

## Developing an HIV consensus tool of health and social PROMs for clinical and community services

The project aimed to enhance clinical and community care practice by identifying a minimum recommended set of health and social Patient Reported Outcome Measures (PROMs) (including Quality of Life) for people living with HIV (PLHIV), which can be incorporated into day-to-day practice of clinical and community services.

### *Key methodological steps*

- **Literature and policy review:** conducted to identify a comprehensive list of existing PROMs (n=147), refined in consultation with a selected advisory group of representatives from community organisations, clinics, government/policy agencies and research institutions working with PLHIV. A refined list of selected PROMs (n=48) was utilised in the Delphi consensus process.
- **Adapted Delphi consensus process:** inclusive of three surveys and one interview round, conducted with more than 40 participants working in community, clinical, government and research settings, to determine agreement/consensus on which PROMs are most important, appropriate and useful tools to be included in a minimum set of recommended PROMs.
- **A final consensus meeting** and three extra individual consultations were conducted with participants who had participated in the Delphi surveys, or who were purposively selected, to finalise the structure of a Group A and Group B PROM set.

### *Key findings and recommendations*

Eighteen PROMs remain at the end of the Delphi consensus process, across 7 domains of health and social outcomes: quality of life, physical wellbeing, psychological wellbeing, treatment related factors, social wellbeing, stigma & discrimination, and welfare, lifestyle & safety (note: PozQoL was assessed in the Delphi consensus as 5 PROMS – one total score and four domains).

The eighteen PROMs have been divided into categories, to form a recommended minimum set (Group A), and additional optional measures (Group B).

**Group A PROMs** achieved the highest level of consensus across community, clinical, government/policy and research settings as the most important, and appropriate tools within their domain areas. These PROMs were then ranked as the most useful by participants for inclusion in the final PROM set. These PROMs can be used independently of each other, but it is recommended, where possible, to use Group A PROMs as a set to build consistent use across services and research for PLHIV.

**All other PROMs were classified into a Group B** line of outcome measures. Group B PROMs also achieved the highest level of consensus across community, clinical, government/policy and research settings as the most important and appropriate tools within their domain areas, however ranked **below** Group A PROMs in usefulness for inclusion in the final PROM set. These can be individually added like building blocks in addition to Group A PROMs. For the Welfare, Lifestyle & Safety domain, constructs were seen as too distinct and complex to be adequately captured by a single PROM in Group A hence all PROMs were listed in Group B.

The final set of PROMs was chosen based on level of consensus achieved in participants' ratings on importance and appropriateness and then subsequent participant rankings on usefulness for inclusion in the minimum recommended set of PROMs.

**Recommended PROM Set**

Domain	Quality of Life	Physical Wellbeing		Psychological Wellbeing	Social Wellbeing	Treatment Related Factors	Stigma & Discrimination	Welfare, Lifestyle & Safety
<b>Group A</b> Total Questions: 20	PozQoL Scale (Total Score)	PozQoL: Functional Subscale (3 questions)	PozQoL: Health Subscale (3 questions)	PozQoL: Psychological Subscale (4 questions)	PozQoL: Social Subscale (3 questions)	Treatment Satisfaction Scale (4 questions)	HIV Stigma Scale: Disclosure Concerns Subscale (3 questions)	
<b>Group B</b> Select PROMs as appropriate				Brief Resilience Scale (6 questions)	Community services and peer support connections for PLHIV (8 questions)	Financial difficulties related to ART treatment (4 questions)	Stigma Indicators Monitoring Project (3 questions)	5-item Reported Financial Wellbeing Scale (R-5) (5 questions)
				HIV Stigma Scale: Negative Self-Image Subscale (3 questions)	Relationships and attitudes towards sex for PLHIV (7 questions)	Treatment related stigma (5 questions)		Housing Instability Index (10 questions)
				Screening tool for cognitive concerns for PLHIV (3 questions)				
<b>Positive Outcomes: HIV PROM (23 Questions)</b>								