



Incorporating quality of life into PLHIV care: developing a consensus tool of health



The Centre for Social Impact (at UNSW) is conducting a project to enhance clinical and community practice by combining a set of recommended health and social Patient Reported Outcome Measures (PROMs; including quality of life) for people living with HIV (PLHIV) that can be incorporated usefully into day-to-day practice of clinical and community services.

This resulting outcome set is likely to enhance care plans and care engagement across services and provide an exciting and timely opportunity to align the monitoring of quality of life and other key PROMs across clinical, community and national outcomes monitoring. The project is funded by an unrestricted grant from Gilead Sciences and has additional ethics approval through ACON and Thorne Harbour Health.

We are conducting an adapted Delphi consensus process, which involves up to three feedback surveys to narrow down the list of outcome measures and an optional final consensus meeting (in an online format), to select the minimum set of most practical PROM candidates to include.

The first survey may take up to an hour, but subsequent surveys will be much shorter (up to 30 minutes) as we reduce the number of potential PROMs.

The research study is looking recruit people who meet the following criteria:

- 18 years of age or older
- **Professionals currently working within a clinical, community, research or government setting related to care for people with HIV or outcomes monitoring. Community professionals includes trained PLHIV peer support workers**
- Have access to a computer
- Are able to participate in up to three survey rounds

Participants meeting the following criteria will be excluded from the study:

- Are under the age of 18 years
- Are general community members, or clients living with HIV (unless they occupy a trained PLHIV peer support worker role)

Participants will be invited to volunteer to complete a series of two or three online surveys between February and April.

On completing the final survey, you will be invited to select an Australian HIV organisation to be provided a \$25 donation as thanks for your time.

To support peer advocates and people volunteering in community organisations, participants who fall into this category can instead be directly reimbursed via a \$25 gift card for their time.

You may also be invited, or can volunteer, to participate in a consensus meeting, which will include a 1.5-hour discussion to determine the final list of PROMs. This will be recorded, and a transcription of the session will be completed by Digital Transcripts for research purposes.

Please click on this link to register your interest in taking part in the research:

https://unsw.au1.qualtrics.com/jfe/form/SV_3wQPopD1rNzJqQK

Please contact the following person via email if you have any questions about taking part in the research:

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If you have questions about the research and would like to contact the Chief Investigator, please reach out to the following person:

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