

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

*Final Report*

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## Acknowledgement of Country

In the spirit of reconciliation, CSI UNSW acknowledges that their operations are situated on Bedegal land, and that the Bedegal people remain the spiritual and cultural custodians of their land, and continue to practise their values, languages, beliefs and knowledge. We acknowledge the Traditional Custodians of the country throughout Australia and their connections to land, sea and community. We pay our respect to their elders and extend that respect to all Aboriginal and Torres Strait Islander peoples.

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## Disclaimer

The opinions in this report reflect the views of the authors and do not necessarily reflect those of the Centre for Social Impact or Gilead.



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# EXECUTIVE SUMMARY

Patient Reported Outcome Measures (PROMs) provide useful information about a patient's perception and experience of their health, quality of life, or functional status. Their use can strengthen person centred care and achieve better and more sustained health outcomes.

The recent development of the PozQoL scale is an example of a PROM. PozQoL provides a quality-of-life measure for people living with HIV (PLHIV), which has been incorporated into community and clinical services, as well as in social research studies. During the PozQoL development and trialling, feedback from the community and clinical sector was that developing a common set of PROMs that had support across the community, clinical and research sector could encourage the consistent use of PROMs, strengthen PLHIV's role in their health care, and increase PLHIV access to timely support.

## Project aim

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 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 (40, 34, 31 responses in each survey respectfully, with some participants in multiple rounds; 5 interviews with 9 participants) working in community, clinical, government and research settings, to determine agreement/consensus on which PROMs are the 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 a Group B PROM set, and to discuss their use and potential implementation challenges in community and clinical settings moving forward.

## Key findings

- Six PROMs were prioritised as the most important, appropriate, and useful tools to use in a minimum set of outcome measures across community and clinical settings (Group A minimum PROM set).
  - Within the minimum recommended set, the PozQoL scale was rated as a sufficient outcome measure not only for measuring quality of life for PLHIV, but also physical, psychological, and social wellbeing. Two other PROMs are also included in the minimum set that focus on disclosure concerns and treatment satisfaction: the Treatment Satisfaction Scale, and the HIV Stigma Scale: Disclosure Concerns Subscale.
- Ten other PROMs rated highly throughout the Delphi consensus process and were classified as Group B PROMs. These can be individually added like building blocks in

addition to the Group A PROMs, where useful and appropriate in clinical and community settings.

- There are no PROMs in Group A measuring the Welfare Lifestyle and Safety Problems & Concerns domain as the results did not indicate a clear shared PROM preference, with feedback suggesting the constructs (i.e., welfare, lifestyle and safety) are distinct and too complex to be captured adequately by a single PROM. The PROMs in Group B in this domain can therefore be selected according to the specific community or clinical context in which they are used.
- The final consensus meeting and individual consultations saw no changes to the structure of the PROM outcome set, however, minor language adjustments were made in how Group A and Group B were labelled and described as well as future considerations for implementation were discussed.
- The Positive Outcomes: HIV PROM was rated as useful, feasible and appropriate by the majority of participants, some of whom considered it to be holistic across the domains it covered. Additionally, some concerns were raised about the length of this PROM (23 items).
- PROMs identified for the Delphi consensus process were limited by the availability of inclusively designed outcome measures that are accessible and appropriate for culturally and linguistically diverse PLHIV.

## Key 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 groups to form a recommended minimum set (Group A) and additional optional measures (Group B).

**The proposed structure is on page 5.**

**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
Group A 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)	
Group 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)				
Positive Outcomes: HIV PROM (23 Questions)								

# PROJECT OVERVIEW

## Project aim/background

Patient Reported Outcomes (PROs) provide useful information about a patient's perception of their health, quality of life, or functional status associated with healthcare or treatment. Clinicians and community workers can use Patient Reported Outcome Measures (PROMs) to measure a range of PROs that are important in providing a more holistic interpretation and assessment of treatment benefits. These tools provide useful information about patient experiences of treatment and health that are reported directly by the patient (Higgins, Thomas, Chandler, Cumpston, Page & Welch, 2019, Weldring & Smith, 2013).

The recent development of the PozQoL scale is an example of a PROM and provides a quality-of-life measure specifically for people living with HIV (PLHIV), which has been incorporated into PLHIV peer, social/welfare and clinical services, as well as in social research studies.

Feedback during the development of PozQoL indicated that providing complementary PROMs that focused on social and health outcomes would aid the implementation and increase acceptance of PozQoL (as a quality-of-life measure) in day-to-day practice.

To incorporate this feedback, we wanted to assemble a minimum number of complementary social and health PROMs considered to be appropriate in these diverse settings for PLHIV. This informs the overall project aim, being 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 PLHIV, which can be incorporated into day-to-day practice of clinical and community services. Seeking consensus on this minimum recommended set also provides the following benefits to the clinical care and community service system:

- Strengthens person led care and QoL monitoring through PROM/social outcome measures,
- Enhances shared care/integrated approaches and communication across clinical and community services,
- Provides a timely opportunity to align the monitoring of quality of life and other key PROMs across clinical, community and national outcomes monitoring,
- Enables the consolidation of reported patient and client outcomes at state/national level.

