

PLHIV & HIV RESPONSE PARTNER CONSULTATION SURVEY

Positive Life NSW
Strategic Plan 2016-2020
Development Report

Acknowledgements

Author: Lance Feeney, Senior Policy Advisor Positive Life NSW

The author would like to acknowledge:

- New South Wales people living with HIV (PLHIV) who responded to the consultation survey.
- HIV Response Partners – NSW Ministry of Health, HIV Community NGOs, Local Health District HIV and Related Programs Managers, Hospital and Private Practice HIV Specialists, Adahps, Multicultural HIV and Hepatitis C Service, The Heterosexual HIV Service (Pozhet) and ASHM.
- Members of the Positive Life NSW Strategic Plan Working Group – Cameron Colwell (Chair), Robert Agati, Jane Costello, David Piper, Ross Berry, Paul Caleo, and Craig Cooper.
- Matt O'Dwyer (initial survey analysis) and Neil Fraser.

Background

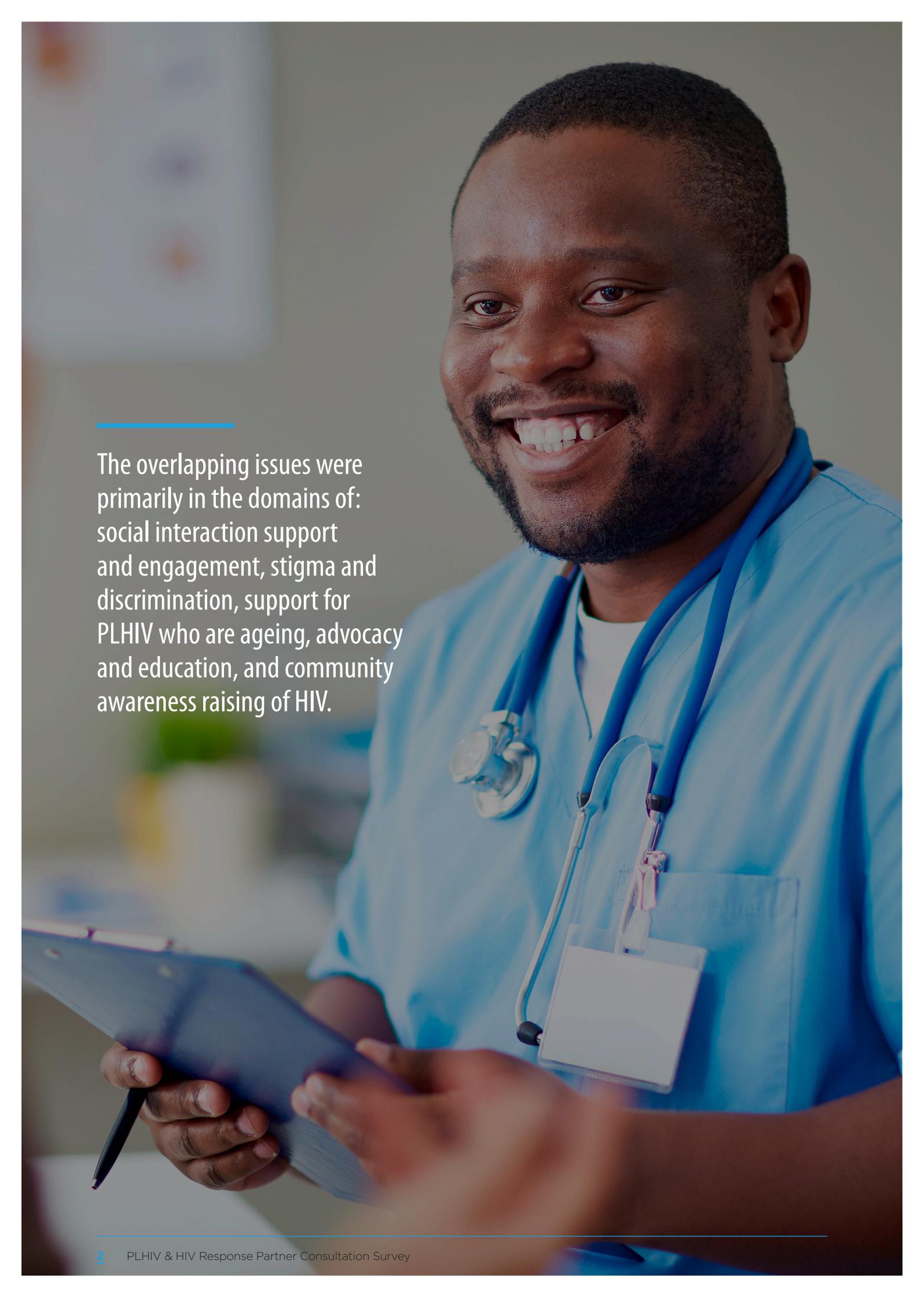
In February 2016, The Positive Life NSW (Positive Life) Board began a process to develop a new four year strategic plan – 2016-2020. To facilitate the strategic plan build, consultation process was implemented with stakeholders including: 1) surveying Positive Life Members and PLHIV in Sydney and regional NSW and, 2) surveying service partners from Government, HIV sector NGOs, Local Health District staff and high caseload HIV clinicians.

This report documents findings from:

- 1) the PLHIV consultation survey and, 2) the HIV Response Partners Consultation Survey.

