



Health
South Eastern Sydney
Local Health District

Stories, Conversations and Consultation

People living with HIV and
implications for future
SESLHD programs and services

Executive Sponsor: Julie Dixon, Director Planning, Population Health and Equity
Directorate of Planning, Population Health and Equity (DPPHE)
South Eastern Sydney Local Health District (SESLHD)

This companion document to the *HIV and Sexual Health Strategy 2019 – 2024* and the *SESLHD HIV and Sexual Health Programs: State of Play 2019* are abbreviated versions of two reports: *People living with HIV community conversations*, December 2017; and, *Stories of living with HIV health service implications report*, Nov 2018, Kath Vaughn Davies (K2 Strategies).

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Executive Summary

This report captures issues that are important to people living with HIV and considers the implications for future SESLHD programs and services. Several mechanisms were used to ensure that the new SESLHD HIV and STI Strategy 2019-2024 is informed by community voices:

Stories of living with HIV – health service implications	Fourteen people from diverse backgrounds recruited through SESLHD health service providers and non-government organisations share their personal stories of living with HIV. These stories are analysed and considered.
People living with HIV – community conversations	Seven in depth group conversations with 53 people living with HIV from across the Sydney metropolitan area. The conversations determined community aspirations, identification of community issues and their solutions.
Client Consultation – service based discussions	Eighteen clients provided reflections on their current service experience of SESLHD HIV and STI services. For further information about these findings please see “SESLHD HIV and Sexual Health Programs: State of Play” report.

Findings – Strengths and Issues

Strengths:

There were many strengths seen in the individuals and communities. There was a clear sense of communities and individuals wanting to be active participants or leaders in solutions and improvements. There was a confidence provided by a history of success in community led action in the HIV communities of Sydney and beyond. There was also clear satisfaction and celebration of the services SESLHD provide.

Issues:

Whilst there are key community and individual strengths, we also found, in some cases unexpected issues or weaknesses. It appears that the community connections of the past have not been maintained, but they are strong foundations to build upon.

Strengths and limitations of this approach

- Three methods of gaining community voice
- Diverse voices were heard both from a demographic perspective and from diagnosis and treatment experiences
- The story approach supported a detailed, deep understanding of the realities and practicalities of living with HIV, from a range of very different perspectives.
- The limitation of our approach was that we did not hear those who are not currently accessing treatment or support for their HIV and there was limited representation from newly diagnosed and young people.
- The findings in this report are intended to be considered with additional evidence sources, including previous consumer/community/client data, peer reviewed evidence and the outcomes of broad consultations completed with health professionals and clients.

Key findings from Stories, Conversations and Consultations

Stories	Community Conversations	Client Consultation
<p>HIV impacts lives day to day across whole of life.</p> <p>For many participants:</p> <ul style="list-style-type: none"> • having HIV has led to significant losses in their lives • impacted on how they feel about themselves, their sense of identity, cognitive strengths, relationships, employment, income, lifestyle, housing, substance use and trauma • experiences and many aspects of physical and mental health • Stigma and discrimination by health services and the broader community • Social isolation 	<p>Significant impact on the daily lives of people living with HIV, including:</p> <ul style="list-style-type: none"> • experiences of social isolation and loss of community • feeling forgotten and left behind, due to a sense that the policy focus on HIV prevention is associated with a shift away from support for people living with HIV • experiences of stigma and discrimination • highlighting of unique issues and challenges experienced by people in different demographic groups e.g. older people, women, culturally and linguistically diverse people 	<p>The importance of specialised HIV and STI services</p> <ul style="list-style-type: none"> • Stigma and access are limitations in the health sector • Disclosure of sexuality and/or HIV status • Limitations in access to gay-friendly services in the outer suburbs of SESLHD

As can be seen from the table above, there was a great deal of convergence around issues. These are reflected in the *Findings* pg 9, which are a synthesis of all the community voices we heard.