## Methods (April – November 2022)

The project was undertaken in two phases:

### Phase 1 – identification of Patient Reported Outcome (PRO) domains and Patient Reported Outcome Measures (PROMs)

This phase involved a scoping of academic and grey literature to identify domains (categories) that have been explored within research and in policy for PLHIV. A selected reference group of people working with PLHIV in community, clinical, government/policy and research settings was also asked to advise on the direction and content of the project. Additionally, we spoke with five people working within community sector organisations for PLHIV across Victoria, New South Wales, and Queensland. This created a loose framework within which we were able to organise the social and health Patient Reported Outcome Measures (PROMs).

Scoping reviews of the academic literature, current policy documents and national datasets (i.e., Futures 10, HILDA) were undertaken. PROMs were also identified that were developed specifically for PLHIV, and more broadly, for people living with a chronic disease. Several PROMs



were not designed for a specific population group but were well aligned with the identified domains. The guiding selection criteria for including PROMs in the study were:

- less than 12 items in length,
- free to access, with no requirements around permission of use,
- developed and tested to demonstrate psychometric assurance,
- or appear within an Australian national dataset.

Researchers in this project discussed the initial PROM list, allowing for exceptions to these criteria, with reference to the focus on a holistic view of healthcare, and with consideration to recommendations by the reference group and community sector consultations outlined above.

## Phase 2 – Adapted Delphi Consensus process

The second phase of the project involved three rounds of surveys to measure consensus of participants on the pre-selected list PROMs at the end of Phase 1, as well as a round of interviews. For the surveys, participants were recruited by email advertisement disseminated through members of the reference group, and through key community and clinical organisations for PLHIV across Queensland, New South Wales, Victoria, Tasmania and South Australia. People working with PLHIV in community, clinical, government/policy and research settings participated in each round of the survey. Participants were encouraged to participate in all three survey rounds, and the process allowed for new participants in Round 2 and Round 3, to ensure there was a sufficient dataset maintained with respect to predicted attrition across surveys. After each round, we excluded PROMs that did not meet inclusion criteria or were deemed unsuitable to progress by the project team and some participants.

Round 1 asked participants (n=40) to rate the **importance** of each PROM for inclusion in the recommended minimum set of social and health PROMs, on a scale from 1-9.

Some participants provided feedback about the Round 1 survey, highlighting a need for a more defined culturally diverse perspective to the Delphi survey through increased readability of the survey and more culturally appropriate PROMs questions. In response to this feedback, we modified the consensus process and conducted 5 additional interviews with 9 participants to understand the specific needs of PLHIV from diverse or minority backgrounds, including perspectives from culturally and linguistically diverse backgrounds, and women.

Round 2 (n=38) asked participants to rate how **appropriate and relevant** each PROM was to their current work with PLHIV on a scale from 1-9, with consideration of different characteristics of PLHIV (e.g., cultural background, preferred language, beliefs about HIV, health literacy, gender, level of English, sexuality and religion). Participants were also asked to nominate one PROM within each PRO domain that would be the least **practical** in their work.

Round 3 (n=32) asked participants to rank the remaining PROMs within each PRO domain, from most to least **useful** to include in the minimum outcome set. In this last round, we also asked participants to consider a newly developed PROM (Positive Outcomes: HIV PROM) for its appropriateness, usefulness and practicality or feasibility for their current work.

A final consensus meeting was conducted over video conference with survey participants who expressed interest in involvement and a range of targeted individuals from community, clinical, government/policy and research settings. Participants were asked to discuss the proposed minimum outcome set including its two-group structure and participants' perspectives on the advantages, barriers, and challenges to using the minimum outcome set in their work. We also asked participants to discuss whether the Positive Outcomes: HIV PROM should be included in the PROM set. Individual consultations were offered to participants who were unable to attend the meeting to ensure a wide breadth of perspectives across community, clinical, government/policy and research settings were captured.



# RESULTS OVERVIEW

## Phase 1: Identification of Patient Reported Outcome (PRO) domains and Patient Reported Outcome Measures (PROMs) results

Six PRO Domains were identified through the scoping searches, discussion with the reference group and consultations with people in the community sector:

- Physical Wellbeing
- Psychological Wellbeing
- Social Wellbeing
- Stigma & Discrimination
- Cognitive Problems & Concerns
- Treatment Related Factors
- Welfare, Lifestyle and Safety Problems & Concerns

A total of 147 PROMs were initially identified, which was reduced to 48 after applying the selection criteria and process described in the methods.

## Phase 2: Adapted Delphi Consensus process results

PROM ratings within each domain were analysed to determine whether they met inclusion criteria, and the total number was reduced in Rounds 1 and 2 (Table 1).

Table 1. Number of PROMs included at each stage of the project.

PRO Domain	Phase 1		Phase 2	
	Initial PROMs identified	Recommended PROMs for Round 1	Round 1 Delphi results (n = 40)	Round 2 Delphi results (n = 34)
<i>Psychological Wellbeing</i>	36	11	6	4
<i>Physical Wellbeing</i>	17	5	4	2
<i>Social Wellbeing</i>	26	7	3	3
<i>Stigma &amp; Discrimination</i>	5	7	4	2
<i>Treatment Related Factors</i>	17	9	5	3
<i>Welfare, Lifestyle and Safety Problems &amp; Concerns</i>	38	8	2	2
<b>Total PROMs</b>	<b>147</b>	<b>48</b>	<b>24</b>	<b>16</b>

NB. Quality of life was not included in the Delphi consensus process due to the project's objective bring to complement PozQoL with additional PROMs in other important domains.

