

# Living Positive Victoria

## Community Engagement Strategy

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'Community Engagement' is defined as a planned process to work with people living with and affected by HIV. This strategy aims to support Living Positive Victoria to act as an authentic agent of the community so that community members can feel confident that the organisation is representing their best interests.



living positive victoria



# ABOUT LIVING POSITIVE VICTORIA

## VISION

Living Positive Victoria shares the vision of the National Association of People with HIV Australia of a world where people living with HIV live their lives to their full potential, in good health and free from discrimination.

## MISSION

Living Positive Victoria is a community-based organisation that works to advance the human rights of people living with HIV.

Its mission is to enable and empower all people affected by and living with HIV in Victoria to be part of the response that seeks an end to the HIV epidemic.

## COMMITMENT TO COMMUNITY ENGAGEMENT

People living with HIV have a right to be directly involved in the response to HIV in Australia, as declared in the greater involvement and meaningful engagement of people living with HIV (UNAIDS GIPA/MIPA Principle).

Living Positive Victoria is committed to engaging with and listening to its members and the communities it seek to represent. The organisation actively invites people living with HIV to become involved and to directly guide and inform the organisation's work.

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# ACKNOWLEDGEMENTS

Living Positive Victoria's Community Engagement Strategy has been developed through consultation with people living with HIV, members, volunteers, staff, and partner organisations.

Living Positive Victoria is grateful to the following individuals and organisations for their input into this strategy:

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Department of Health and Human Services, State Government of Victoria  
Melbourne Sexual Health Centre  
National Association of People with HIV Australia (NAPWHA)  
Positive Women Victoria  
Prahran Market Clinic  
Royal District Nursing Service  
Victorian AIDS Council (VAC)

20 participants chose to remain anonymous.

Cover design by Prue Marks, Ography Pty Ltd.

# INTRODUCTION

A key action of Living Positive Victoria's 2014-2017 Strategic Plan and 2015-2016 Business Plan is to publish an agency-specific Community Engagement Strategy. For Living Positive Victoria, 'Community Engagement' is defined as a planned process to work with people living with and affected by HIV. This strategy aims to support Living Positive Victoria to act as an authentic agent of the community so that community members can feel confident that the organisation is representing their best interests.

Living Positive Victoria chose to create this strategy due to the following anticipated benefits:

## For the organisation:

1. Community input can improve the quality of organisational policies and practices, making them more practical and relevant.
2. Conducting consultations to develop this strategy can ensure that services are being delivered in an effective and efficient way for the communities that the organisation represents.
3. Engaging communities is a mechanism for the organisation to check the health of its relationships. It provides the opportunity for the organisation to explore ways in which Living Positive Victoria and its communities can work more closely on issues of concern.
4. Ongoing engagement enhances a reputation as open, accountable and willing to listen.

## For communities:

1. Through a purposeful consultation process, there will be opportunities for a diversity of voices to be heard on issues that matter to people.
2. Communities are able to self-identify their priorities.
3. The recommendations in this strategy have been developed through direct consultation, so that communities share in decision-making and know they can work with the organisation to accomplish these goals.
4. Individuals within communities may become more empowered and proactive with regard to issues that affect them.

Living Positive Victoria believes that engaged communities are more resilient communities. They are communities that are enabled with knowledge and skills and empowered with a positive attitude to make informed choices about their health and wellbeing and to contribute to social change and social justice.

# DEVELOPING THE STRATEGY

Living Positive Victoria engaged an external consultant to develop this strategy. The consultant did so by scheduling consultations with the following stakeholder groups:

- People living with HIV
- Members
- Volunteers
- Staff
- Partner Organisations

Consultations were conducted from June to August 2015. The consultation questions were tailored for each stakeholder group; however each consultation gathered information on seven overall themes:

1. Defining 'community engagement'
2. Levels of engagement with Living Positive Victoria
3. Living Positive Victoria's role within the Victorian HIV service and advocacy sector
4. Living Positive Victoria's role within participant-identified communities impacted by HIV
5. Experiences providing feedback to Living Positive Victoria
6. What Living Positive Victoria is doing well
7. What Living Positive Victoria could do to improve

This strategy summarises participants' responses and proposes four recommendations for Living Positive Victoria to better engage people living with HIV. In total, the consultant spoke with 50 people to develop this strategy. All participants had the opportunity to provide feedback to a draft version of this strategy.

