIPA/MIPA principles.

- Direct involvement of peer organisations in the
- conceptualisation and prioritisation of the domains,
- development of items,
- promotion and community engagement,
- **decisions concerning the refinement of the final scale,**
- Sector mobilisation for the implementation trial



# What did partnership and MIPA achieve?

- Balancing of statistical rigour, conceptual accuracy, and practical use
- Deeper understanding of the complexity of the experience of PLHIV
- Strengthened the relationship across research, community, clinical and industry
- Non-reliance on individuals with HIV
- Credibility and authenticity within the PLHIV community was demonstrated through action more than reputation
- Strong participation and recognition of PozQoL among PLHIV

# CURRENT DEVELOPMENTS FOR POZQOL

- Incorporated into some clinical services but logistical challenges to be resolved
- Incorporated within most PLHIV peer programs across Australia and increasing number of community support programs.
- Incorporated into Australian national PLHIV studies, and some implementation science studies.
- PozQoL is now the PLHIV QoL indicator for the Australian National HIV Strategy

- **Implementation kit and resources being refined**

- **PozQoL Website in development**

**[pozqol.org.au](http://pozqol.org.au)**

- **Translated into 13 languages (to date)**
- **PozQoL used social research and implementation research in North America and planned studies in Europe**

# IN CLOSING...

To achieve Fast Track City goals we need adapt in tandem with PLHIV.

Indicators of QoL are useful as both an input to, and an outcome of, optimising care.

- **Input** – such as guiding care plans as well as referral to peer and other community/support services.
- **Outcome** – to monitor how the adaptations we are all making across our services are working across different groups of PLHIV.

To guide this, we need to:

- partner with PLHIV at a policy and service level to guide priorities
- monitor QoL within our day to day practice of our services (rather than only in research studies).

PozQoL may make this more viable.

# PozQoL Website

Website is currently in development

We have a temporary website which hosts most of the key documentation and translations

[www.pozqol.org.au](http://www.pozqol.org.au)

# THANK YOU

## **ARCSHS Colleagues**

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

# DISCLOSURE AND ACKNOWLEDGMENT

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- *Living Positive Victoria,*
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- *Indebted to the participation of PLHIV in research*