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POZQOL:
VALUING QUALITY OF LIFE AMONG PLHIV

Australian Research Centre in Sex, Health & Society

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ACKNOWLEDGEMENT OF COUNTRY

We acknowledge the traditional owners of this country that we are standing on today and honour the Elders, past, present and emerging.

POZQOL:
VALUING QUALITY OF LIFE AMONG PLHIV

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2 National Association of People with HIV Australia
3 Living Positive Victoria
4 The Alfred
5 Bobby Goldsmith Foundation
6 Queensland Positive People
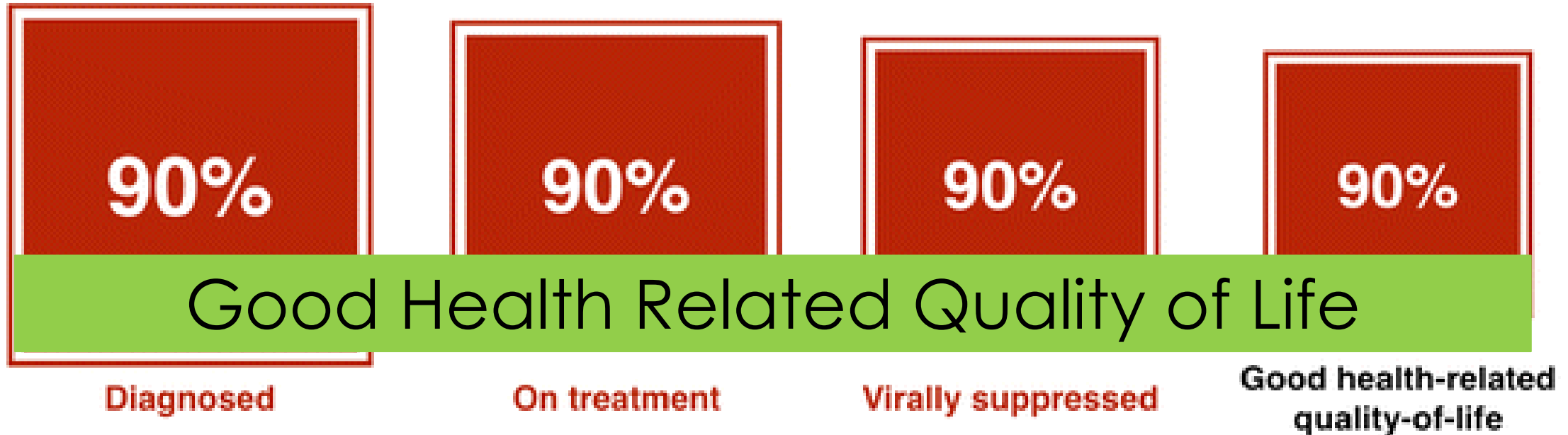7 Positive Life NSW
8 ViiV Healthcare Australia
9 ViiV Healthcare Global

PLHIV IN RESEARCH

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

Much of the fight against HIV and AIDS relies upon people living with HIV continuing to put themselves forward and this research and our fight against HIV and AIDS is indebted to those past and present.

90% — Diagnosed
90% — On treatment
90% — Virally suppressed
90% — Good health-related quality-of-life

Good Health Related Quality of Life

*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. 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.

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PozQoL Project was an alignment of priorities of peer organisations, clinical and community services, research, and industry

Imbedded within GIPA/MIPA principles,

Funded by ViiV Healthcare and significant in kind from across the HIV sector

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Australian Research Centre in Sex, Health & Society — ARCSHS

PositiveLifeNSW
the voice of people with HIV since 1988

qpp
Queensland Positive People

living positive victoria
PEOPLE LIVING WITH HIV/AIDS VICTORIA

napwha national association of people with HIV australia

ViiV Healthcare

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

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IMPLEMENTATION TRIAL OF POZQOL

To assess the <u>usability, acceptability, and usefulness</u> of the PozQoL scale in the day to day work of different health and community services (online survey and interviews)