Contents

Summary findings	3
Priority issues identified by PLHIV for Positive Life's Strategic Plan 2016-2020	4
Priority issues identified by HIV Response Partners	6
The PLHIV Survey	8
Findings	9
PLHIV rank issues considered important by Positive Life	9
Additional issues identified by PLHIV and not included in the options listed	10
Priority issues for PLHIV in NSW	10
Outcomes desired from priority issues	13
Gaps in the work of Positive Life	14
Strengths to build on	15
Increasing reach and PLHIV engagement in NSW	15
The HIV Response Partners Survey	16
Findings	17
Top strategic issues for Positive Life	18
Gaps in current work	19
Strengths	20
Increasing reach and PLHIV engagement in NSW	20
Appendix 1	21
Demography of respondents to PLHIV Survey (N=80)	21

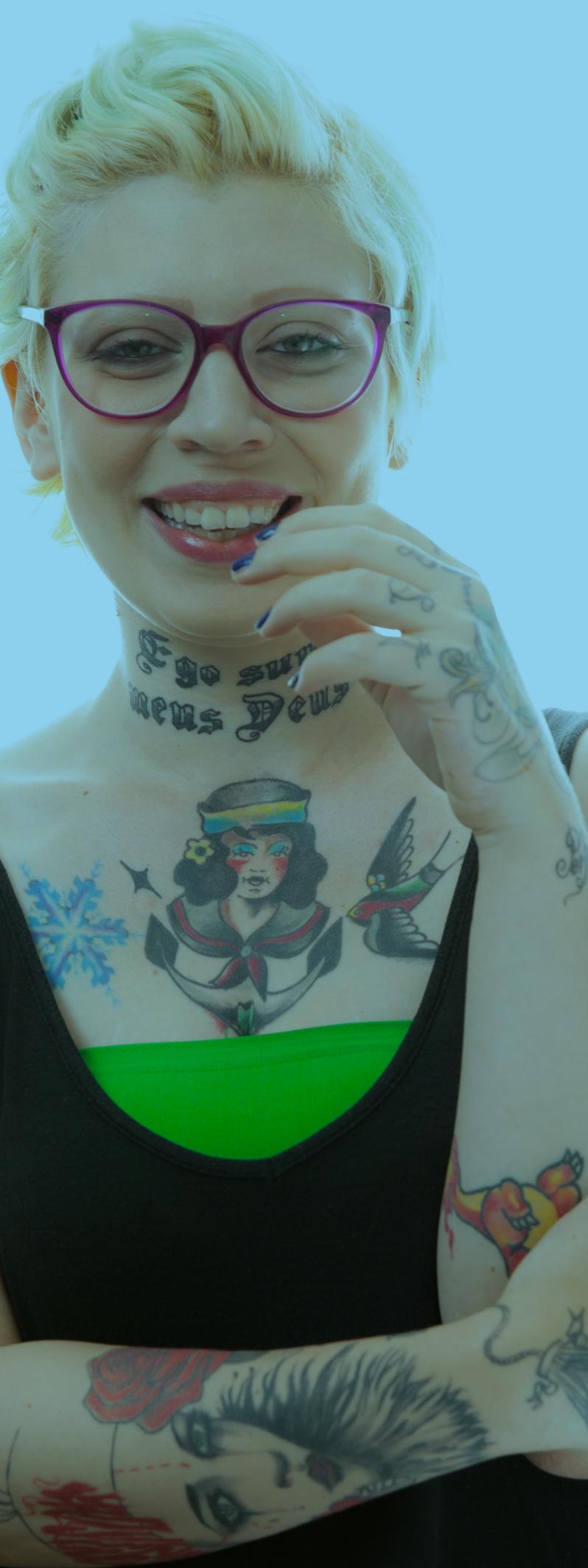


The overlapping issues were primarily in the domains of: social interaction support and engagement, stigma and discrimination, support for PLHIV who are ageing, advocacy and education, and community awareness raising of HIV.

Summary findings

Overlap was noted in the priority issues identified by people living with HIV (PLHIV) and HIV Response Partners during the consultation to develop a new four year Positive Life NSW (Positive Life) Strategic Plan (2016–2020). The overlapping issues were primarily in the domains of: social interaction support and engagement, stigma and discrimination, support for PLHIV who are ageing, advocacy and education, and community awareness raising of HIV.

Additionally, gaps were identified by PLHIV and HIV response partners in relation to Positive Life's engagement with minority groups of PLHIV including: 1) outer-metro and regional and rural PLHIV, 2) heterosexuals with HIV, 3) newly diagnosed PLHIV and younger PLHIV, and 4) PLHIV who are ageing. PLHIV and HIV response partners also noted the need for Positive Life to improve communication and collaboration with other community NGO partners and reduce fragmentation between gay men, heterosexual and CALD PLHIV and those who are younger/older or live in regional/rural NSW.



Priority issues identified by PLHIV for Positive Life's Strategic Plan 2016–2020

- **Increase opportunities for social interaction, support and engagement,** particularly for PLHIV who are: 1) older with chronic and complex health conditions, 2) marginalised and/or socially or physically isolated (CALD, heterosexual, rural and regional) and 3) impacted by psychosocial issues (i.e. mental health, AOD, and/or poverty).
- **Address stigma and discrimination** by: 1) working to reduce HIV associated stigma and discrimination and 2) addressing the gap between those who are living well with HIV and those who are not.
- **Increase support for PLHIV who are ageing with HIV** including: 1) providing information, support and advocacy to enable PLHIV to access appropriate and affordable health and support services and better manage HIV and other chronic and complex health conditions, 2) access affordable and non-discriminatory aged care and nursing home facilities and 3) access affordable and appropriate social housing.
- **Advocacy** to: 1) decriminalise HIV transmission and remove the requirement to disclose HIV status before sex, 2) ensure clinical and support services are affordable and meet the emerging health care and support needs of PLHIV who are ageing with chronic and complex health conditions, including mental health and neurocognitive disease, 3) support access to affordable and appropriate social housing in metropolitan Sydney and regional NSW and 4) support the ongoing and emerging treatment and care needs of PLHIV in NSW.
- **Education** on: 1) issues associated with HIV and ageing and managing co-morbidities including HCV, 2) managing mental health conditions, 3) new treatments and the importance of maintaining an undetectable viral load, 4) medical records, health data usage/linkage and health care rights in general, 5) the impacts of late HIV diagnosis and 6) the negative impacts of HIV-associated discrimination.
- **Community awareness raising,** about: 1) the impacts of HIV stigma and discrimination, 2) the impact of treatment on health and transmission risk, and 3) what it's like to live with a chronic manageable condition such as HIV in 2016.