Results from the additional interviews after Round 1 highlighted some important themes within three main areas:

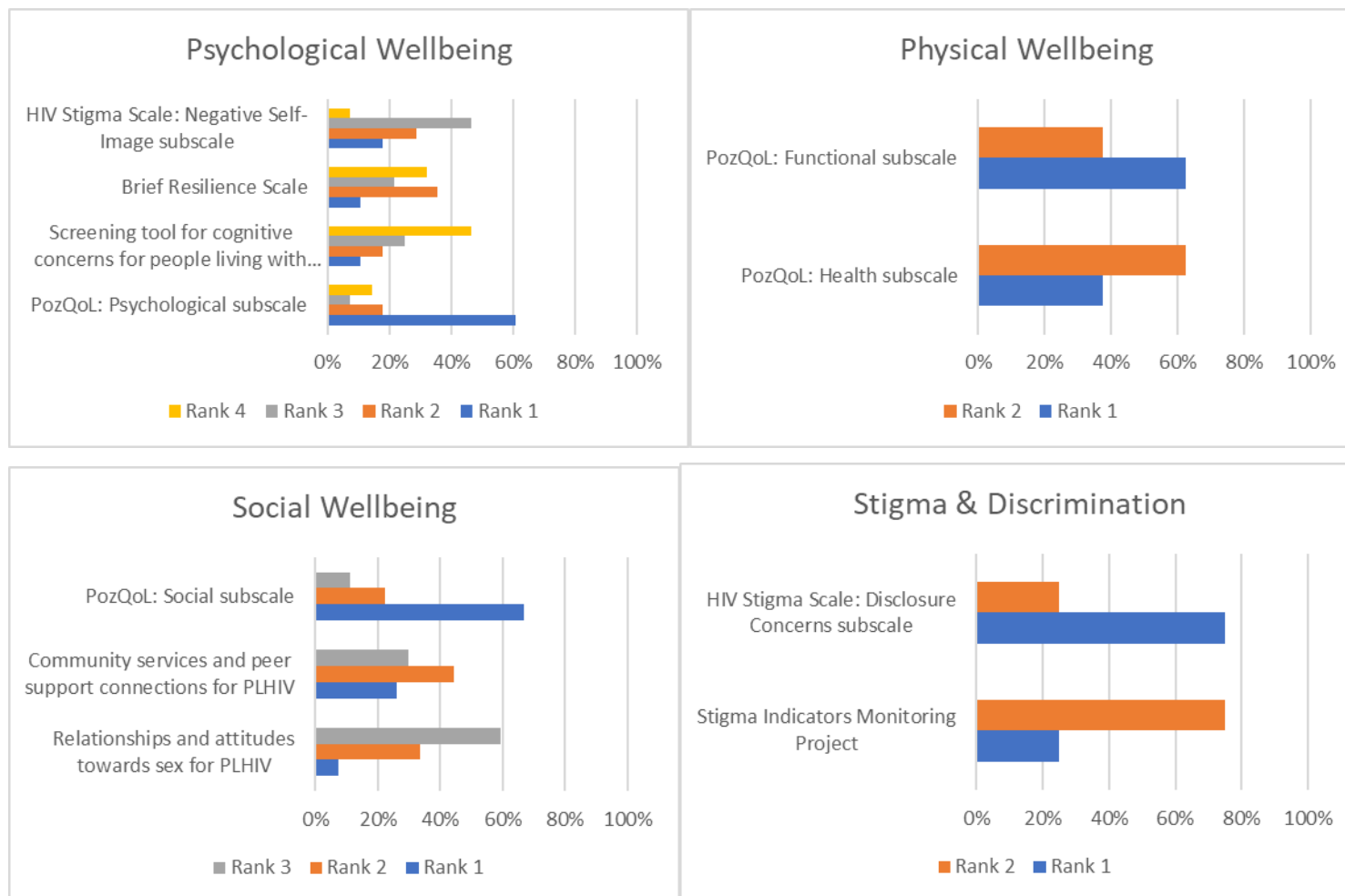
- There was a need for stronger deliberate consideration of language and culture in the PROM list and Delphi survey design.
- Our Delphi study and corresponding PROM list is constrained by the limited availability of inclusively designed PROMs that are appropriate for use with culturally and linguistically diverse groups.
- There are specific PROMs that are considered more important or salient, and/or there are specific concepts of social and health outcomes that are understood differently to PLHIV in diverse linguistic and cultural groups (i.e., psychological wellbeing and stigma)
- There are implications in the implementation and practical use of PROMs, especially around people's understanding of their purpose and utility in clinical and community settings when working with people from diverse backgrounds.