Considerations for future: The SESLHD 5-year plan for HIV services

- 1** Develop a targeted HIV health service engagement strategy to improve HIV health service access and engagement by less engaged population groups
- 2** Continue to provide integrated, holistic care for participants whose ability to access and engage with appropriate health care is being negatively affected by a wide range of social determinants of health such as housing, income, employment, interpersonal relationships, substance use and a wide range of comorbid physical, cognitive and mental health issues
- 3** Maintain and create a broader range of opportunities for social connection and social networking for people living with HIV, that meet the unique needs of those who are most socially isolated
- 4** Offer programs to help build resilience in people living with HIV
- 5** Continue to provide trauma-informed, HIV-specific health and community services to meet the unique and complex needs of people with experiences of trauma and abuse
- 6** Maintain and strengthen delivery of holistic, centralised HIV-specific services: broadening services, incorporating general practice, considering telehealth, extending HIV care coordination
- 7** Deliver health professional education and training (including Fellows): how to work respectfully with people with HIV
- 8** Develop an aging and HIV strategy: planning for holistic health and support service delivery as people age, including supporting individuals to plan for aging, incorporating early intervention initiatives to keep people out of hospital and nursing homes for longer noting that stigma and discrimination is still an issue for people living with HIV
- 9** Develop more online access points like live chats online or SMS communication for appointments

1. Introduction

Stories of Living with HIV: this report captures issues that are important to people living with HIV and considers the implications for future programs and services.

1.1 Informing future HIV programs and services

In 2018, South Eastern Sydney Local Health District (SESLHD) Planning, Population Health and Equity Directorate reviewed its models of HIV/STI service and program-delivery, to ensure they are 'fit' for a rapidly changing future context (Box 1). The review included consultations with an extensive range of stakeholders¹ to inform a SESLHD HIV and STI Strategy 2019-2024 (Table 1).

TABLE 1 CORE COMPONENTS OF THE SESLHD 5-YEAR PLAN FOR HIV AND STI SERVICES

Population needs	a map of current and emerging population needs, with particular reference to equity and accessibility across SESLHD
Community-led services	identification of community assets, and opportunities for collaboration and changing the balance of power towards the service user
Models of care	description of proposed models of care and service configurations to address these
Business needs	a plan to address SESLHD priorities for future years including organisational structure, workforce and resources.

As outlined in the SESLHD Community Partnerships Strategy 2015, SESLHD is strongly committed to community engagement, ensuring community voices are genuinely heard and understood, and a shift towards health service co-design and delivery. To inform the SESLHD 5-year Plan for HIV and STI Strategy, a series of consultations using different methodologies were completed with a wide range of clients of SESLHD HIV and STI services. Together, these consultations aimed to ensure that the SESLHD 5-year Plan reflects the current community context for the plan, consumer experiences of programs and services, and consumer and community preferences for delivery of future programs and services.

This report outlines the findings from one of the consumer/ community consultation methodologies: in-depth qualitative interviews to explore people's stories of living with HIV and what those stories might mean for future service delivery.

Box 1 Examples of the changing context of HIV programs and services

- mainstream availability of Pre-Exposure Prophylaxis (PrEP) for HIV prevention
- new approaches to diagnostics, such as home testing options
- new treatment initiatives for STIs
- the changing demographics of people newly diagnosed with HIV
- the changing demographics (including spread of residential locations) of people who are accessing SESLHD HIV services
- a 'wave' of people who are entering older age while living with HIV

¹ Stakeholders consulted during development of the 5-year Plan for HIV Services include: GPs, clinicians, health promoters, allied health staff, Non Government Organisations, the SESLHD Planning Unit, Primary Health Network and service consumers and community members.

1.2 Building on previous community consultations

The stories of living with HIV add to a range of recent consultations undertaken by SESLHD and other organisations, using different methodologies.