Gaps

- **Engagement,** with: 1) outer-metro and regional PLHIV, 2) heterosexuals with HIV, 3) newly diagnosed and younger PLHIV, 4) PLHIV who are ageing, 5) volunteers.
- **Collaboration:** improved communication and collaboration between community health organisations such as ACON, BGF, Pozhet Multicultural HIV and Hepatitis C Service, 2) reduce separation between PLHIV population groups (i.e. gay men, heterosexuals and CALD PLHIV, and rural and regional PLHIV).



Priority issues identified by HIV Response Partners

- **Advocate**, to: 1) ensure the voice of PLHIV in NSW remains central in the HIV response, 2) maintain strong advocacy, visibility and community representation and identify and comment on barriers to health and support service access as well as on emerging issues for PLHIV, 3) decriminalise HIV transmission, 4) support smooth access to community dispensing, social housing, integrated care and drug rehabilitation programs, 5) improve service access for rural and regional PLHIV and 6) advocate for PLHIV who are homeless and living in poverty.
- **Social support and engagement**, particularly for: 1) ageing PLHIV, isolated and marginalised PLHIV, 2) newly diagnosed PLHIV, 3) heterosexual and CALD PLHIV and 4) outer metropolitan, regional and rural PLHIV.
- **Ageing PLHIV**, including: 1) increased support for PLHIV who are ageing, 2) strategies to improve resilience and to live healthier and happier lives, 3) improved integrated care and 4) increase forward planning for PLHIV who are entering nursing homes and aged care facilities.
- **Education**, including: 1) to improve understanding of the health and transmission benefits of cART and maintaining a undetectable viral load, 2) for heterosexual men and women living with HIV, 3) to improve community understanding of the impacts of multi-morbidity and health monitoring and treatment of chronic and complex health conditions.
- **Treatment and care**, including: 1) supporting rapid treatment commencement for newly diagnosed PLHIV and linkage to care and 2) supporting PLHIV with strategies to maintain adherence, particularly in the context of multi-morbidity and polypharmacy.
- **Stigma and discrimination**: work to reduce HIV associated stigma and discrimination, particularly in marginalised and minority populations with HIV.

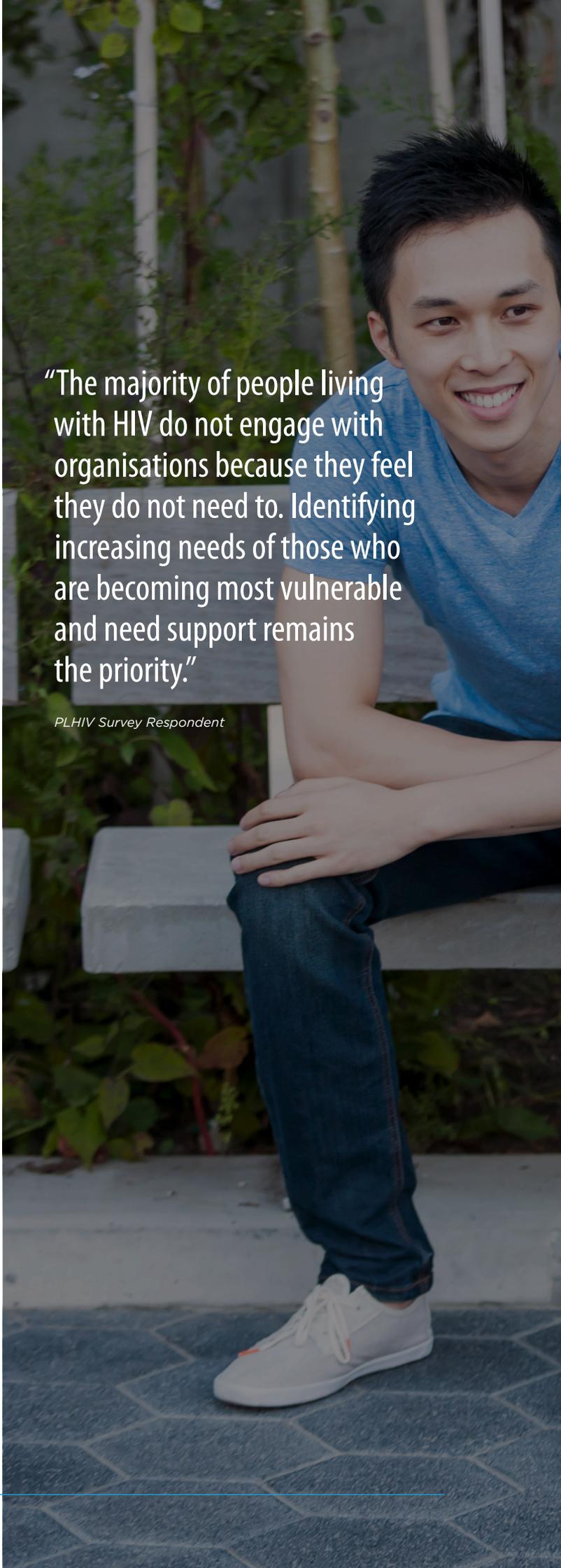
Gaps

- **Collaboration** including: 1) improve liaison and coordination with partner community organisations on key pieces work, 2) improve relationships with other HIV sector agencies, 3) reducing overlap with existing services.
- **Engagement** with: 1) heterosexual PLHIV, 2) regional and rural PLHIV, 3) PLHIV in outer metro areas, 4) CALD PLHIV and 5) younger PLHIV.
- **Education**: support rural and regional HARP units with limited health promotion capacity.