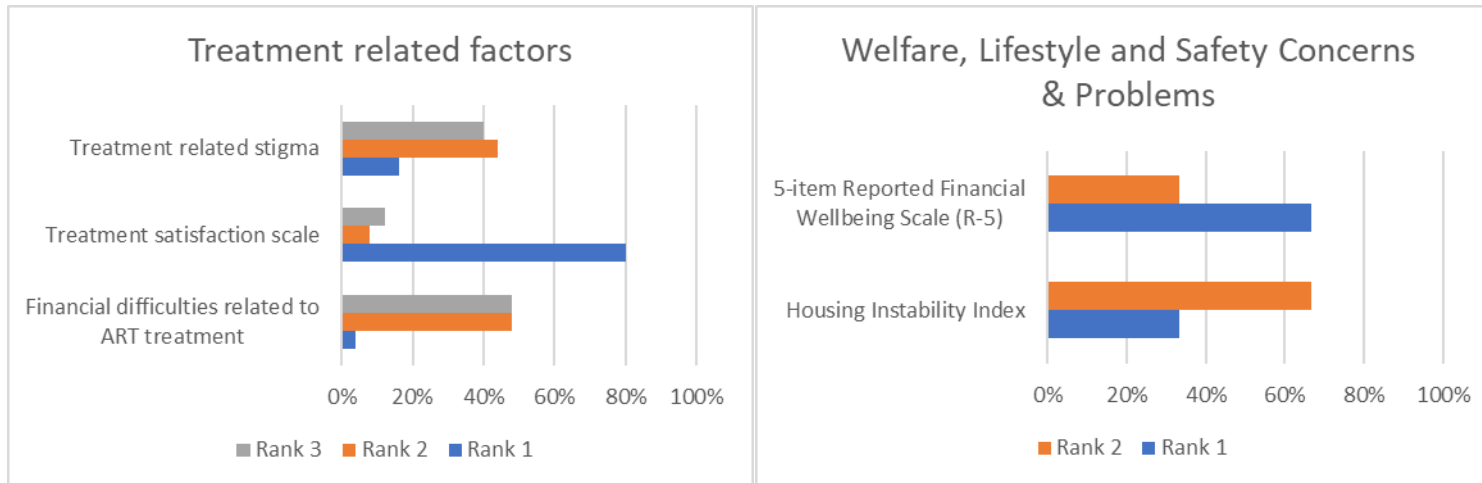
We implemented the following practical outcomes as a result of the findings:

- Purposive recruitment in Round 2 of the Delphi to deliberately encourage respondents from, or working with people from, diverse backgrounds to participate in the survey, and to offer practical help in responding to the survey if needed.
- Excluded PROMs that, while meeting inclusion criteria based on the Round 1 results, were advised to contain complex or outdated language (i.e., SMAQ Simplified Medication Adherence Questionnaire – term “careless” in question wording conveys judgement about why someone was unable to take their medication).

In Round 3, PROM rankings within each domain were analysed to determine the percentage of participants who ranked each from the highest possible ranking (1) to the lowest (2-4, depending on each domain). PROMs within each of these domains were categorised into a Category 1 & 2 structure by selecting the top-ranking PROM(s) from each domain. This was achieved by approximating which PROM received the greatest proportion of highest-ranking nominations. Note that this initial Categories 1 & 2 structure was revised into Group A and B post the final consensus meeting and extra targeted consultations based on feedback.

