

Co-Designing Quality of Life Priorities for PLHIV in Australia: Findings from a National, Community-Governed Delphi Study

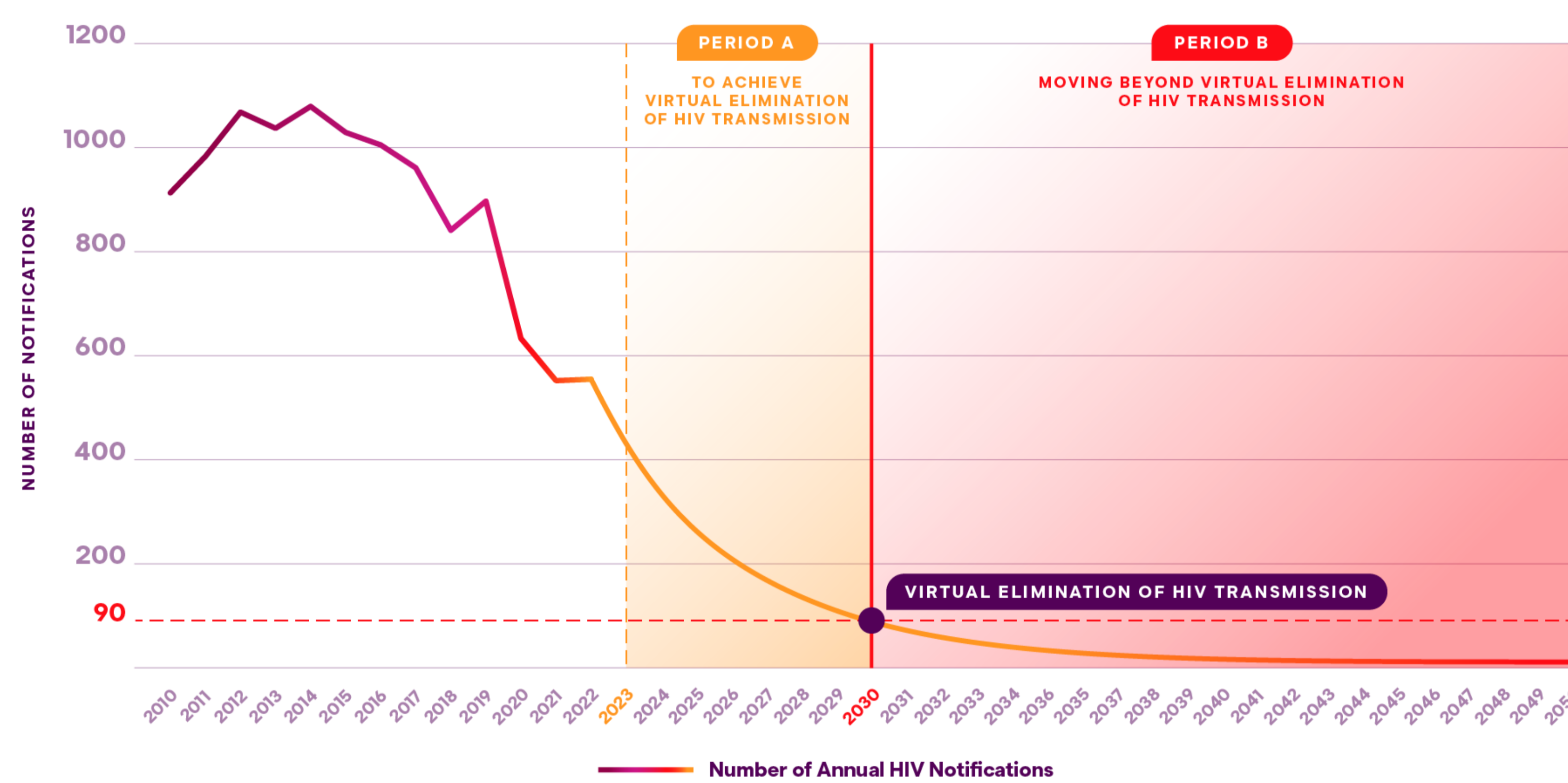
Tiffany R. Phillips 1,2,3, Aaron Cogle 4, Scott Harlum 4, Harrison Sarasola 5, Andrea Kindinger 5, Jason J. Ong 1,2

1 CENTRAL CLINICAL SCHOOL, MONASH UNIVERSITY, MELBOURNE, VIC, AUSTRALIA 2 MELBOURNE SEXUAL HEALTH CENTRE, ALFRED HEALTH, MELBOURNE, VIC, AUSTRALIA 3 UNIVERSITY OF NOTRE DAME, SYDNEY, NEW SOUTH WALES, AUSTRALIA 4 NATIONAL ASSOCIATION OF PEOPLE WITH HIV IN AUSTRALIA, SYDNEY, AUSTRALIA 5 HEALTH EQUITY MATTERS, MELBOURNE, VICTORIA, AUSTRALIA

INTRODUCTION

Combination antiretroviral therapy has transformed HIV into a chronic, manageable condition; however, viral suppression alone does not capture the broader health and wellbeing of people living with HIV (PLHIV). In Australia, PLHIV continue to experience reduced quality of life driven by stigma, mental health, social determinants, and ageing-related challenges. As the national response shifts toward virtual elimination of HIV transmission, there is a growing need to define and prioritise actions that support long-term quality of life. This study aimed to establish cross-sectoral consensus on the key priorities required to improve quality of life for PLHIV in Australia.