Appendix 1 contains more information on the process of developing this strategy. Appendix 2 contains the question sets used in the consultations.



# LEVELS OF ENGAGEMENT

Four distinct levels of engagement emerged from the consultations. These levels are not a hierarchy; rather they are different ways of engaging with the organisation. Respondents range from engaging the organisation on all four levels over many years to a single level on a shorter and more recent time frame.

People living with and affected by HIV engage Living Positive Victoria in the following levels:

## 1. Individual – Peer Support and Education

Living Positive Victoria provides peer support and education to individuals living with and affected by HIV. Participants acknowledge that this type of support is received in various methods. Some participants subscribe to the organisation's Poslink newsletter, which provides information about HIV in a peer-based format. Many participants felt comfortable to start talking about their HIV status after hearing from a representative of the Positive Speakers

Bureau. Other participants speak directly to staff and volunteers at the organisation about concerns regarding treatment, sexual health, accessing supports, and resilience.

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*“LPV helped me understand my medication and what having an undetectable viral load really means.”*  
- Member

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## 2. Community – Volunteering and Groups

Many respondents had participated in Living Positive Victoria's Phoenix group program for people recently diagnosed with HIV. After completing Phoenix, people often choose to remain engaged with the organisation by attending Planet Positive social events.

Volunteering with the organisation is another popular form of engagement, as people feel that they're giving back to a community that supports itself.

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*“I heard a Positive Speaker talk about feeling isolated in a nursing home and thought ‘that could be me’. I'm less fearful now about entering aged care, because I know speakers are helping to educate that community.”* - Volunteer

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## 3. Sectoral – Partnerships and Feedback

The organisation is highly regarded for its willingness to partner with other agencies to work collaboratively towards a common goal, such as recent work with Positive Women Victoria to provide peer support to women living with HIV. People living with HIV feel that the feedback they provide to Living Positive Victoria will positively influence the broader sector.

## 4. Systemic – Advocacy and Campaigns

Repealing Section 19A of the Crimes Act 1958 (Vic), which was being used to criminalise HIV non-disclosure, was cited as an example of respondents requesting action and Living Positive Victoria advocating on their behalf. The ENUF campaign, the organisation's anti-HIV stigma and anti-discrimination campaign, directly involves people living with and affected by HIV in its activities and response.

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*“LPV sits at a high level of response in the sector and really embodies the principle of ‘speak with us, not for us’. LPV is a powerful advocate for social change.”* – Partner Organisation

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# ORGANISATION'S ROLE WITHIN HIV SECTOR

When asked to provide an understanding of the broad HIV service and advocacy sector in Victoria, most respondents said that the sector has a dual focus: a) prevention and outreach for people at risk of HIV transmission; and b) treatment and care for people living with HIV.

A major theme that emerged regarding Living Positive Victoria's role within the broader Victorian HIV sector was the concept of **living well**. Respondents stated that Living Positive Victoria is a peer-led organisation that provides health promotion programs and advocacy for people living with HIV. Rather than providing direct aid, participants acknowledged that the organisation is focused on capacity-building and resilience.

Participants found it easier to explain the organisation's role by focusing on specific programs that they had engaged with. These programs were identified as representing the core mission, vision and values of Living Positive Victoria. The two most common examples used were:

## Case Study #1: Positive Speakers Bureau (PSB)

**Purpose:** Provide a human face to HIV to help reduce fear, myths, stigma and discrimination.

**Target Audience:** Secondary schools and universities, hospitals and clinics, organisations that have not had previous formal training in HIV-related issues (example: Corporate organisations).

**Program Design:** Speakers are trained to talk about their personal experiences of living with HIV. These stories often include messages regarding stigma and discrimination, homophobia, sexuality, social justice and equity, and access to healthcare. Each presentation is tailored for the requesting audience.

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***"The Speakers Bureau is run extremely well. It allows people living with HIV to take an active role in educating the broader community. You can see the changes in attitude that people have after hearing a speaker, it's just magnificent." – Composite Quote***

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## Case Study #2: Positive Leadership Development Institute Australia (PLDI™)

**Purpose:** Offer people living with HIV an opportunity to develop leadership and resilience skills.

**Target Audience:** People living with HIV who have shown emerging potential for leadership and who reflect the diversity of the positive community.