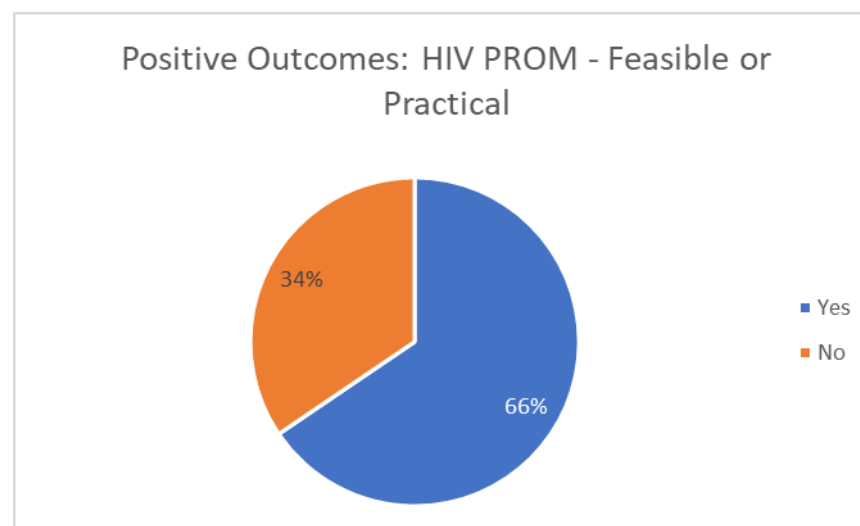
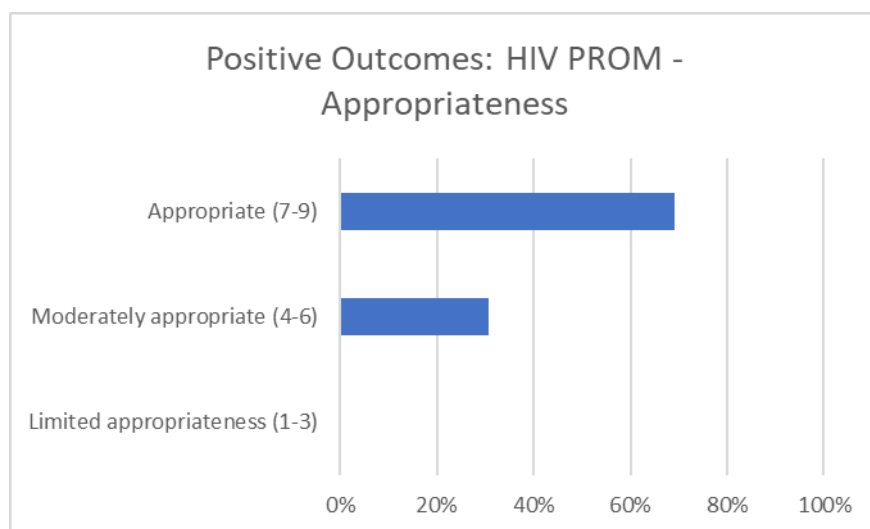
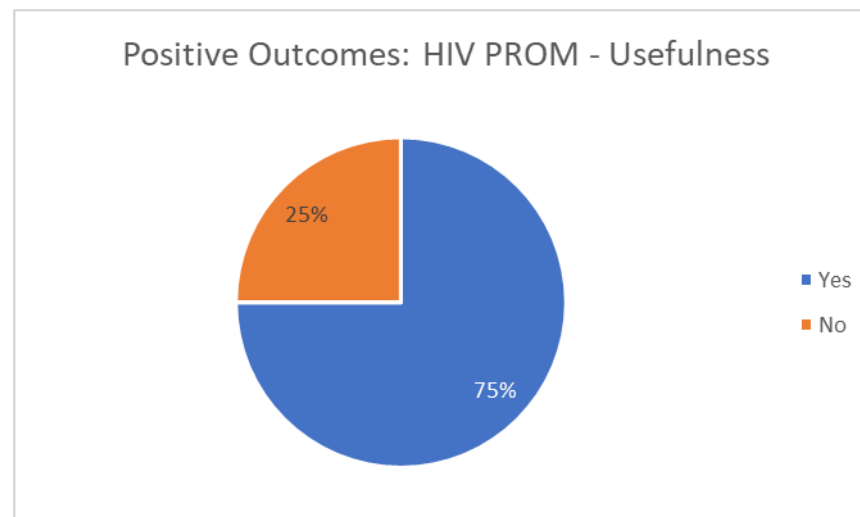
Round 3 results are displayed below in six graphs:





Positive Outcomes: HIV PROM had recently published its psychometric testing and so was considered by the research team as important to incorporate late in the study. We asked participants to rate the Positive Outcomes: HIV PROM which could be considered as an alternative tool to measure social and health outcomes for PLHIV.

The majority perceived the PROM to be useful, appropriate and feasible to use in their current work. In open response feedback, people thought the PROM was holistic but were concerned about the length (23 questions).



## Final Consensus Meeting and Consultations

In the final consensus meeting and follow up individual consultations, participants discussed the proposed structure of the final PROM set, its content, length and use in their current work. During the consultation, participants identified positive aspects of the PROM set, including that:

- For those already engaged in care, the outcome set was seen as a “brilliant” tool, that provides a “menu of options” and has good breadth across key areas of health and social outcomes.
- The Group A and B structure was helpful to facilitate individualisation of PROMs to suit the priorities and client profile of each service, depending on their needs (e.g., relevance of disclosure concerns for instance). Guidance around how to administer and use the outcome set and collected data, as well as support for clients who are from culturally and linguistically diverse backgrounds would be important.
- PROMs can be used for different purposes (e.g., they provide an opportunity to start a conversation about people’s social and health outcomes that may not otherwise be covered in a consult, improving referral pathways). However, some participants acknowledge that there is risk in asking people about these outcomes, without being able to provide a follow-up support service.
- The opportunity for clinical and community services to be using the same or similar PROMs was seen as being simpler for clients, for supporting shared care models, and for services to discuss trends and issues for PLHIV.
- For services already using PozQoL (and other PROMs), fewer barriers were perceived for integration of the PROM set into current practice.

Participants also identified challenges to implementing the PROM set including:

- Difficulty reaching PLHIV who are not in care, or in time constrained or regional HIV services.
- Lack of feasibility in using some of the lengthier Group B PROMs was raised by multiple participants.
- The option to only use specific PROMs from the wider set and personalise the tool to each organisations’ needs may have a counter effect when organisations are unable to track individual and group outcomes over time due to inconsistent data collection, and uncertainty around the intended test-retest timeframe of the PROM set.
- People working in community and clinical settings without a background and training on outcomes measurement may find it challenging to utilise the tool effectively and to understand the purpose of PROMs.
- PLHIV accessing multiple services or community organisations may be asked to complete the same PROMs multiple times.

When asked about the Positive Outcome: HIV PROM, some participants acknowledged that the PROM’s questions cover many of social and health domains and could be useful as an addition to or as an alternative to the Group A and Group B structure.

However, there were varying opinions regarding the best use of Positive Outcome: HIV PROM. One participant raised the potential for using the Positive Outcome: HIV PROM to assess a broad range of outcomes at surface level, and then subsequently using the PROM set to delve deeper into specific areas of concern. Other participants noted that the Positive Outcome: HIV PROM is too long to be used as an initial PROM and that just using PozQoL from Group A initially would work better, with Positive Outcome: HIV PROM and other Group B options as a mechanism to delve deeper.