As reported in part two of this report - "People Living with HIV - Community Conversations", the Community Partnership Unit coordinated 7 in depth group conversations with 53 people living with HIV from across the Sydney metropolitan area, using the Harwood Method of consultation. The conversations highlighted issues that have a significant impact on the daily lives of people living with HIV, including:

- experiences of social isolation and loss of community
- feeling forgotten and left behind, due to a sense that the policy focus on HIV prevention is associated with a shift away from support for people living with HIV
- experiences of stigma and discrimination
- highlighting of unique issues and challenges experience by people in different demographic groups e.g. older people, women and culturally and linguistically diverse people.

Results from a 2016 survey of people living with HIV indicates that the issues highlighted through the Harwood conversations are experienced by a broader population. The 80 survey respondents ranked the following issues as the highest priorities for Positive Life NSW to address in future:

1. Support to manage ageing, HIV and other multiple chronic health conditions
2. Reduce HIV stigma and discrimination
3. Ensure that health and mainstream services meet needs
4. Address poverty, social isolation and support skills building
5. Reduce late stage HIV/AIDS diagnoses
6. Advocate/Support treatment commencement and adherence
7. Remain motivated and engaged in treatment and care.

1.3 Findings

The challenges of recruiting people with lived experience of HIV reflects the challenges and gaps that SESLHD health services face in engaging some groups of people in accessing and engaging with appropriate health services.

Lived experiences: life with HIV

The day to day impacts of HIV across whole of life

HIV has had far-reaching impacts across all elements of participants' lives, affecting their health and quality of life. For many participants, having HIV has led to significant losses in their lives and has impacted on how they feel about themselves, their sense of identity, cognitive strengths, relationships, employment, income, lifestyle, housing, substance use, trauma experiences and many aspects of physical and mental health. In some cases, these impacts have affected participants' ability to engage with appropriate health services and to access appropriate treatment.

Participant experiences are consistent with published evidence demonstrating clear and significant impacts of HIV on people's daily lives, functioning and health.

Stigma and discrimination

Participants have experienced stigma and discrimination associated with their HIV. Reported examples are in interpersonal settings, when seeking housing or employment and in other settings such as legal contexts.

Stigma and discrimination have been experienced in health services – including in SESLHD. In most cases participants attribute it to the attitudes and behaviour of relatively inexperienced individual health professionals. An example of a discriminatory SESLHD policy was identified.

Participant experiences are consistent with Australian and international research. Addressing stigma and discrimination is a priority. People's perceptions of HIV-related stigma, isolation and discrimination are likely to persist and are associated with isolation and depression.

Tackling stigma requires interventions across the general population (at individual, community and societal levels) and within health services (also at individual, service environment and policy levels).

Social connection and isolation

Some participants are particularly socially isolated and seem especially vulnerable in their physical and mental health. Evidence shows that the quality of social relationships is an important factor in psychosocial wellbeing. Other participants have experienced life-changing benefits from connecting with others with HIV, including benefits for health and quality of life. Others would like to connect more but are unable to find other people with HIV who are 'like them'. Participants identify many opportunities for improving social connection for people living with HIV.

Participants recommend that SESLHD:

- improves the broader population's understanding of HIV
- helps people living with HIV to build their confidence and resilience in the face of discrimination
(e.g. through multi-faceted Activate program and sharing stories)
- strengthens education and training for health professionals (especially those not in HIV-specific services) regarding HIV and how to interact with people living with HIV in a positive and respectful way
- extends health service policies for chronic conditions to people with HIV
(e.g. parking discounts for people with cancer)
- create more opportunities for social connection and social networking with other HIV positive people who are in a similar situation or demographic
- provide ongoing support groups for people living with HIV
- strengthen the breadth of centralised HIV expertise offered by Albion Centre
- enhance client engagement processes
- incorporate telehealth/ e-health models into the mix of options for centralised HIV service delivery
- employ HIV care coordinators
- integrates general practice into Albion Centre
- makes Albion Centre more welcoming for clients who do not identify with demographics of the majority of clients
- offers options for ongoing social connection and support with the HOT team following discharge

Considerations around trauma

Participants' feelings of shame, low self-esteem and experiences of trauma and abuse seem intertwined with their experiences of living with HIV, mental health and resilience in the face of issues like stigma and discrimination. Evidence shows that stressful events and trauma can negatively affect the disease progression of HIV.