Planning for the Long Tail of the HIV Epidemic in Australia



METHOD

Co-designed, community-led Delphi technique.

Focus Group: steering committee comprised of 16 cross-sectoral experts in the HIV response developed a set of consensus statements

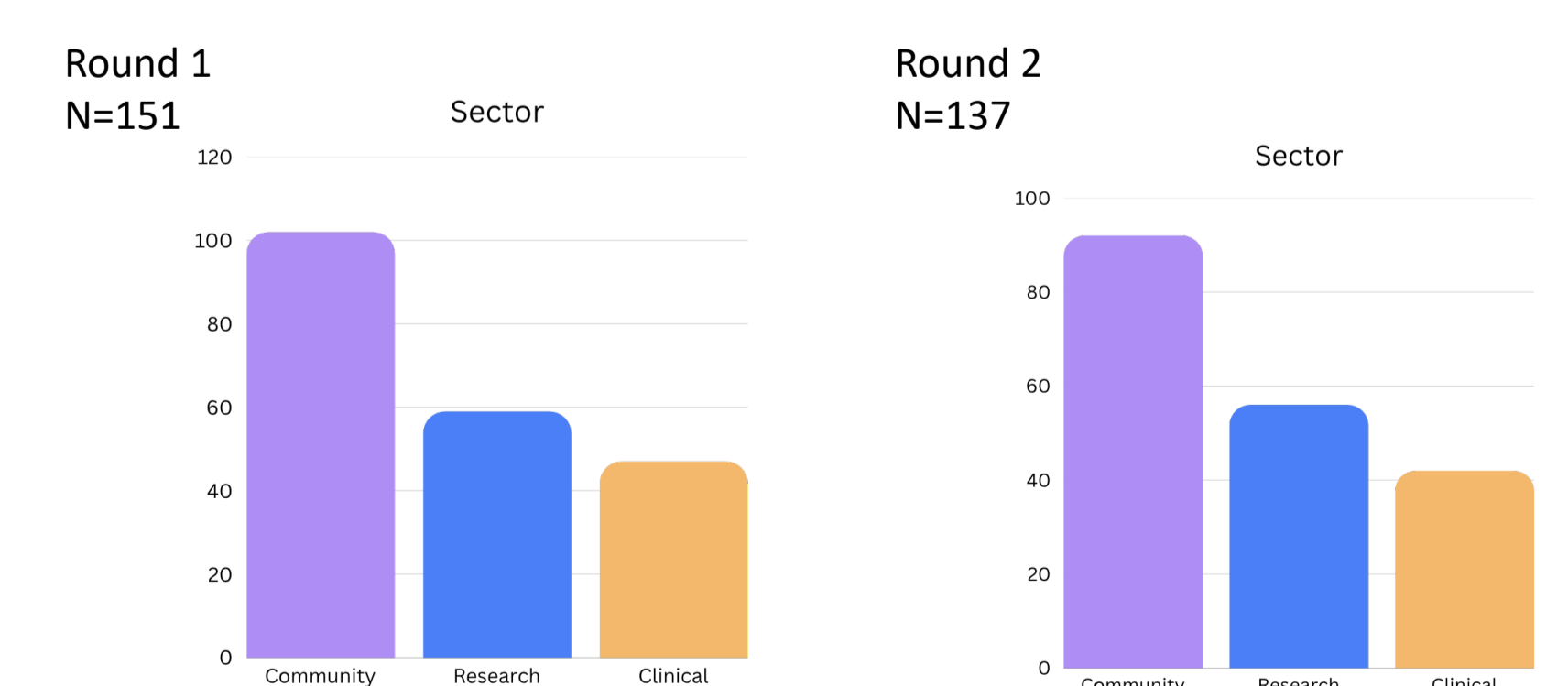
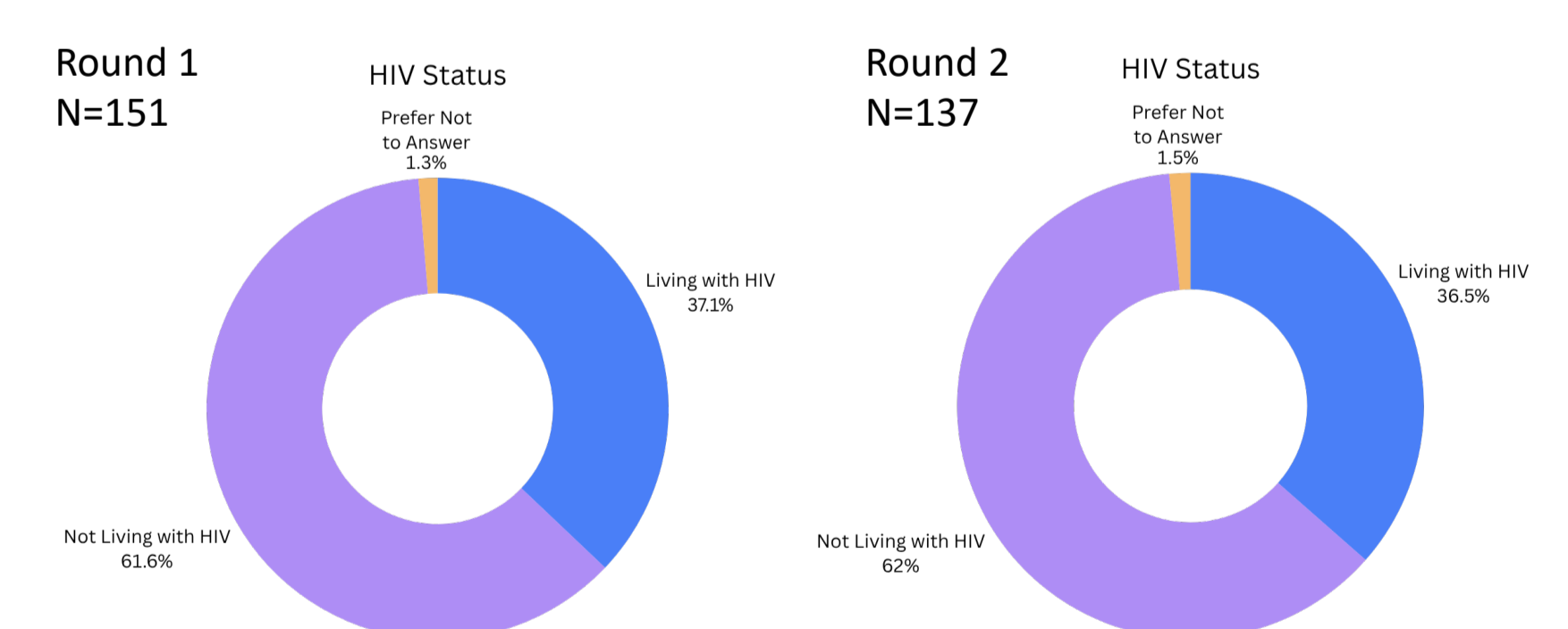
Round-One: Statements to 168 experts across Australia. Participants rated their agreement (4-point Likert scale) on the importance of each statement in achieving and moving beyond the elimination of HIV transmission. Each statement required 80% agreement (combining 'Agree' and 'Strongly Agree') to reach consensus