Several participants noted that future development and implementation of the PROM set would benefit from directly involving people living with HIV to ensure we capture what is important to them.

Given the diversity of services for PLHIV across community and clinical settings, there is no “one-size-fits-all” solution to the standardised usage of PROMs however the PROM set is an important and useful option to consider even when it’s ultimately decided to be non-feasible in a particular setting.

Feedback also highlights the need to develop a guidelines document to accompany the PROM set to ensure people using it in clinical and community settings understand its purpose. The guidelines should include clear instructions on how to help people complete it, and how to assess and interpret the results.

Further feedback around the language of the PROM set included that labelling PROMs within Category 1 and Category 2 implied a hierarchical use of PROMs.

Based on the feedback from the final consensus meeting and consultations detailed above, no changes were made to the list of PROMs within Group B however the following adjustments were actioned:

- Changed labels of the two groups from Category 1/2 to Group A/B to reduce implication of hierarchy.
- Changed definitions of Group A and B to explicitly state that the groupings referred to the level of consensus and rankings achieved for each PROM as opposed to their level of importance.



## FINAL OUTCOMES SET

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.

Domain	Quality of Life	Physical Wellbeing		Psychological Wellbeing	Social Wellbeing	Treatment Related Factors	Stigma & Discrimination	Welfare, Lifestyle & Safety
Group A 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)	
Group 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)				
Positive Outcomes: HIV PROM (23 Questions)								

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# APPENDIX – DETAILS OF GROUP A AND GROUP B PROMS

Social and Health Outcomes PROM minimum set for PLHIV

## Quality of Life

This survey is intended for people living with HIV. We would like to ask you about your health, relationships, life satisfaction, and wellbeing. Please indicate how much the following statements apply to you on a scale from 1 – not at all to 5 – extremely.

### PozQoL Scale (Brown et al., 2018)

	1 not at all	2 slightly	3 moderately	4 very	5 extremely
1. I am enjoying life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I worry about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I lack a sense of belonging with people around me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I feel that HIV prevents me from doing as much as I would like.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I feel good about myself as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Having HIV limits my opportunities in life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I worry about the impact of HIV on my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I feel in control of my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I am afraid that people may reject me when they learn I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Managing HIV wears me out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I feel that HIV limits my personal relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I fear the health effects of HIV as I get older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am optimistic about my future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Physical wellbeing

### PozQoL Functional Subscale (Brown et al., 2018)

Please indicate how much the following statements apply to you on a scale from 1 – not at all to 5 – extremely.

	1 not at all	2 slightly	3 moderately	4 very	5 extremely
1. I feel that HIV prevents me from doing as much as I would like.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Having HIV limits my opportunities in life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Managing HIV wears me out.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### PozQoL Health Subscale (Brown et al., 2018)

Please indicate how much the following statements apply to you on a scale from 1 – not at all to 5 – extremely.

	1 not at all	2 slightly	3 moderately	4 very	5 extremely
1. I worry about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I worry about the impact of HIV on my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I fear the health effects of HIV as I get older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Psychological wellbeing

### PozQoL Psychological Subscale (Brown et al., 2018)

Please indicate how much the following statements apply to you on a scale from 1 – not at all to 5 – extremely.

	1 not at all	2 slightly	3 moderately	4 very	5 extremely
1. I am enjoying life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I feel good about myself as a person.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel in control of my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I am optimistic about my future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate the extent to which you agree with each of the following statements by using the following scale: 1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree.

**Brief Resilience Scale (Smith et al., 2008)**

	1 Strongly Disagree	2 Disagree	3 Neutral	4 Agree	5 Strongly Agree
1. I tend to bounce back quickly after hard times.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I have a hard time making it through stressful events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. It does not take me long to recover from a stressful event.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. It is hard for me to snap back when something bad happens.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I usually come through difficult times with little trouble.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I tend to take a long time to get over set-backs in my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**HIV Stigma Scale: Negative Self-Image Subscale (Reinius et al., 2017)**

	1 Strongly Disagree	2	3	4 Strongly Agree
1. I feel guilty because I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. People's attitudes about HIV make me feel worse about myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel I'm not as good a person as others because I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Screening tool for cognitive concerns for people living with HIV (EACS, 2018, appears in ASHM Monitoring Tool)**

	Yes	No
1. Do you experience frequent memory loss (e.g. do you forget special events or appointments etc)?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you feel that you are slower when reasoning, planning activities or solving problems?	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have difficulties paying attention (e.g. to a conversation, book or movie)?	<input type="checkbox"/>	<input type="checkbox"/>

## Social wellbeing

### PozQoL Social Subscale (Brown et al., 2018)

Please indicate how much the following statements apply to you on a scale from 1 – not at all to 5 – extremely.

	1 not at all	2 slightly	3 moderately	4 very	5 extremely
1. I lack a sense of belonging with people around me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I am afraid that people may reject me when they learn I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I feel that HIV limits my personal relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Community services and peer support connections for PLHIV (Norman et al., 2022)

The following questions are about the role that friends and other people with HIV have had in your life over the past 12 months.