Service experiences

Centralised HIV health services

Participants value access to centralised, HIV-specific health services.

In Albion Centre, participants value the co-location of a broad range of HIV-specific services, have confidence in the HIV expertise of health professionals, feel welcomed and understood, value the customer service focus, appreciate the confidentiality of having a pharmacy outside their own local communities, and value the incidental opportunities for social interactions when visiting the centre.

Holistic, personalised care coordination and support

Participants with complex health conditions and life circumstances highly value the services offered by the HOT team. Clients of the service appreciate that the service is HIV-specific; comes to them; is flexible and responsive to the real range of issues affecting their health; provides practical help; and focuses on their personal strengths.

HIV-specific mental health services

Access to HIV-specific mental health services is highly valued by participants across many points in the HIV journey. Such services have had a positive, transformative impact for many.

Services for non-HIV-specific care

Elements of service delivery that contribute to a positive experience for people living with HIV include: services collaborating with a person's HIV team or HIV expertise; health professionals have a highly respectful approach; and service accessibility.

Health professionals' skills and attributes

Positive experiences in health services are attributed by many to the personal attributes and skills of health professionals. Friendly and welcoming attitudes of staff, long-term relationships with health professionals, caring attitudes, and excellent communication skills all contribute to positive experiences. Conversely, disrespectful approaches (including discriminatory ones), high staff turnover, and poor communication skills all contribute to negative experiences.

Participants recommend that SESLHD:

- maintain availability of HIV-specific mental health services
- integrates a broader concept of 'health' into the health service delivery approach
- strengthen support for newly diagnosed people
- strengthen community-based, holistic services
- strengthen sexual health service responses to domestic violence
- provide earlier-stage support (crisis prevention)
- communication skills training for health professionals
- stronger management and training of Fellows
- training for health professionals in how to work respectfully with people with HIV
- helps people to actively plan for their future care (eg aging clinic)
- offer aging-related services earlier to those who need them (based on need, not age)
- continue to offer HIV-specific services as people age with HIV
- develop a plan now for HIV aged care service provision
- consider opportunities for clustering in aged care services, to foster HIV expertise
- advance programs that help build people's resilience, life-skills and social networks
- promotes commitment and responsibility of those enrolled in a program or course to attend and complete the course
- maintain (and increase) the breadth of support services that have been available through BGF in the past
- provide clear, transparent information about which programs and services are available and to whom

The role of general practice

Having a regular GP can help with care coordination for people with multiple health conditions and help streamline communications. However, not all those with a regular GP involve their GP in HIV management. Reasons for this include: previous experiences in which GPs have not had the expertise to manage the complexities of their illness; lack of access to local s100 GPs who are experienced in managing HIV; and the out-of-pocket cost of seeing a GP compared to bulk-billed services.

Services for people as they age

Older people living with HIV are the first generation to age and there are many unknowns. There is fear, anxiety and doubt about the ability of health care and aged care services to meet the needs of people living with HIV in the near future. There is also an awareness that people living with HIV may have aging related complications, such as arthritis and dementia, earlier than the broader population.

A focus now on forward-planning for future aging-related needs is recommended to benefit both individuals and the health system.

Additional programs and support

Additional programs and support services (such as exercise opportunities, life-skills programs, financial support, employment support, and social opportunities) have a significant impact on participants' lives and are highly valued.

Finding out about available programs, services and supports

People living with HIV find it difficult to access information about programs, services and supports that might be available to them.