**Program Design:** A weekend workshop facilitated by previous PLDI graduates that aims to identify and build a personal sense of agency and capacity in participants to translate into resilient practices and strengthened community outcomes.

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***"Attending PLDI was an incredibly motivating experience. Very good for personal growth. A massive confidence boost for engaging in the HIV sector." – Composite Quote***

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# COMMUNITIES IMPACTED BY HIV

Asking participants to determine which communities they identify with and which communities are impacted by HIV in Victoria proved to be a controversial topic. A third of respondents stated that HIV impacts everyone in Victoria and that splitting the issue into specific groups is too divisive. The remaining two-thirds of respondents acknowledged that HIV could impact anyone, but that specific communities would benefit from an approach that recognised their unique voice, issues and concerns.

The communities that participants identified as impacted by HIV in Victoria are:

- Gay men and other men who have sex with men (MSM)
- Women
- Heterosexual men
- Culturally and linguistically diverse communities (CALD)
- Aboriginal and Torres Strait Islanders
- Migrants and refugees
- People who use substances
- Sex workers
- International students

The following quotes represent the complexity of engaging communities impacted by HIV:

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*“Every community is touched in some way by HIV, there’s no restrictions. HIV is seen as an MSM disease but it isn’t. LPV should focus more on CALD communities. There’s a lot of discrimination in smaller cultural communities that need targeted education and a place to go.” – Member*

*“It’s hard to consider HIV as one community; the risk is that smaller groups will get less attention. There’s MSM (some gay, some not), other men, women from Sub-Saharan Africa, Asia, Australia. There’s great diversity within smaller cohorts. People are geographically, culturally, sexually, generationally diverse. HIV is skewed to one gender in Victoria, but it affects women incredibly also. Women with HIV have had to fight harder for representation and advocacy.” – Partner Organisation*

*“I’m part of gay and HIV communities and LPV represents both of them well. I don’t know how they could improve.” – Member*

*“Sub-communities need targeted peer support. People living with HIV are disproportionately affected by mental health. We all need peer support with good psychosocial underpinnings to talk about guilt and shame.” - Volunteer*

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# FEEDBACK EXPERIENCES

Giving feedback to Living Positive Victoria has been a mostly positive experience for consultation participants. Respondents identified that they have given feedback to the organisation in the following ways:

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*“They always listen to me.” - Member*

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- Verbal feedback to relevant volunteer, staff, or manager
- Evaluation form upon completion of a program
- Feedback survey following an event or activity
- Participating in a consultation to develop a new initiative

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*“Never had a problem. LPV is always open to listen. Feedback given receives straightforward, transparent answers.” – Composite Quote*

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One-tenth of respondents indicated that the organisation could improve its feedback processes. These five participants expressed concern that, while their feedback appeared to be heard and received, there was no follow-up and no identified change. The respondents requested a more structured, formalised feedback model from the organisation.

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*“Feedback can be interpreted negatively. There’s no real outcomes from feedback given to LPV. It’s understandable that not everything can be fixed but some things can be improved.” – Composite Quote*

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# AREAS OF STRENGTH

According to the respondents, Living Positive Victoria excels at the following:

## 1. Engaging gay men living with HIV

The organisation has an established reputation for providing peer-based support and advocacy to gay men living with HIV. Respondents that identify as gay men living with HIV feel that they are well-represented demographically by the staff and volunteers of Living Positive Victoria and that the organisation can competently advocate on their behalf.

## 2. Providing short-term wellness interventions

Health promotion programs provided by Living Positive Victoria are recognised as being very helpful to the people who attend them. Respondents often mentioned engaging the organisation due to a number of specific issues and feeling those issues were adequately addressed in a program that supported their wellbeing.

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*“Phoenix changed my life. The best weekend I ever spent.” - Member*

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## 3. Communications

Respondents agreed that Living Positive Victoria is a preferred source for up-to-date information on a range of topics related to HIV. The Poslink newsletter is held in high regard and participants stated that they frequent the organisation’s social media pages. There was an acknowledgement that the organisation is very accountable and transparent in its activities through the publication of organisational documents on its website.

