



HIV & AGEING FORUM

Community Engagement and
Consultation Report

APRIL 2019

Executive Summary

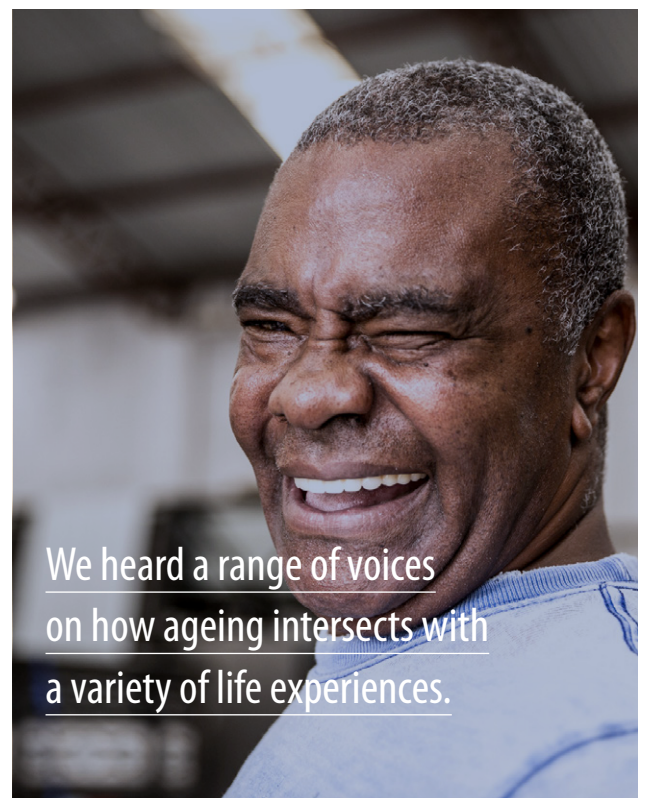
The community consultation was an opportunity for Positive Life NSW (Positive Life) staff and board members to engage and consult with people living with HIV (PLHIV) and our partners, friends and family on the multiple issues and impacts of HIV and ageing. The forum created a safe space and an opportunity for us to reflect on and validate the range of experiences of our peers in the context of the impact of ageing. It highlighted and clarified that HIV impacts PLHIV through ageing, financially, socially and across healthcare needs. We heard a range of voices from the different groups of PLHIV on how ageing intersects with a variety of life experiences and how we maintain our independence, dignity and self-care, in the face of inevitable frailty and decline.

Concerns about ageing with HIV

Many participants living with HIV shared their concerns and challenges about ageing with HIV. These themes were around maintaining dignity and privacy throughout ageing, and the protective factors of friendship and connection we actively seek to mitigate the impacts of ageing with HIV. Community members shared personal experiences which highlighted the issues of intersectionality between disability, mental health, independence, dignity and privacy concerns against a backdrop of pill-burden, adherence, financial and security concerns. Positive Life staff provided details about upcoming work which aims to gain an insight into ageing with HIV and how we might be able to meet these challenges as both an agency, and as a community.

Ageing with HIV Research

Data titled *Ageing with HIV* from the HIV Futures 8 provided by Jennifer Power, Senior Research Fellow at the Australian Research Centre in Sex, Health and Society, confirmed both a steady increase of PLHIV in Australia as well as a steady increase in the group of PLHIV 50 years and over. This data, presented by Brent Clifton, Positive Life Board Director, demonstrated that PLHIV 50 years and over were more likely to report significant financial stress, an increased decline in physical health, and an increased range of co-morbidities. Despite this, PLHIV aged 65 and older reported a higher overall sense of wellbeing than any other group and reasons for this remain unclear.



We heard a range of voices
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PLHIV use a range of approaches in our efforts to age well with social connections (friends), diet and exercise and acceptance, being the top three strategies. Intimacy, sex and love, rate high in PLHIV endeavours to mediate the impacts of ageing. Activities that PLHIV engage in to support the process of ageing well include physical expressions like hugs, intimacy and exercise. Other supports included meditation and attitudes like 'relax', 'letting things go' and holding 'no grudges'.

While all participants mentioned the challenges and anticipated fading of health and vigour as we age, discussion during the forum was unexpectedly upbeat and included many strategies and examples of PLHIV maintaining control throughout this inevitable decline.

the forum and the room was laid out with chairs surrounding large circular tables with the aim of encouraging inclusion, discussion and to contribute to the free-flowing conversation dynamic amongst all participants. The forum was held at the Adina Hotel at Railway Square, so people could easily attend the forum and access the venue via public transport (buses, trains, light rail, Uber, taxi etc.).