Health systems challenges

Challenges in the health system have a significant impact on people's experiences of health services and access to appropriate health care. These include the out-of-pocket costs associated with medication for people with chronic, complex conditions and referral systems that require additional GP involvement.

Participants recommend that SESLHD:

- offer a system where relevant services contact previous or potential clients, to see if they might want to use the service
- offer a system where services can access your records from other services
- provide regular communication (e.g. newsletter) from health service units to regular clients
- communicate broadly about all of the available programs, services and supports across organisations.

2. Approach to collecting stories about living with HIV

Conducted by an independent specialist in client/patient story collection and analysis. Support was provided by the Community Partnership Unit and governance by a multidisciplinary Working group (of consumer representatives and health service providers).

2.1 Overview of the approach and governance

Planning, capturing and reporting on stories of people living with HIV was completed between June and October 2018. Figure 1 summarises the overall process used.

FIGURE 1 THE APPROACH TO COLLECTING STORIES OF LIVING WITH HIV

STEP	DETAIL	OUTPUT
GOVERNANCE	Working group meeting 1 – approach & interview questions	Consultation plan, information & consent forms, interview discussion guide
RECRUITMENT	Service providers ² recruit interview participants; interviewer books interviews ³	Consented interview participants
INTERVIEWS	14 telephone interviews (average 1-1.5 hours long) Participant wellbeing call and participant payment	Participant's written stories
ANALYSIS & REPORT PREPARATION	Qualitative thematic analysis Synthesis into a succinct report	Draft report
GOVERNANCE	Working group meeting 2 – implications of findings for programs & services	Implications, integrated into final report

² Albion Centre, HIV Outreach Team, Sydney Sexual Health Centre, Positive Life, & HIV/AIDS & Related Programs Unit

³ One third (n=7) of the consented participants were lost at this stage: they did not attend their scheduled interview or did not respond to attempts to book the interview

2.2 Benefits and limitations of the approach

The report produces information that is intended to be considered in the context of many different evidence sources, including outcomes of broader consultations with a much larger number of SESLHD health service users and health professionals involved in providing HIV care (via a broad-reaching, 9-month consultation project to inform SESLHD HIV and STI Strategy 2019-2024).

The project approach supported a detailed, deep understanding of the realities and practicalities of living with HIV, from a range of very different perspectives. The depth of understanding is important for informing future programs and services that will meet people's real-life needs.

While the approach supports identification of a wide range of issues affecting people living with HIV, it does not identify how common those issues are for people living with HIV. Therefore, the report deliberately avoids mentioning how many participants hold a certain perspective or have experienced an issue – numbers are meaningless in this context. To help mitigate this, key findings were considered in the context of additional information sources and evidence, including broader surveys of people living with HIV.

Many of the participants seem to be living with unique and complex health-related needs and situations. For the most part, they have also been living with HIV for quite some time (an average of 21 years). The perspectives of a broader spectrum of people living with HIV, including those of very healthy people and of newly diagnosed people, may be different from those represented in this report. The recruitment approach relied on people attending a SESLHD service. Therefore, the report also does not include perspectives of individuals who are not currently accessing treatment or support for their HIV.

Insights into the benefits and challenges of the larger HIV-specific services within SESLHD are included in this report. Experiences of some of the smaller SESLHD HIV-specific services are not represented and could differ from experiences in the services discussed in this report.

3. About the participants

14 people with diverse characteristics and experiences shared their stories of living with HIV.

3.1 An interesting, diverse group of people

A diverse group of people with a range of different backgrounds, interests and passions shared their stories of living with HIV. Participants have a range of **strengths**, **activities that bring them joy** and **passions** (Figure 2).