## 4. Advocating and campaigning for people living with HIV

Living Positive Victoria’s efforts to advocate for the rights of people living with HIV at a governmental and policy level along with the organisation’s projects that seek to educate the broader community about HIV and other sexually transmitted infections have been noticed and appreciated by respondents.

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*“If you want answers, go to LPV.” - Volunteer*

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## 5. Putting a public face to HIV

Recognition as a peer-led organisation has resulted, based on the respondents, in an organisation that provides genuine and compassionate representation of people living with HIV.

## 6. Leadership within the HIV sector

Partner organisations that participated in consultations have a high regard for Living Positive Victoria. The organisation’s members and volunteers that responded expressed that the organisation is well-placed to inform the work of other organisations that are involved in the response to HIV.

# AREAS OF IMPROVEMENT

The respondents indicated that Living Positive Victoria could improve in the following areas:

## 1. Engaging communities beyond gay men living with HIV

There was agreement that despite the organisational mandate to represent all people living with HIV in Victoria, the organisation has too much of a focus on gay men living with HIV to be completely responsive to other communities impacted by HIV.

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*“Making LPV visible to diverse communities requires a restructuring of services.” - Staff*

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## 2. Mediating between people living with HIV and other support services

As the organisation is well-regarded for its ability to represent the needs and issues of people living with HIV, respondents requested that Living Positive Victoria take an active role in providing health, mental health, sexual health, homeless, migrant and refugee and other support services with information regarding how people living with HIV would prefer to be supported. This area of improvement was shared among all respondent groups.

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*“I’d like to see more effort supporting the mental health issues that can accompany living with a long-term medical condition. I’ve noticed there are a lot of older men that are living with HIV that are very isolated. We need to reach out to these people, as they’re unlikely to come into the LPV office for support.” – Volunteer*

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## 3. Communicating the differences between the Victorian AIDS Council (VAC), the Positive Living Centre (PLC), and Living Positive Victoria

Although Living Positive Victoria separated from the Victorian AIDS Council and the Positive Living Centre to become its own organisation in the 1990’s, there remains confusion about what makes these organisations distinct, how they work in partnership and where their boundaries are.

## 4. Physical accessibility of staff and office space

Living Positive Victoria’s office in Southbank was cited as somewhat inaccessible for communities impacted by HIV. The office’s closure at 5pm Monday-Friday with weekend availability only when a program is scheduled was viewed as inaccessible to people who work full-time.

## 5. Following through on great ideas

Many respondents stated that the organisation often produced great, inspiring ideas to improve the lives of people living with HIV. However, these respondents felt that there occasionally was little follow-up from Living Positive Victoria on these ideas. People acknowledged that the organisation might discuss an idea on social media or mention a new initiative at a meeting but these ideas and initiatives did not lead to tangible outcomes.

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*“Creativity and passion could trickle down more. There’s little follow-up on great ideas. LPV puts a paper out but nothing happens. Follow through would enhance credibility.” – Partner Organisation*

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# RECOMMENDATIONS

Considering the responses from consultation participants and the organisational capacity of Living Positive Victoria, the consultant makes the following recommendations to improve the organisation's community engagement by the end of the current 2014-2017 Strategic Plan:

## 1. Develop Service Maps and Referral Pathways

The current Strategic Plan aims to promote effective health and wellbeing strategies for people living with HIV while also reducing the number of occasions that a member would need direct aid and assistance from Living Positive Victoria. To achieve these objectives and better engage diverse communities, the organisation should develop Service Maps and Referral Pathways. This would involve liaising with hospitals, mental health services, migrant and refugee supports, sexual health clinics, and other community organisations to assess what services can be provided how accessible the services are for people living with HIV. In exchange, the organisation can provide these support services with resources to better serve people living with HIV. This recommendation builds upon Living Positive Victoria's ability to develop strong partnerships and their high regard within the community.