	No	Yes, once or twice	Yes, occasionally	Yes, regularly
1. In your friendship or social networks, is there at least one other person who is also living with HIV that you talk to about living with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. In your friendship or social networks, is there at least one other person who you believe is not living with HIV that you talk to about living with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. In the past 12 months, have you accessed advice or support from someone living with HIV who is working with a community organisation or health service (such as peer educator, peer support worker, or peer navigator)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	No	Yes	Unsure	
4. In the last 12 months, have you utilised a peer navigator program?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5. In the last 12 months, have you participated in a peer education or peer support workshop for people living with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6. In the last 12 months, have you participated in an online forum or network for people living with HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	



7. What online forums for people living with HIV are you a member of?

Other, please specify:

TIM (The Institute of Many)

Yes

No

8. Are you currently an employee or volunteer for an HIV community organisation?

**Relationships and attitudes towards sex for PLHIV (Norman et al., 2022)**

Please indicate how you feel about the following statements:

- 1. I prefer to have a relationship with someone who also has HIV.
- 2. I am afraid of transmitting HIV to my partner or potential partner.
- 3. HIV has had a negative effect on my sexual pleasure.
- 4. I have avoided sexual and intimate relationships since I was diagnosed with HIV.
- 5. I enjoy sex more when my viral load is undetectable.
- 6. I enjoy sex more when I know my partner is on PrEP.
- 7. I am confident that I will not transmit HIV to a sexual partner when my viral load is undetectable.

	1 Strongly agree	2 Agree	3 Neither agree or disagree	4 Disagree	5 Strongly disagree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Treatment Related Factors**

**Treatment Satisfaction Scale (Norman et al., 2022)**

Please indicate how much the following statements apply to you:

- 1. I am happy with my treatment.
- 2. I am unhappy with the side effects of my treatment.

	1 not at all	2 slightly	3 moderately	4 very	5 extremely
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	3. I find my treatment convenient.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	4. I feel confident to ask my doctor for a treatment review if I feel it is needed (e.g., due to side effects, or to try new treatment combination).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Financial difficulties related to ART treatment (Norman et al., 2022)</b>		Yes	No		
	1. In the past 12 months, have you ever not taken your HIV antiretroviral treatment/medication because of financial difficulties?	<input type="checkbox"/>	<input type="checkbox"/>		
	Over the past 12 months, how difficult has it been for you to afford out-of-pocket costs related to:	Very difficult	Somewhat difficult	Not at all difficult	
	2. HIV healthcare, not including medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	3. HIV treatment medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
	4. Other (non-HIV) medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

<b>Treatment related stigma (Cama, Brener, Slavin &amp; De Wit, 2015)</b>		1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree
	1. If I go to an HIV clinic I am concerned that someone might see me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	2. I am concerned if I have physical changes from HIV medications people will know I have HIV.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	3. I avoid taking my HIV medications in public.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	4. I worry that treatment side effects can make my HIV status apparent to others.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	5. I worry that people might see me collect my HIV medications from the pharmacy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Stigma & discrimination**

**HIV Stigma Scale: Disclosure Concerns Subscale (Reinius et al., 2017)**

- 1. I work hard to keep my HIV a secret.
- 2. Telling someone I have HIV is risky.
- 3. I am very careful who I tell that I have HIV.

	1 Strongly Disagree	2	3	4 Strongly Agree
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Stigma Indicators Monitoring Project (Cama et al., 2018)**

1. In the last 12-months, to what extent have you experienced any stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse, bullying) in relation to your HIV status:

	Never	Rarely	Sometimes	Often	Always
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In the last 12 months, to what extent do you agree that the following occurred because of your HIV?

- 2. Health workers treated me negatively or different to other people.
- 3. People didn't want to have sex or an intimate relationship with me.

	Never	Rarely	Sometimes	Often	Always	Not applicable
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Welfare, Lifestyle & Safety**

**5-item Reported Financial Wellbeing Scale (R-5) (Botha,**

How well do the following statements describe you or your situation?

- 1. I can enjoy life because of the way I'm managing my money.
- 2. I could handle a major unexpected expense.

	1 Not at all	2 Very little	3 Somewhat	4 Very well	5 Completely
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>De New &amp; Nicastrò, 2020)</b>	When it comes to how you think and feel about your finances, please indicate the extent to which you agree or disagree with the following statements:	1 Disagree strongly	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree
	3. I feel on top of my day-to-day finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	4. I am comfortable with my current levels of spending relative to the funds I have coming in.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	5. I am on track to have enough money to provide for my financial needs in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