Round-Two: Revised statements from Round-one and one additional statement drafted following content analysis of free-text responses in Round-One were sent for scoring

INTERPRETATION

This community-governed Delphi demonstrates strong cross-sectoral consensus that quality of life should be a central outcome of the contemporary HIV response in Australia. The findings highlight the need to move beyond biomedical targets toward integrated, person-centred care addressing mental health, stigma, social determinants, and ageing. Achieving meaningful improvements in quality of life will require coordinated action across clinical, community, and policy settings, with PLHIV leadership embedded throughout.

PARTICIPANT DEMOGRAPHICS



CONSENSUS STATEMENTS

Consensus statements that reached 80% approval following the Delphi process among 151 (Round-One) and 137 (Round-Two) clinicians, researchers and community members working in the HIV sector in Australia. Participants ranked the importance of each statement for achieving the elimination of HIV in Australia and for moving beyond HIV elimination. All of these statements reached 80% agreement for both achieving and moving beyond HIV elimination.

Set 1: Defining "Quality of Life" for PLHIV-now and beyond the virtual elimination of domestic HIV transmission

- A holistic approach is essential to improving quality of life and includes tackling social determinants of health, such as experiences of stigma, social isolation, financial insecurity, visa uncertainties and housing.*
- Ensure that HIV care promotes positive sexual wellbeing and fulfilment by supporting the sexual health needs of people with HIV.*
- Healthcare systems should empower people living with HIV to be recognised as the central source of knowledge about their own health and to have the support to take an active role in decisions and coordination of their care..
- Mental-health and trauma-informed care are central to quality of life; services must acknowledge and address historical trauma and ongoing mental health issues through holistic, person-centred approaches
- Physical health must be maintained with effective monitoring of and, to the extent possible, prevention of co-morbidities for which people living with HIV have increased risk.
- Mobility, accessibility, and affordability of care for people living with HIV should be prioritised through innovative approaches such as telehealth, improved transport options, and reduced travel-related costs.
- The expectation of a pain-free life should be the standard: Known and emerging long term side effects such as neuropathy and chronic pain must be actively assessed, managed and minimised.