The PLHIV Survey

A short electronic survey was developed targeting PLHIV in NSW. The survey was promoted through membership networks and via social media and was open for approximately four weeks – from Friday 8 April to Monday 25 April 2016. The survey received 80 responses. The demographic profile of survey respondents can be viewed in Appendix 1. Although 80 responses represent only approximately 0.8% of the diagnosed population with HIV in NSW, it can be argued that the 80 individuals took the time and had the interest to provide input into the work of Positive Life.

The survey asked respondents a series of questions. These included: 1) ranking issues that Positive Life thought a priority, 2) identifying the top three issues and outcomes they would like achieved by positive Life, 3) identifying gaps in the work of Positive Life, 4) identifying strengths that Positive Life could build upon and 5) suggesting ways that Positive Life could engage with and reach more people with HIV in NSW.



“The majority of people living with HIV do not engage with organisations because they feel they do not need to. Identifying increasing needs of those who are becoming most vulnerable and need support remains the priority.”

PLHIV Survey Respondent

Findings

PLHIV rank issues considered important by Positive Life

Respondents were asked to rank from 1-10 [where 1 is not a priority, and 10 is the highest priority] a list of issues. Rankings were in the following order [most important to least important]:

Priorities in order (most important to least)	Rating average	Rank
Support to manage ageing, HIV and other multiple chronic health conditions	8.51	1
Reduce HIV stigma and discrimination	8.41	2
Ensure that health and mainstream services meet needs	8.27	3
Address poverty, social isolation and support skills building	7.79	4
Reduce late stage HIV/AIDS diagnoses	7.70	5
Advocate/Support treatment commencement and adherence	7.69	6
Remain motivated and engaged in treatment and care	7.49	7
Housing and tenancy support	7.33	8
Support better understanding and access to PrEP	6.78	9
Help to notify partners about a recent HIV or STI infection	6.26	10

Additional issues identified by PLHIV and not included in the options listed

In addition, respondents were offered the opportunity to identify issues that weren't in the priorities nominated by Positive Life. The following issues were described in order of priority:

Education across a range of domains

including: [n=10]:

- General population - HIV, living with HIV and the impact of HIV treatment and undetectable/detectable viral load on transmission [n=6]
- To schools about HIV, HIV transmission and living with HIV [n=1]
- Complementary/alternative therapies [n=1]
- To Rural and regional populations to support LGBTI youth, and to address bullying, mental health, suicide) [n=1]
- To the rural medical community about PrEP [n=1]

Legal reform:

- HIV disclosure, remove s79 [n=6]

Improved HIV services in rural and remote areas [n=3]

Social interaction/events [n=3]

Empowerment, self-worth and resilience building [n=2]

Support for PLHIV who are [n=2]:

- Working [n=1]
- In HIV sero-discordance relationships [n=1]

Other issue identified by individual respondents included: an increased focus on heterosexuals with HIV, financial aid and assistance to PLHIV living in poverty, support to PLHIV in custody, addressing housing and tenancy issues for PLHIV, and increasing access to PrEP in rural and regional areas.

Priority issues for PLHIV in NSW

Respondents were then asked (in an open ended question) to identify the top three priorities that *they* consider Positive Life should progress over the next four years. The following responses were identified in order of priority:

Social interaction, support and engagement, targeting [n=31]:

- Older PLHIV and those impacted by chronic and complex health conditions
- PLHIV with mental health conditions
- All PLHIV regardless of sexual identity gender and age
- PLHIV who are isolated and marginalised
- Regional and rural PLHIV

Stigma and discrimination including [n=21]:

- Work to challenge, reduce and overcome HIV associated stigma
- Work to challenge, reduce and overcome discrimination against PLHIV
- Address the divide between those who are living well with HIV and those who are not

Ageing and HIV [n=19]:

- Information about ageing with HIV and manage multiple chronic health conditions
- Support services to assist PLHIV to managing ageing and other multiple chronic health conditions
- Responsive, affordable and non-discriminatory aged care and nursing home facilities for PLHIV
- Access to affordable and appropriate social housing
- Support for socially isolated and older PLHIV to develop meaningful community connections

Education on [n=18]:

- Issues associated with HIV and ageing
- New HIV treatments and the importance of adherence and maintaining an undetectable viral load
- HIV training of medical staff in hospitals and medical services (doctors and nurses)
- The negative impacts of HIV-associated discrimination
- Managing co-morbidities, including Hepatitis C
- Mental health conditions and management
- For the general community living with HIV and the advances in HIV treatments and prevention
- Medical records, health data usage and data linkage
- Heterosexuals with HIV and late diagnosis
- Young people at risk of HIV
- Diet and healthy eating

Advocacy for [n=18]:

- Legal reform and the removal of section 79
- De-criminalisation of HIV transmission
- PLHIV's treatment and care needs
- Support services to help manage ageing, HIV and other chronic health conditions
- Skilled support services to manage mental health and neurocognitive disorders
- PLHIV living in poverty and access to affordable clinical services
- Chronic Disease Health Care Card
- Expanded access to PrEP for all people at risk of HIV
- Support service for partner notification for BBVs and STIs
- Cheaper access to specialist care
- Social Housing
- Cure for HIV

Community awareness raising including [=15]:

- Impacts of stigma and discrimination
- Impacts of HIV and ageing
- Improved public understanding of HIV and living with HIV in 2016
- The impact of undetectable viral load on transmission risk

“The ageing PLHIV population needs support.”