<b>Housing Instability Index (Rollins et al., 2012)</b>		No	Yes
	1. In the past 6 months, have you had to live somewhere that you did not want to live?	<input type="checkbox"/>	<input type="checkbox"/>
	2. In the past 6 months, have you had difficulty (or were unable to) pay for your housing?	<input type="checkbox"/>	<input type="checkbox"/>
	3. Have you had trouble getting housing in the past 6 months?	<input type="checkbox"/>	<input type="checkbox"/>
	4. Do you expect that you will be able to stay in your current housing for the next 6 months?	<input type="checkbox"/>	<input type="checkbox"/>
	5. In the past 6 months, have you had to borrow money or ask friends/family or others for money to pay your rent/mortgage payment?	<input type="checkbox"/>	<input type="checkbox"/>
	6. In the past 6 months, how many times have you moved?		
	7. Have you had trouble with a landlord in the past 6 months?	<input type="checkbox"/>	<input type="checkbox"/>
	8. In the past 6 months, has your landlord threatened to evict you?	<input type="checkbox"/>	<input type="checkbox"/>
	9. In the past 6 months, have you been served an eviction notice?	<input type="checkbox"/>	<input type="checkbox"/>
	Unlikely	Likely	
10. How likely is it that you will be able to pay for your housing (e.g., rent/mortgage) this month?	<input type="checkbox"/>	<input type="checkbox"/>	

**Domains: Physical wellbeing, Psychological wellbeing, Social Wellbeing, Treatment Related Factors, Stigma & Discrimination, Welfare, Lifestyle & Safety**

**Positive Outcomes: HIV PROM (Harding et al., 2020)**

Please answer the following questions about any problems or worries that you have had over the past 4 weeks. Your answers are really important to us. They will help us to improve your HIV care by making sure that we can focus on the things that are most important to you.

1. What have been your main problems and worries over the past 4 weeks that you would like to be addressed?

a. \_\_\_\_\_  
 b. \_\_\_\_\_  
 c. \_\_\_\_\_

2. In general, how would you rate your health and wellbeing over the past 4 weeks? Please think about both physical and emotional wellbeing.

	Excellent	Good	Average	Poor	Very poor
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Do you feel you have enough information to manage your HIV?

	Enough Information, The right amount for me	Information received, but hard to understand	Information received, but would like more	Very little information, and would like more	No information received, and would like information
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The next few questions ask you more about your physical health and wellbeing.

4. Over the past 4 weeks, how much have you been affected by pain? This could include headache, joint pain, neuropathy (which might include pins and needles or burning pain) or any other pain in your body

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Over the past 4 weeks, how much have you been affected by stomach or bowel problems? This could

	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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include sickness, diarrhoea, bloating, feeling sick or other stomach or bowel problems

6. Over the past 4 weeks, how much have you been affected by problems with your memory or concentration?

7. Over the past 4 weeks, how much have you been affected by problems with your sleep?

Always      Most of the time      Sometimes      Occasionally      Not at all

8. Over the past 4 weeks, have you been physically able to carry out your usual activities? This could include washing, dressing, housework, work, study, leisure activities, socialising, as well as other things.

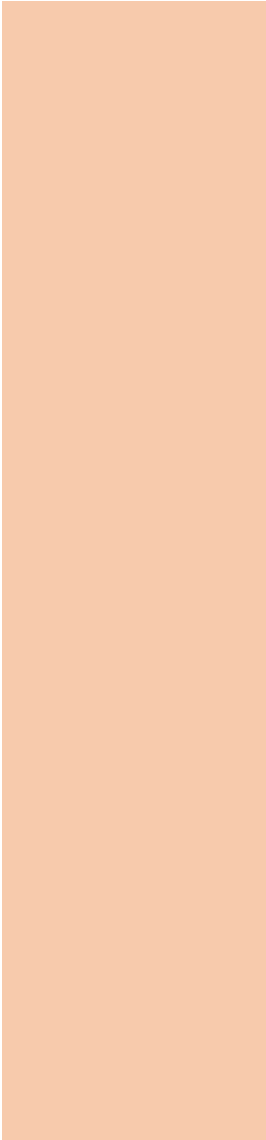
The next few questions ask you more about your emotional health and wellbeing.

Not at all      Occasionally      Sometimes      Most of the time      Always

9. Over the past 4 weeks, have you been feeling anxious or worried?

10. Over the past 4 weeks, have you been feeling depressed or low in mood?

11. Over the past 4 weeks, have you felt worried about telling someone about your HIV status?



	Always	Most of the time	Sometimes	Occasionally	Not at all
12. Over the past 4 weeks, have you felt good about yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Over the past 4 weeks, have you felt at peace?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The next few questions ask you more about your home and social life.	Not at all	Occasionally	Sometimes	Most of the time	Always
14. Over the past 4 weeks, have you been worried about your safety in your relationships? This may include intimate relationships, or relationships with family, friends and other people around you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Over the past 4 weeks, have you or anyone close to you been worried about your drug or alcohol use?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Over the past 4 weeks have you been worried about money?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Over the past 4 weeks have you been worried about your housing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Over the past 4 weeks have you been worried about your immigration status?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Over the past 4 weeks have you felt that you have had enough support from people around you? This may include partners, friends, family, support groups and other networks.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



These last few questions ask you more about sex and intimate relationships.

20. Over the past 4 weeks, have you been worried about sex or intimacy?

Not at all

Occasionally

Sometimes

Most of the time

Always

21. Over the past 4 weeks, have you been worried about your sexual health?

22. Over the past 4 weeks, have you been worried about contraception?

23. Over the past 4 weeks, have you been worried about starting a family or having a child?

Thank you for taking the time to answer these questions. Your answers are really important to us. They will help us to improve your HIV care by making sure that we can focus on the things that are most important to you.