FIGURE 2 PARTICIPANTS' **STRENGTHS**, **ACTIVITIES THEY ENJOY** AND **PASSIONS**



3.2 Snapshot of participant demographics

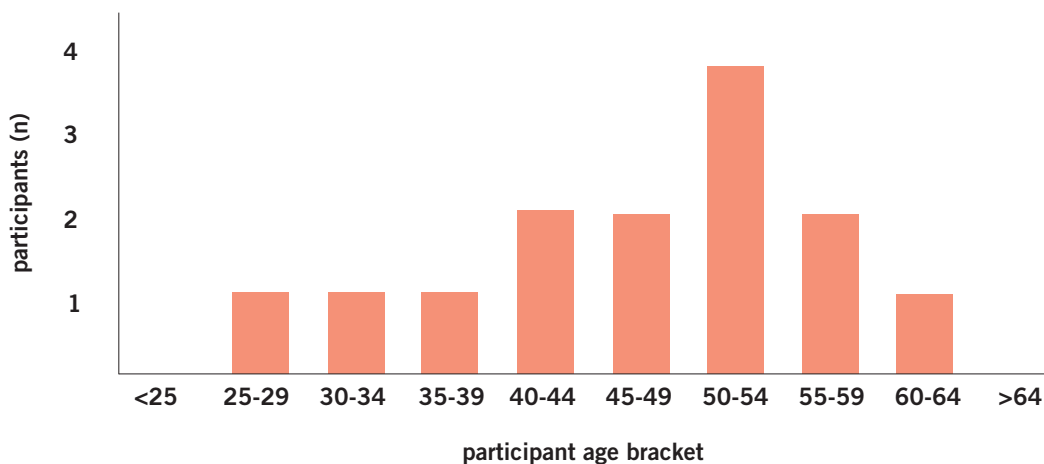
Gender

Participants included: 2 females; 10 males; 2 people who identified as gender queer/fluid.

Age

Participants ranged in age from late twenties to early sixties, with an average age of 48 years

FIGURE 3 PARTICIPANT AGE DISTRIBUTION



Sexual orientation

Participants identified as: heterosexual (n=4); gay (n=8); queer (n=1); not specified (n=1).

Residential area

12 participants currently live within the SESLHD boundaries and 2 live outside them.

Country of origin and cultural identity

10 participants were from Australia (including 3 who had some Aboriginal heritage), 1 was from New Zealand, 2 were from Thailand and 1 was from Brazil.

HIV diagnosis and treatment

The number of years since participants' HIV diagnosis ranges from 5 to 34 years, with an average of 21 years. Four had been diagnosed in the 1980s, 2 in the 1990s, 4 in the 2000s and 4 since 2010. One participant had been born with HIV. Most (n=10) believe their HIV was diagnosed relatively early. Participants have had a range of treatment experiences. Some lived with HIV for many years before treatment became available; some had avoided treatment for many years; and others had started treatment as soon as they were diagnosed.

Other health issues

Many participants spoke about a wide range of health issues that they're managing in addition to their HIV.

These include: mental health, substance use, joint health, dental health, cardiovascular conditions, cognitive function, hepatitis C, gall bladder problems, deep vein thrombosis, autoimmune conditions and accident injuries.

Many issues appear to be linked to, or exacerbated by, HIV and HIV treatment.

Participants' exposure to SESLHD HIV services

All participants had recent exposure to at least one service within the SESLHD region. The number of participants with recent exposure to each of the key SESLHD HIV services is listed in Table 2.

TABLE 2 NUMBER OF PARTICIPANTS WHO HAVE ACCESSED SERVICES IN THE SESLHD REGION IN THE LAST YEAR

HIV Outreach Team (HOT team)	8 accessed the HOT team
Albion Centre	8 accessed Albion Centre
Prince of Wales Hospital	2 accessed Prince of Wales (HIV services and beyond)
Sydney Sexual Health Centre	2 accessed Sydney Sexual Health Centre
St Vincent's Hospital	5 accessed St Vincent's Hospital (HIV services and beyond)
Holdsworth House	2 accessed Holdsworth House
East Sydney Doctors	3 accessed East Sydney Doctors

3.3 Considerations for future

It was challenging to recruit participants from some backgrounds to take part in sharing their stories. Consequently, the experiences of some groups of people are missing from the report. These include the experiences of newly diagnosed people, young people, people from middle eastern and African backgrounds, people with current significant drug and alcohol issues, people who are transsexual and people who are not currently accessing services for their HIV.