PLHIV Survey Respondent

Outcomes desired from priority issues

Respondents were asked to identify outcomes they would like achieved from the issues identified in the previous question. The following responses were reported:

Increased opportunities for social interaction, support and engagement, to:

- PLHIV on limited incomes
- Isolated PLHIV, PLHIV with mental illness and PLHIV who are marginalised
- Build social networks, reduce loneliness and improve mental health
- Intergenerational interaction

Stigma and discrimination:

- Increased profile of HIV in media
- Collaborative campaigns
- General community develops a better understanding of the modern reality of HIV infection in 2016
- “Special status” of HIV is removed
- Reduced HIV stigma and discrimination of PLHIV by gay and general community members

Ageing with HIV and multi-morbidity:

- More peer-based services
- Education, support and advocacy
- Acceptance of PLHIV in aged care facilities
- Aged Care Guidelines to uphold rights
- Access to affordable aged care facilities
- Access to affordable social housing
- Chronic Health Care Card for PLHIV on low incomes
- Better care coordination
- Support to manage the impacts of HIV Associated Neurological Disorder (HAND)

Medical and Allied Health Care Workers:

- Have better understanding of HIV

Advocacy:

- Decriminalise HIV transmission
- Better access to PrEP
- Immediate access to cART
- Better access to social housing for PLHIV in need
- Analysis of late presenters to improve education and testing initiatives

Community awareness:

- Better understanding of the lived experience of PLHIV and the impact on transmission of cART and UVL
- HIV can be contracted by heterosexuals

Mental Health:

- Information and support services for mental health self-management

Gaps in the work of Positive Life

Respondents were asked to identify gaps in the current work of the agency. The following issues were identified:

Rural & Regional:

- Better access to HIV services in regional/rural areas

Education:

- Regional/rural GPs – HIV treatments and services
- To regional/rural high school students about HIV
- TasP and UVL and its impact on HIV transmission

Engagement:

- With outer-metro and regional PLHIV
- With newly diagnosed PLHIV
- With younger PLHIV
- With PLHIV who are ageing
- More social engagement opportunities/events
- Women with HIV
- More peer-based service delivery for ageing and mental health
- Volunteers
- Reaching out to PLHIV rather than expecting them to come to Positive Life

Advocacy:

- Removal of requirement to disclose HIV before sex (s79)
- More social workers
- Affordable access to dental services
- Highlight antidiscrimination laws for medical/ancillary staff and penalties for breaches

Collaboration:

- Improve communication and collaboration between community health organisations
- Reduce fragmentation between PLHIV groups (i.e. heterosexual, CALD, PWID)
- Positive Life should be the lead agency incorporating and coordinating all other PLHIV groups

Strengths to build on

There is potential to build on strengths. Respondents were asked to identify the current strengths of Positive Life. The following issues were identified:

Communication and education:

- Provision of Information on HIV
- The Positive Speaker Bureau – bringing the lived experience of HIV to the general public
- Reducing stigma and discrimination
- Increased media presence and agency visibility

Opportunities for peer discussion:

- Discussion forums – Peer2Peer and + Connect

Staff and board:

- Leadership on HIV-associated issues
- Dedicated and skilled staff who are HIV-positive
- Dedicated and skilled Board who are HIV-Positive
- Openness to ideas and willingness to support other HIV agencies
- Improved relationships with other agencies in the HIV sector

Community engagement and support:

- Opportunities provided for social engagement and networking with other PLHIV
- HIV Work Ready

Advocacy:

- Effective advocacy to government
- Quality policy work

Increasing reach and PLHIV engagement in NSW

Respondents were asked how Positive life can engage with and reach more people with HIV in NSW. The following ways were identified:

Communication:

- Reintroduce hard copy Talkabout
- Stronger social media presence
- Community surveys that provide opportunities for input
- Improve Talkabout
- Community radio
- Don't just rely on social media
- Online chat room
- Direct service delivery
- More presentations at conferences

Social engagement:

- Increased opportunities for social engagement
- Rural and regional social events and engagement by staff
- For heterosexual PLHIV
- Work more closely with TIM

Physical environment:

- Leave 414 Elizabeth Street and relocate to an office with more space

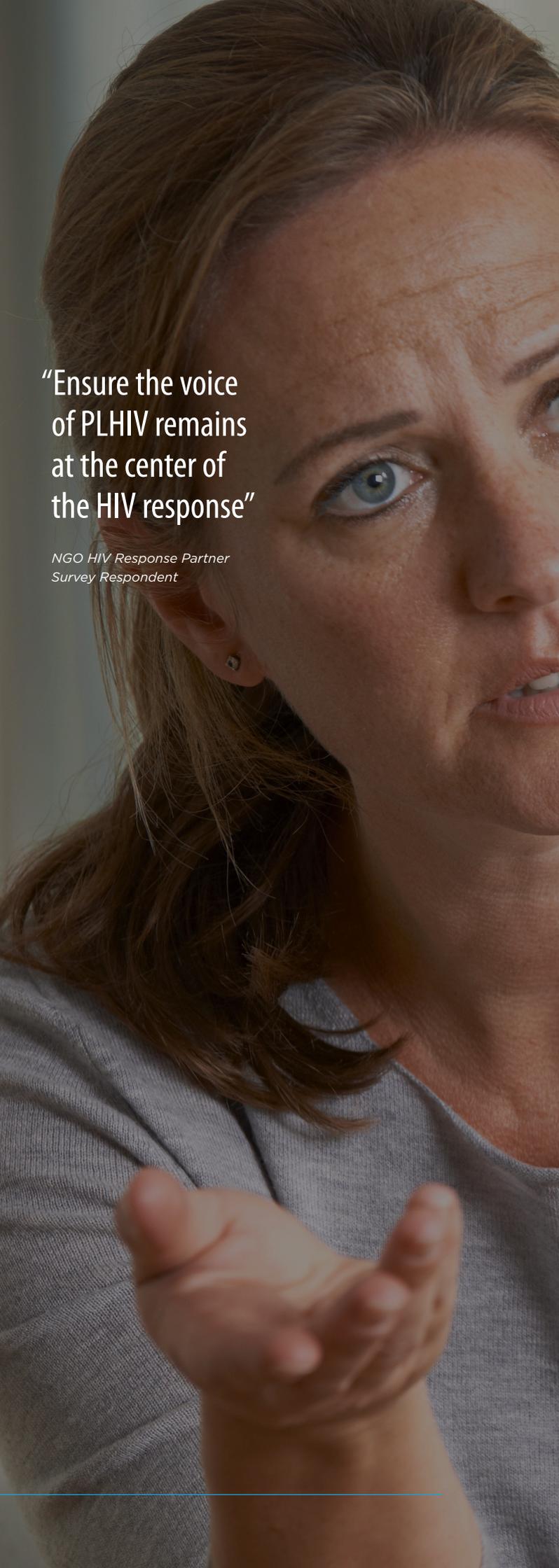
The HIV Response Partners Survey

The second part of the consultation was with HIV response partners. Positive Life developed and implemented a short electronic survey.