## 2. Offer culturally-specific Peer Support

The term 'peer' within the organisation's current peer support activities predominately means that the person providing support is living with HIV. Peer support has been proven to be incredibly beneficial for people living with HIV. As such, the organisation should seek to engage peers that are representative of diverse communities. Offering people the option to access support provided by a person from their own cultural background and in their preferred language may improve the organisation's ability to engage people from culturally and linguistically diverse communities while providing a vibrant definition of 'peer support'

## 3. Conduct community-based Population Health Research

Living Positive Victoria is frequently asked to promote recruitment for research studies and to report on research findings to their membership. The organisation should go one step further and start conducting its own community-based population health research studies. This can be accomplished in partnership with universities, research institutes, and other organisations. There is great value in a peer-led organisation providing representation on a project's research team from conception to publication. Conducting research would also allow Living Positive Victoria to improve its own programs and to express its members' needs to other organisations from an evidence-based approach.

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***"I haven't had a lot of communication that suggests LPV are holding other services to account for their work with people living with HIV. LPV should be an intermediary that surveys people on their needs and then reports to other organisations."* – Partner Organisation**

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## 4. Offer support outside of current office space and business hours

People working full-time during the week currently find it difficult to access Living Positive Victoria. The organisation should have staff and/or volunteer resources available to people living with HIV on the evenings and weekends. This could be accomplished by a staff member working a PM shift once a week (example: 1pm-9pm), an regular online group that is facilitated on a Saturday, or by having more staff and/or volunteers posted offsite to provide support to communities in a more accessible manner.

## CONCLUSION

The consultations conducted to develop this strategy clearly demonstrated that Living Positive Victoria is comprised of passionate representatives that are entirely committed to working with people living with HIV.

The organisation's current 2015-2016 Business Plan has made a commitment to various community engagement activities that will help achieve the aims identified in this strategy's introduction. As an example, the organisation's commitment to supporting women living with HIV, in Appendix 2 of the 2015-2016 Business Plan, features a multifaceted approach that includes health promotion programs, financial support, women's involvement on program reference groups, partnerships and training.

Similarly, accomplishing the new recommendations presented in this strategy will help the organisation achieve its 2014-2017 Strategic Plan and will allow for greater engagement with all of the communities impacted by HIV in Victoria.

Thank you again to the people who participated in consultations to develop this strategy.