To assess how <u>sensitive</u> the PozQoL scale is in measuring <u>changes</u> in health-related quality of life as a result of interventions or services (analysis of client data)

- **Where**: clinical services, peer programs, community/welfare services, (7)
- **When** : 6 to 12 month period across organisations in 2018/19
- **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
- demonstrated the impact of programs/interventions

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
- Capacity/readiness of organisational 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
PozQoL Total Score	0.291	(0.178, 0.404)	**0.000***	95
PozQoL Health Concerns	0.286	(0.080, 0.492)	**0.006***	95
PozQoL Psychological	0.272	(0.096, 0.448)	**0.002***	95
PozQoL Social	0.364	(0.206, 0.522)	**0.000***	95
PozQoL Functional	0.168	(-0.014, 0.351)	**0.070**	95

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

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IMPLEMENTATION TRIAL OF POZQOL

Sensitivity of PozQoL – Community and peer services

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

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

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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

- **Translated into 13 languages (to date)**

- **PozQoL used in social research and implementation research in North America and planned studies in Europe**

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IN CLOSING…

To achieve long term quality of life 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

THANK YOU

ARCSHS Colleagues

Gosia Mikołajczak,' Anthony Lyons,' Jennifer Power'

Partner Organisation colleagues and their clients for generous support

NAPWHA,
Positive Life NSW,
Living Positive Victoria,
Queensland Positive People,
Thorne Harbour Health,
Acon,
Positive Life NSW,

Alfred Health,
Thorne Harbour Health,
Bobby Goldsmith Foundation,
WA AIDS Council,
Prahran Market Clinic,
ViiV Healthcare

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DISCLOSURE AND ACKNOWLEDGMENT

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ADDITIONAL SLIDES IF QUESTIONS

Intervention	Scale	Average Score at Pre	Post – Pre (change)	95% CI	p value	N
Newly Diagnosed PLHIV workshop	PozQoL Total Score	2.821	0.520	(0.297, 0.744)	0.000*	23
	PozQoL Health Concerns	2.341	0.732	(0.332, 1.132)	0.001*	23
	PozQoL Psychological	3.185	0.293	(-0.043, 0.630)	0.084	23
	PozQoL Social	2.710	0.526	(0.269, 0.782)	0.000*	23
	PozQoL Functional	2.928	0.488	(0.105, 0.872)	0.015*	23
PLHIV Retreat	PozQoL Total Score	3.267	0.236	(-0.035, 0.507)	0.084	17
	PozQoL Health Concerns	3.196	0.196	(-0.082, 0.474)	0.154	17
	PozQoL Psychological	3.515	0.132	(-0.294, 0.559)	0.520	17
	PozQoL Social	2.765	0.590	(0.209, 0.972)	0.005*	17
	PozQoL Functional	3.529	0.052	(-0.394, 0.498)	0.807	17
Welfare/Community Services Combined	PozQoL Total Score	3.163	0.212	(0.057, 0.368)	0.008*	55
	PozQoL Health Concerns	2.964	0.127	(-0.180, 0.434)	0.410	55
	PozQoL Psychological	3.185	0.306	(0.051, 0.561)	0.020*	55
	PozQoL Social	3.085	0.226	(-0.004, 0.457)	0.054	55
	PozQoL Functional	3.321	0.071	(-0.178, 0.319)	0.572	55
All services combined	PozQoL Total Score	3.089	0.291	(0.178, 0.404)	0.000*	95
	PozQoL Health Concerns	2.854	0.286	(0.080, 0.492)	0.006*	95
	PozQoL Psychological	3.244	0.272	(0.096, 0.448)	0.002*	95
	PozQoL Social	2.937	0.364	(0.206, 0.522)	0.000*	95
	PozQoL Functional	3.263	0.168	(-0.014, 0.351)	0.070	95

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

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

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For full details, implementation guide and resources on PozQoL go to

www.pozqol.org.au

Note – website is under construction but all current resources are available

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