The survey asked respondents a series of questions including: 1) the area in which they worked, 2) the top three strategic issues that Positive Life needs to progress over the next four years, 3) gaps in the work of Positive Life, 4) strengths that we could build on, and 5) ways that Positive Life could engage with and reach more people with HIV in NSW.

The survey link was distributed to key individuals who work closely with Positive Life. They included representatives from a) the NSW Ministry of Health, b) non-government organisations, c) Local Health District HIV and Related Programs Units (HARP) and d) selected s100 prescribers. The survey was open for just over four weeks, from 22 April to 11 May 2016. 15 responses were received. The pie chart on the following page illustrates the percentages of respective respondents.

We thought it important to attribute to HIV response partners the types of issues they raised. In the brackets following each issue, we note the type of HIV response partner who identified the issue. For example (NGO x4) indicated that 4 different HIV sector NGOs provided similar feedback. Other HIV response partners include: (HP)=health professional, (LHD)=Local Health District Employee, and (Gov)=NSW Ministry of Health.



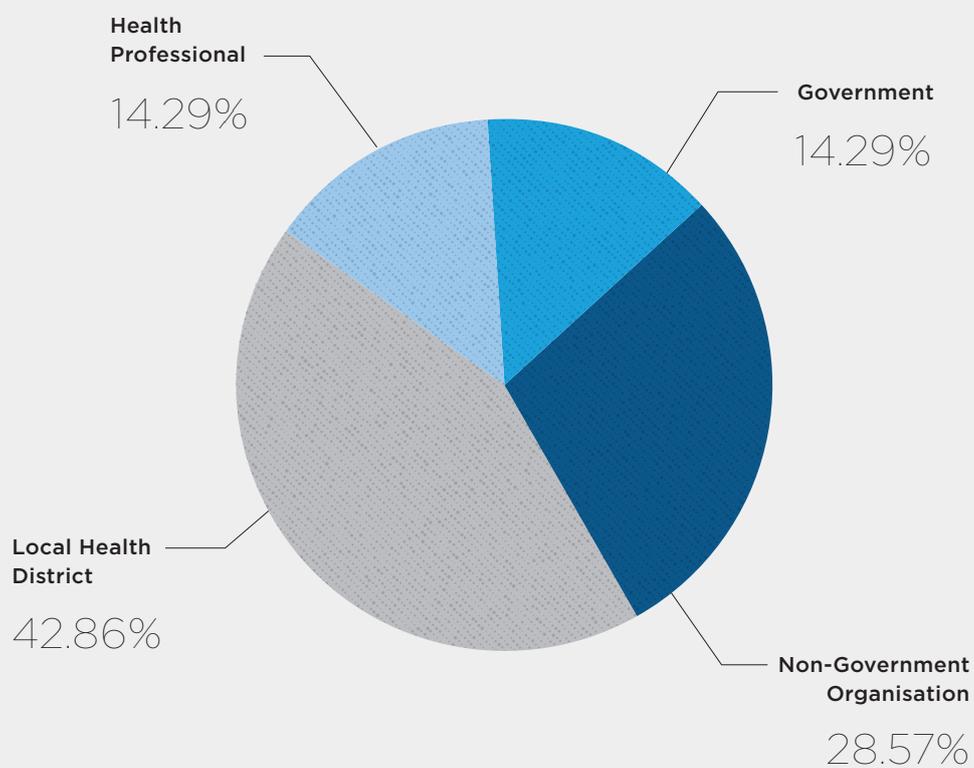
“Ensure the voice of PLHIV remains at the center of the HIV response”

*NGO HIV Response Partner
Survey Respondent*

Findings

Q1. Which of the following best describes the area in which you work in the NSW HIV response?

Answered: 15 Skipped: 0



Top strategic issues for Positive Life

HIV response partners were asked to identify the top strategic issues that Positive Life needs to progress over the next four years. The following issues were identified in order of priority:

Advocacy:

- Ensure the voice of PLHIV remain at the centre of the HIV response and maintain strong advocacy, visibility and representation and identify and comment on barriers/emerging issues on behalf of PLHIV - (LHD x 2), (NGO x 4), (HP)
- Decriminalisation of HIV transmission and treat HIV as a Public health issue - (NGO x 2)
- Ensure smooth access to community dispensing of s100 drugs - (LHD)
- For Social Housing for PLHIV - (HP)
- For improved integrated care (in particular for ageing PLHIV) - (NGO)
- Methamphetamine rehab programs for those in crisis (HP)
- For PLHIV impacted by poverty, homelessness - (HP)
- Improve service access for rural and regional PLHIV - (LHD)
- Work closely with LHDs - (LHD)

Social Support and engagement:

- For ageing PLHIV - (LHD)
- For isolated and marginalised PLHIV - (NGO), (LHD x3)
- For PLHIV newly diagnosed with HIV - (LHD)
- For heterosexual men and women with HIV - (LHD x3)
- For outer metro and regional/rural PLHIV - (Gov), (LHD)
- For CALD PLHIV - (LHD)
- Focus on psychological self-support strategies - (HP)

