

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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- Improving quality of life for people living with HIV involves clinical and community initiatives.
- Patient Reported Outcome Measures (PROMs) are tools currently used to measure these outcomes, but there is limited consensus in which to use. We commenced a Delphi consensus building study across community, clinical and research settings to identify measures in areas including social, psychological and physical wellbeing.
- There is a gap in cultural and linguistic inclusiveness of current available PROMs. Adapting the Delphi process to include qualitative interviews allowed diverse views to be heard and incorporated into the consensus process.

Background

There is value and opportunity to achieve consistency in a small set of PROMs clinical, community and research settings. This will improve the capacity to monitor QoL, and better identify for whom interventions are most successful and who is being left behind.

Study 1

Two Delphi consensus survey rounds were conducted to refine a list of 47 social and health PROMs that are important, relevant and practical across settings. **10 PROMs have been identified from this list across community, clinical and research participants (n=40).** These are organised to date into 5 categories including: psychological, social and physical wellbeing, treatment factors, and welfare and lifestyle factors.

Study 2

Five group interviews with nine participants were conducted in response to feedback that the Delphi consensus process excluded marginalised voices. **Nuanced needs for PLHIV from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds, and women, may not be captured within the Delphi consensus process without deliberate consideration of culture and language when implementing and using PROMs, and considering understandings of PROM outcomes depending on background.**



Do you want to take part in
establishing the consensus
tool of health and social
PROMs?



“Culturally and linguistically diverse people & women living with HIV...these numbers are small, but the issues are huge...they get missed out.”

Innovation and significance

An adapted Delphi process that included qualitative interviews is required to ensure diverse voices are privileged in the process of reaching consensus on 47 initial PROMs. This is necessary to ensure:

- the PROMs are fit for purpose in community and clinical settings, and
- all PLHIV, regardless of their cultural and linguistic background, can access the PROMs to enhance holistic patient-led care, and the evaluation of shared-care models.

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