

GIPA in Action – PLHIV leadership in the development of a PLHIV quality of life scale for the community, health and policy sector

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GIPA and Research

The greater and meaningful involvement of people with HIV/AIDS (GIPA) has been a foundation of effective responses to HIV. However, in research this has often been limited to consultation rather than full collaboration.

The PoQoL Study

To improve evaluation of community and health services and enhance evidence for advocacy, HIV organisations needed a short, empirically validated and easy to incorporate quality of life scale for PLHIV.

A partnership of PLHIV peer organisations, researchers, and health industry was established to pool resources and develop the PozQoL scale. This partnership was committed to GIPA being at the centre of the process.

PozQoL Partnership

The PozQoL partnership involved active direction from PLHIV peer leadership in the:

- conceptualisation of the research approach,
- prioritisation of the QoL domains to be included in the scale,
- development and review of scale items,
- engagement and mobilisation of the PLHIV community to support the validation survey (465 PLHIV participated), and
- analysis and decisions concerning the refinement of the final scale.

GIPA achieves stronger outcomes

Benefits of the partnership with PLHIV peer leadership included:

- a deeper understanding of the complex experiences of PLHIV related to QoL,
- ensuring a balance of statistical rigour, conceptual accuracy, and practical use of the PozQoL scale,
- strengthened relationship across research, community and health sector,
- opportunity to demonstrate credibility and authenticity within PLHIV community, and
- advocacy for PozQoL to now be the recognised indicator for QoL in the National Australian HIV Strategy.



Conclusions

Following GIPA principles enabled the study to ensure the research rigour was complemented by practical and conceptual considerations, and high community engagement.

The PozQoL scale is currently being field-tested by 15 community, support and healthcare programs for PLHIV in Australia, and being used in national surveys of PLHIV in Australia and the USA.

The development of the PozQoL has demonstrated the benefits of full collaboration to achieve high quality research outcomes.

PozQoL Scale

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

Response scale: 1 – not at all; 2 – slightly; 3 – moderately; 4 – very; 5 - extremely



Further details

For more information about the PozQoL scale, please take a copy of our broadsheet or contact:

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PozQoL has been developed by the Australian Research Centre in Sex, Health, and Society in partnership with ViiV Healthcare Australia, National Association of People with HIV Australia, Living Positive Victoria, Positive Life NSW and Queensland Positive People.