Ageing:

- Support for people ageing with HIV - (LHD), (NGO)
- Strategies to improve resilience for PLHIV who are ageing - (HP)
- How to live longer and healthier with HIV - (Gov)
- Improve integrated care - (NGO)
- Forward planning for PLHIV entering nursing homes - (HP)

Education:

- Continued strong health promotion/peer education to PLHIV - (NGO), (LHD)
- For heterosexuals and women with HIV - (LHD)
- About impact of cART, UDVl and PrEP on prevention - (NGO x2), (Gov)
- Ensuring contemporary HIV narrative reaches all affected individuals - (Gov)
- Better understanding of the Health impacts of HIV and multi-morbidity - (LHD), (HP)

Treatment and care:

- Rapid treatment support for newly diagnosed PLHIV and linkage to care - (NGO), (LHD)
- Strategies to support adherence in the context of multiple tablets for multi-morbidities - (HP), (LHD)

Stigma and discrimination:

- Work to reduce HIV stigma and discrimination - (NGO x2)
- Work to reduce HIV stigma and discrimination in minority populations - (LHD)

Gaps in current work

Respondents were asked to identify gaps in the current work of Positive Life. The following domains were identified:

Collaboration:

- As pressure increases on s100 prescribers, there will be a need to engage with other health care providers i.e. GPs – (NGO)
- Better liaison with sector partners
- Supporting leadership from PLHIV outside the paid HIV sector – (NGO)
- Reduce overlap with existing services – (NGO)
- Improve coordination with partner organisations on key pieces of work – (NGO)

Engagement:

- Heterosexual Men and Women with HIV – (Gov), (NGO)
- Rural/regional PLHIV
- PLHIV in outer metropolitan areas
- CALD PLHIV
- Younger PLHIV

Referral:

- Refer out, rather than trying to do it all

Health promotion:

- Health promotion support for rural and regional Sexual Health Services with no health promotion capacity

“More support for rural and regional PLHIV.”

*HIV Response Partner
Survey Respondent*

Strengths

Respondents were asked to identify the current strengths of Positive Life, so that we can build on them. The following strengths were identified:

Advocacy:

- Strong policy understanding, skills and voice, effective advocacy processes and broader high visibility policy engagement, which set the tone for the HIV sector. This is where Positive life is strongest – (NGO x4), (LHD)

Treatment and care:

- Strong understanding and engagement with changing treatment dynamic and provision of valuable individual support to PLHIV as well as a broader policy engagement on treatment and care – (NGO)

Staff:

- Expertise and experience – (Gov)
- Approach to partnership and professional generosity – (Gov)
- High visibility in community and sector, strong advocacy voice
- Sensible staff and approach

Positive Life generally:

- Small dynamic organisation punching above its weight, impressive range of community engagement and information distribution including improved social media – (NGO), (Gov)
- Strong community history, ongoing community support, peer-led/driven – (NGO)
- Commitment, experience, compassion, well informed organisation in touch with community and its changing needs – (HP)

Increasing reach and PLHIV engagement in NSW

Respondents were asked to identify ways that Positive Life could increase the reach of the agency and engage more PLHIV in NSW. The following ways were identified:

Engagement:

- Regional/rural PLHIV – (NGO)
- Heterosexual women and men with HIV – (Gov), (LHD), (NGO)
- Marginal groups of PLHIV i.e. CALD – (HP)
- Strengthen links with LHDs

Positive Speaker Bureau (PSB):

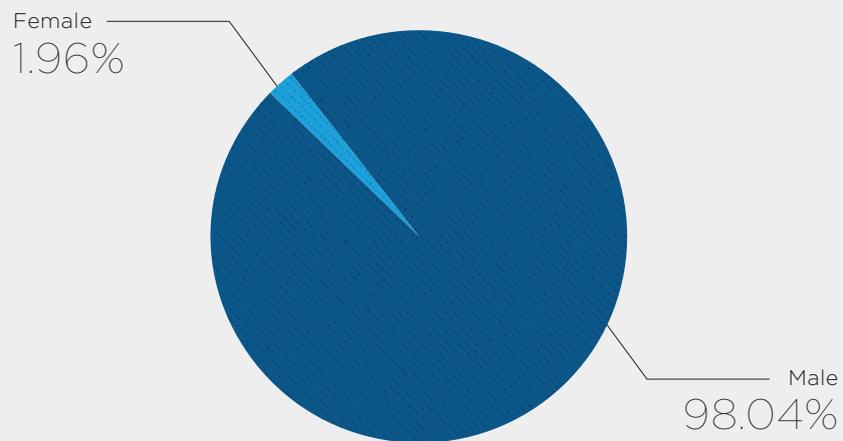
- Continue to improve the PSB
- Continue to increase HIV awareness in general population and reduce stigma and discrimination

Appendix 1

Demography of respondents to PLHIV Survey (N=80)

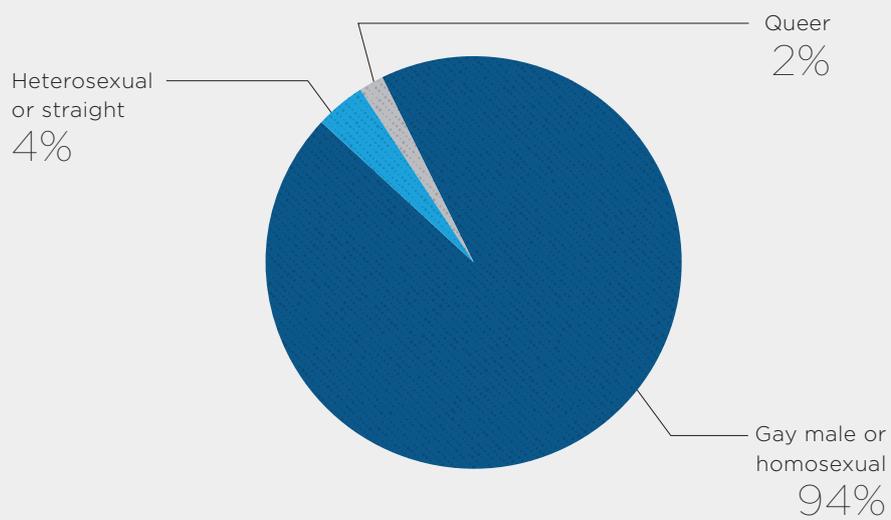
Q9. What is your current gender identity?