The challenges and gaps in participation appear to reflect the challenges and gaps that SESLHD health services face in engaging some groups of people in accessing and engaging with appropriate health services.

People living with HIV community conversations

Community Aspirations, Issues and Solutions

December 2017

Over a year from December 2016 to 2017, we have had seven in depth group conversations with 53 people living with HIV from across the Sydney metropolitan area.

As people spoke about the community they want:

They wrestled deeply with what the concept of community meant for them and identified aspirations for their “place” in the wider community, and in the HIV community – that is, the community created through people living with HIV interacting with each other.

- **For the wider community:**
 - People want a community which is inclusive and accepts people as they are, even if they are different from others, without stigma or discrimination, in which they can experience respect, empowerment and participate and engage meaningfully.
- **For the community created through people living with HIV interacting with each other:**
 - People described a community that is rich in its own diversity and complexity.
 - People want this community to be able to communicate and relate in a united way. They want people of different backgrounds and experiences to be able to connect with, understand and learn from each other, while also acknowledging the aspirations and needs specific to each of the community's sub-groups.
 - All sub-groups wanted safe spaces where they can gather for mutual support and social interaction.

Main concerns seen as barriers to achieving these aspirations

The following main concerns were common across all sub-groups.

1. Social isolation and loss of community

People shared that living with HIV has both initial and ongoing social and emotional impact. Unless this reality is genuinely acknowledged and adequately supported, social isolation becomes a considerable risk:

- *"You feel alone- after speaking to a counsellor and after you leave the room...you still feel alone".*
- *"You feel alone because you don't know who to talk to. Health workers don't always understand because they are not HIV positive themselves."*

People felt that the strength and vibrancy of the community has diminished in recent years. For example, the community was visibly present in Oxford Street throughout the 1980s and 1990s, but has since disappeared.

- *"You could go out to certain pubs and clubs at any time of the day or night and you'd find friends and support and people to talk to [about your shared interests and experiences]"*.

People felt there are fewer opportunities to connect through organised social events; and/or reported that when social events do occur, few people know about them. They felt that increased access to a physical (hub or drop in) space, rather than to digital space, would foster stronger social connections. They wanted more community events which target specific sub-groups, for example events for older people, alcohol and drug free events, or events specifically for women:

- *"A place to go where there are no labels, you are seen as a human being."*

2. Being left behind and forgotten

People were concerned about being left behind or forgotten by the broader community, service providers and government. They felt that the focus of the state government's current HIV Strategy on prevention of new infections conveys the message that the issue of HIV has been addressed and resolved; and has shifted resources and empathy away from people living with HIV:

- *"The focus is now on prevention, which means the people living with HIV for a while have been left out."*

People felt that holistic social services are required, and must include more than medical care. In the context of limited resources, clear pathways for health and social services are required, along with support to navigate these pathways, for example using peer workers or volunteers. People also reported a desire to have a voice; and to be considered valued members of the broader community.

3. Stigma and discrimination

People were concerned about ongoing stigma and discrimination around HIV. While all sub-groups described the damage done by HIV-related stigma and discrimination, the impacts were reported to manifest differently across different sub-groups. There was clear evidence of internalised stigma:

- *"I felt like a bag of toxic waste [after receiving my diagnosis]."*

Stigma and discrimination are linked to concerns about disclosure of HIV status, which was seen to limit people's opportunities in many aspects of their lives:

- *"Those with power are stigmatising and those without are powerless to do anything about it."*
- *"HIV is always a hurdle. The challenges of disclosure prevent you from making new friends, applying for jobs, accessing good housing. No matter what, HIV is always there. Even if it's invisible it can't be ignored."*