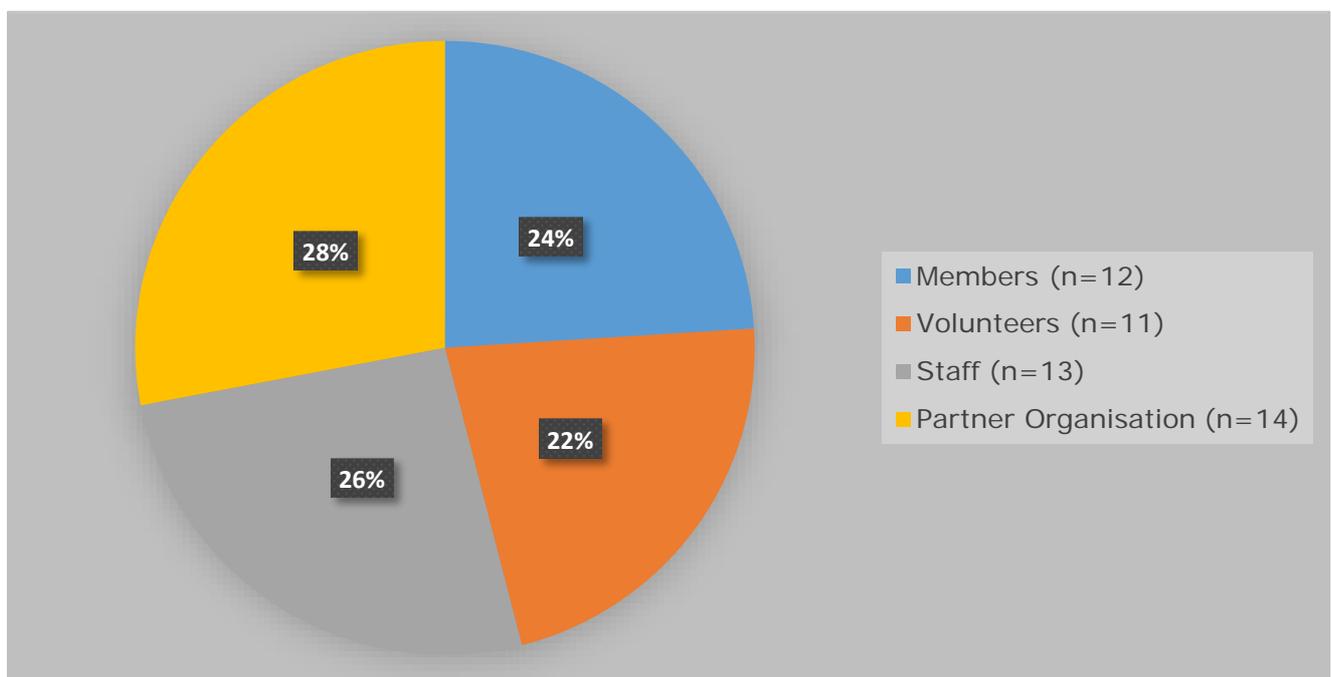
# APPENDIX 1 – METHODOLOGY

## Recruitment & Consent Process

Snowball sampling was utilised to recruit consultation participants. The consultant asked participants to mention the project to people who may be interested in contributing to this strategy, with a focus on recruiting participants from a diverse range of backgrounds. Demographic information (examples: age, gender) was not formally collected to ensure participant anonymity within a small sample size. Each participant signed a consent form that detailed the project, confidentiality, potential benefits and potential discomforts of participation, and how participants could learn of the project's results. Participants chose to be acknowledged by name in the strategy or to remain anonymous. Members and volunteers were compensated with a \$25 grocery voucher.

## Profile of Respondents

Participants in these consultations all had a pre-existing relationship with Living Positive Victoria as members, volunteers, staff, and representatives of partner organisations. Some respondents fit within more than one stakeholder group (example: a member and a volunteer); these respondents were asked by the consultant to primarily identify with one group to determine which question set would be used. Participants identified as:



## Consultation Structure

Respondents contributed to the strategy through individual and small group consultations. Each consultation lasted 45 minutes to one hour and followed a semi-structured interview format whereby a pre-determined set of open-ended questions was combined with the opportunity for the consultant to further explore participant responses. Appendix 2 contains the question sets.

## Data Collection & Analysis

The consultant took detailed notes throughout the consultations. These notes were then entered into NVivo data analysis software to produce visual representations of the data (example: word clouds) to help identify key themes. These themes were presented to the organisation's Board of Directors at their annual retreat to ensure that the strategy's findings fit within the organisation's capacity. Member checking was then utilised as all respondents had five days to provide feedback to a draft version of this strategy.

## APPENDIX 2 – QUESTION SETS

The following universal questions were asked of all consultation participants:

1. What does the term “community engagement” mean to you?
2. What is your understanding of the HIV service and advocacy sector in Victoria?
3. What is Living Positive Victoria’s role within that sector?
4. In your opinion, what is Living Positive Victoria doing well?
5. In your opinion, what could Living Positive Victoria do to improve?
6. How have you provided feedback to Living Positive Victoria?
7. How have you felt about those feedback experiences?

The following questions were tailored to specific stakeholder groups:

### Members

1. How has Living Positive Victoria engaged you personally?
2. How has Living Positive Victoria helped you with HIV-related issues and concerns, if at all?
3. What communities do you identify with?
4. How has Living Positive Victoria engaged those communities, if at all?

### Volunteers

1. As a volunteer, how do you engage with Living Positive Victoria?
2. What has your experience been as a representative of Living Positive Victoria?
3. What communities do you identify with?
4. How has Living Positive Victoria engaged those communities, if at all?

### Staff

1. Please describe your role and duties at Living Positive Victoria.
2. How does your role fit within the organisation’s mission, vision and values?
3. What has your experience been as a representative of Living Positive Victoria?
4. In your opinion, what specific communities are affected by HIV in Victoria?
5. How does Living Positive Victoria engage with the communities you mentioned, if at all?

### Partner Organisations

1. Please describe your organisation’s relationship with Living Positive Victoria.
2. What has your experience been with representatives of Living Positive Victoria?
3. In your opinion, what specific communities are affected by HIV in Victoria?
4. How does Living Positive Victoria engage with the communities you mentioned, if at all?