Answered: 51 Skipped: 29



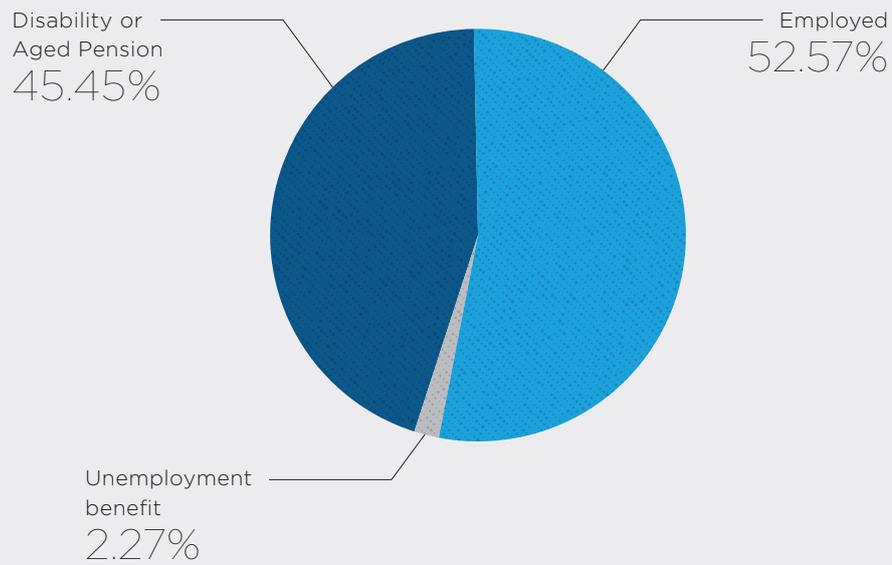
Q12. How do you identify?

Answered: 50 Skipped: 30



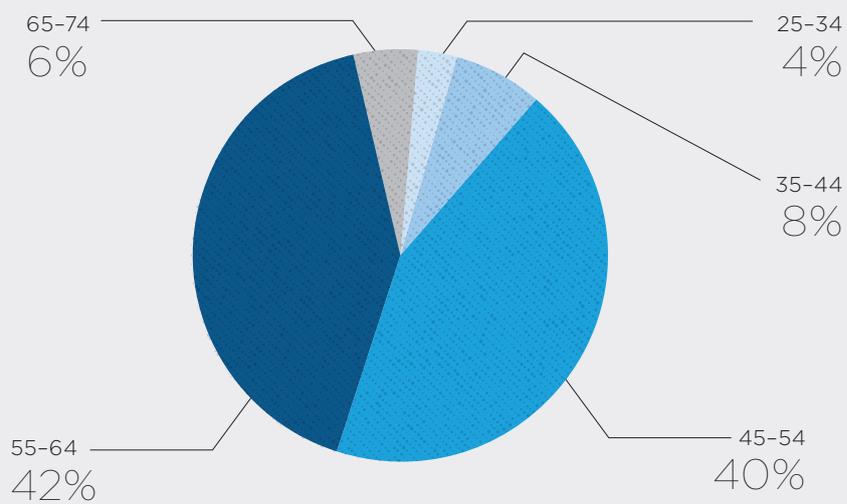
Q16. What is your main income source

Answered: 44 Skipped: 36



Q17. What is your age?

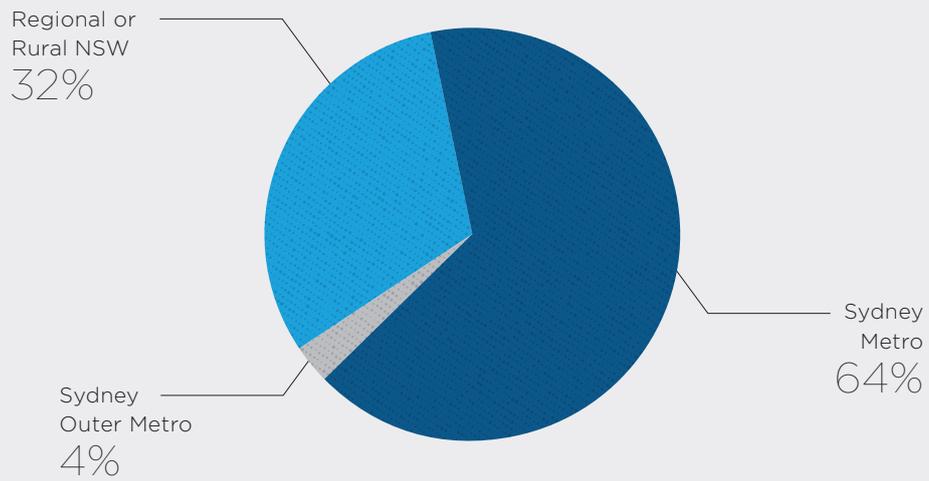
Answered: 50 Skipped: 30



Q18. Where do you live?

Answered: 50

Skipped: 30



Location Suite 5.2, Level 5, 414 Elizabeth Street, Surry Hills NSW 2010

Mail PO Box 831, Darlinghurst NSW 1300

Phone 02 9206 2177 **Freecall** 1800 245 677 **TTY** 131 450 www.positivelife.org.au

PositiveLifeNSW
the voice of people with HIV since 1988