Set 2: Gaps need to be fixed to improve quality of life

- Ensure systematic training of health and aged-care workers in HIV care, cultural safety and stigma reduction, equipping them to support people living with HIV across their lifespan and health continuum
- Services must continue to evolve from acute infectious-disease management toward whole-person, lifespan-oriented, multidisciplinary care that prioritise integrated chronic care models⁹.Expand nurse-led HIV testing programs that are funded by Medicare rebates.
- Repeal or reform laws that criminalise HIV transmission or exposure, aligning legislation with current scientific evidence and human rights principles to reduce stigma and discrimination
- Guarantee equitable access for Medicare-ineligible people living with HIV to an expanded range of essential care and services, and not solely to treatments and routine monitoring
- Normalise, optimise and individualise barrier-free HIV testing to eliminate late diagnoses of HIV when the health burden may be higher
- Ensure public health messaging provides clear, evidence-based guidance on pregnancy and breastfeeding to promote understanding and reduce stigma
- Preserve and accurately archive HIV history and lived experiences of people living with HIV, ensuring this history is recorded and represented by the community itself
- Increase access to tailored alcohol and other drug harm-reduction services, treatment, and voluntary recovery supports for people living with HIV.*
- Ensure sustained access to HIV treatment prescribing by expanding workforce capacity through multiple models, all ideally supported by HIV peer navigators.
- Safeguard clinical knowledge and continuity of care by planning for clinician retirements and ensuring secure, long-term retention of HIV medical records
- U=U messaging should be re-designed in partnership with the diversity of people living with HIV, Government and clinicians to ensure accuracy, inclusivity, and relevance to the general public

Set 3: Centre the lived experience of PLHIV who encounter additional barriers in policy & program design

- Ensure HIV services are accessible to people in rural and regional areas through outreach services, mobile clinics, telehealth, and strategies to strengthen workforce capacity and retention¹². Sustain workforce education to clinicians on HIV treatment options.
- Increase and sustain funding for targeted peer support for all people with HIV who need and want it.*¹⁴. Ensure new and approved subsidised treatment options are made available.
- Create and increase the resourcing of culturally safe spaces that support people living with HIV from Aboriginal and Torres Strait Islander communities to access peer support and culturally informed information about HIV and available support services¹⁶. Strengthen the management of each new diagnosis, including peer-led contact tracing, linkage to care and rapid initiation of HIV treatments.
- Create and increase the resourcing of culturally tailored spaces that support people living with HIV from culturally and linguistically diverse backgrounds to access peer support and culturally sensitive and language-appropriate information about HIV and available support services
- Address the intersectional stigma and barriers facing people who live with HIV who experience intersecting forms of marginalisation due to culture, ethnicity, gender, sexuality, disability, injecting drug use, sex work, or long-term survival of HIV.*
- Expand access to trained interpreters who can provide stigma-free, culturally safer support, to reduce language barriers in healthcare and improve quality of life for people living with HIV who do not speak English

Set 4: New interventions for improving quality of life

- Expand access to new treatment technologies and availability of clinical services and expertise to support these choices so that they are available to all people living with HIV, particularly those with additional barriers to access.
- Ensure ongoing and consistent ART supply to prevent risk of shortage from global disruptions and minimize associated anxiety within the community²⁰. Remove harmful legislation that criminalises HIV transmission.
- Expand access to mental health and social support services tailored for people living with HIV, including peer-led counselling and trauma-informed psychological support
- Translate existing clinical monitoring protocols into accessible, co-designed screening schedules that enable PLHIV to oversee and track routine tests and medication reviews across ART milestones and ageing needs, in partnership with their clinicians²³. Provide education and increase awareness in the general public on a contemporary understanding of HIV, including as a chronic and manageable disease, and U=U (Undetectable = Untransmittable).
- Incorporate patient-reported outcome measures (e.g. PozQoI) into routine HIV care to track quality of life beyond viral suppression.²⁵ Remove mandatory HIV testing laws.
- Expand the removal of co-payments for ART and other essential medications to be nationwide and permanent for people living with HIV
- Develop and fund research programs to improve physical functioning and reduce comorbidity risks
- Integrate alcohol and other drug harm-reduction and non-judgemental pain management into HIV care*