- *"I told my son to not tell his mates [about my HIV positive status] because they won't understand."*
- *"You can't tell your friends about dating. They tell you not to date as you have HIV."*
- *"[HIV-related stigma and discrimination] limit opportunities that other people take for granted."*

Lack of affordable, accessible, safe and appropriate housing was highlighted. Some people reported their only housing options to be dysfunctional and unsafe:

- *"[Public housing] throws a lot of troubled people together" and encourages "constant surveillance by police."*
- *"[Living in public housing] you feel like you're not part of a community at all."*
- *"Where I live [in public housing] it's Murphy's Law – if anything can go wrong it will."*

People felt that although awareness and education about HIV has decreased in recent years, it is still required. Education was considered necessary, especially for specific parts of the broader community, such as aged care service providers.

Specific issues and actions

As people talked about their concerns, different sub-groups identified specific issues, and actions to address them.

Women

Women living with HIV want a sense of belonging, respect and empowerment within an inclusive community. But they are concerned that the following barriers stand in the way of achieving those aspirations: a loss of connection with community; social isolation; and a feeling of neglect by the broader community; and ongoing HIV-related stigma and discrimination.

As women living with HIV talk about these concerns, they talk specifically about their lack of opportunities to connect and be together; a lack of focus of services on HIV positive women's specific issues such as pregnancy; protecting their children from stigma and discrimination; and their vulnerability with regards to psychological abuse and domestic violence. They believe we should focus on providing women with opportunities to be together in safe spaces for socialisation and pampering; establishing peer support workers; and reorienting or establishing services to provide holistic psychosocial support in a women/family friendly way. Pozhets and Leichhardt Women's were specifically identified as trusted organisations.

Older people living with HIV

Older people living with HIV want to have a sense of belonging and to feel included and accepted within the community of people living with HIV. But they are concerned that as they age, they become less visible and more socially isolated. This is due to economic hardship and a lack of age appropriate social and emotional supports:

- *"We don't see each other like we once did."*

As older people living with HIV talk about their concerns, they talk specifically about feeling unwelcome at social events; that services are tailored towards the younger person; that their opinions and experience are not acknowledged; and the general lack of understanding about the lived experience of ageing with HIV, e.g., complex health issues due to chronic illness; loss of many friends; and estrangement from families. Additionally, they feel that services have reduced the range of social opportunities made available to their clients; and that communication about specific social events is poor, isolating people who do not access social media or online resources.

They believe provision of a peer-led, daytime, outdoor-oriented, free of charge drop-in space specifically for older people would be of benefit. Likewise, a widely-advertised forum designed to share the results of these conversations and to raise awareness about HIV and ageing would be a positive initiative. Such events should be held in venues where people feel comfortable, and must ensure that community voices were not overpowered by agendas of existing services. There was strong and consistent support of Positive Life, PozHets, the HIV Outreach Team, the Albion centre, NSW Health and Ankali as trusted organisations. People with 'lived experience' were also deemed by conversation participants as credible and trustworthy.

Culturally and linguistically diverse community members living with HIV

People from culturally and linguistically diverse backgrounds want a safe place to be accepted, regardless of HIV status. This need was particularly pressing for people who arrived in Australia as refugees, who face the additional fear that disclosure of their HIV status may compromise their refugee status. They are concerned about their cultural community learning their HIV status. As people talk about this concern, they talk specifically about avoiding interaction with their cultural community out of fear:

- *“Asian women don’t want other Asian women to know they are HIV positive.”*

One man who arrived as a refugee described the positive experience he had with Australian immigration and refugee health services, who accepted his HIV status, in stark contrast to health authorities in his own country of origin.

Due to a lack of time, this conversation did not discuss the actions required to address participants’ concerns, nor the organisations they considered trustworthy.



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