

Incorporating quality of life into care for people living with HIV (PLHIV): developing a consensus tool of health and social Patient Reported Outcome Measures (PROMs) for clinical and community services

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Background:

Achieving good quality of life (QoL) for people with HIV (PLHIV) includes clinical and community initiatives. PozQoL measures QoL of PLHIV and is a commonly used Patient Reported Outcome Measure (PROM) in Australia. Complimenting PozQoL with other social and clinical PROMs may encourage patient led care and PROM use across settings. A research, community, clinical, and policy collaboration was created to form a consensus on recommended PROMs.

Approach:

Phase I: six domains were prioritized (psychological wellbeing, social wellbeing, physical wellbeing, stigma and discrimination, welfare, lifestyle and safety concerns, treatment-related factors) in consultations with PLHIV peer staff and people working in community, clinical, and policy settings. 47 PROMs were identified through a literature review and categorized within each domain.

Phase II: 40 people working in HIV community, clinical, policy and research settings agreed to participate in a three-round Delphi consensus survey process to select a set of recommended PROMs.

Outcomes/Impact:

The first survey revealed 7 of the 47 PROMs met inclusion criteria across the participant group (n=40), with an additional 18 PROMs meeting inclusion criteria within at least one of the three panel groups:

- Clinical panel (n=17) achieved consensus on 1 PROM
- Community panel (n= 13) achieved consensus on 2-3 PROMs within each domain,
- Policy and research panel (n=11) achieved consensus on PROMs within stigma and discrimination, and welfare and lifestyle domains.

The study found greater cultural and linguistic inclusiveness was required, highlighting a significant gap in diversity of current PROMs.

Innovation and Significance:

Consensus on 24 initial PROMs across the six domains was achieved, while identifying cultural and linguistic limitations of current PROMs. Further Delphi rounds (underway) will refine the list of PROMS and test acceptability. Consensus on a

short list of PROMS will support holistic patient-led care, and evaluation of shared care models.

Disclosure of Interest Statement:

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