Positive Life CEO, Craig Cooper welcomed forum attendees, followed by Aunty Ann Weldon who conducted a Welcome to Country. Positive Life Communications and Policy Officer, Bella Bushby, introduced the function and use of the Mentimeter www.mentimeter.com and invited attendees to share their thoughts, experiences and impressions through a variety of methods anonymously, including a mobile number to text questions through to a staff member. She posed the first question of the forum: *Describe your concerns about ageing with HIV?* Participants were invited to offer as many words, as many times as they chose, without restriction throughout the first half of the forum to populate a Word Cloud. Support was offered for people who didn't have access to mobile phone or were unable to use one. 50 responses were received in total which is an average of 1.7 entries per person.



Positive Life Consultant and Special Representative, long-term community elder and person living with HIV, Lance Feeney, set the scene of the community consultation for attendees, whereby a sizable and growing proportion of PLHIV in New South Wales are 65 years and over. He discussed this in terms of the Australian Commonwealth Home Support Program *My Aged Care*, where PLHIV 65 years and over (Aboriginal and Torres Strait Islander PLHIV 50 years and older) are eligible to access services to live as independently as possible for as long as possible in their own home.

Lance referred to three main pieces of work that Positive Life is planning to investigate in the needs of PLHIV and ageing. He briefly outlined the first piece of work being an upcoming Positive Life Ageing Survey which will be a national survey targeting PLHIV, carers, partners, family, service providers, aged care service providers in home-care and facilities. This survey will then provide data of PLHIV who are ageing which will feed into Positive Life's second piece of work which will be a submission into the Royal Commission into Aged Care Quality and Safety. The third piece of work titled the Silver Warriors programme will be to assist PLHIV in navigating the aged care system.

Three community members shared their 'rapid-fire' personal experiences and thoughts over the next fifteen minutes. Community member Tim Moffitt, an Aboriginal gay man living with HIV and living with a physical disability, spoke about his interactions with service providers, the challenge of medication adherence and the side effects. He briefly shared an experience of undesirable side effects of medication (*peripheral neuropathy*) which has caused him to reflect on the tenuous nature of his independence living with a physical disability. He spoke about his main concern of remaining connected with his community. He also shared his worries of being admitted to a nursing home in his older years, and being exposed to religion or religious values that may influence the staff and their practice of caring for him. He also shared how his HIV may not be the cause of his primary issues, rather he feels his mental health holds more influence than his experience of HIV.

The forum highlighted and clarified that HIV impacts PLHIV through ageing, financially, socially and across healthcare needs.

Positive Life Board Director Stephen Lunny spoke of his personal experience as a gay man where he feels his experience of HIV is 'relatively good', a testament to his experience of living with HIV in the era of antiretrovirals and reasonably good health. He shared how preparing for the forum had prompted him to think more personally about ageing with HIV. His main concern is about maintaining self-care in the face of illness and frailty, and in keeping his dignity, while avoiding stigma of his sexuality and HIV. He said he'd begun considering strategies to manage his future security surrounding ageing, such as increasing his superannuation contributions.

Community member and elder, John Waterstreet, shared his relatively positive experience of being an older gay man living with HIV in the Blue Mountains, where he enjoys living in his community where the average age is 65 years or older. He described the NDIS scheme as ageist and very difficult to access or navigate. He spoke about an increasing pill burden, of which he is now up to 13 pills a day, yet he feels his ability to maintain adherence is good. As a vocal patient, familiar with challenging his clinicians, John described his life as active, sociable and engaging. He expressed his intention to live a full long life to at least an age of 106.

around the shortage of services and the variation of limited access for PLHIV across segments, culture, ethnicity and language, gender and sexuality. While all 'rapid-fire' presenters and numerous participants mentioned the challenges and anticipated fading of health and vigour as we age, discussion during the forum was surprisingly upbeat, and included laughter, humour and many shared strategies and examples of PLHIV maintaining control throughout this inevitable part of life of ageing.

How do you age well?

Montimeter

A word cloud visualization of responses to the question 'How do you age well?'. The words are arranged in a circular pattern, with larger words indicating higher frequency. The most prominent words are 'connection', 'exercise', 'diet', 'social connection', 'friends', 'eat well', 'acceptance', 'love', 'pets', 'sex', 'information', 'pride', 'employment', 'happiness', 'enough money', 'lower stress', 'stay up to date', 'brain exercise', 'intimacy', 'don't give s dc', 'give up smoking', 'honour', 'enjoyment', 'stable housings', 'food', 'good sleep', 'meditation', 'humour', 'hot-sex', 'healthy food', 'laughter', 'elder abuse', 'hobbies', 'dignity', 'self love', 'socialise', 'practice', 'dv family violence', 'healthy relationship', and 'pride'. The words are color-coded: blue for 'connection', 'exercise', 'diet', 'social connection', 'friends', 'eat well', 'acceptance', 'love', 'pets', 'sex', 'information', 'pride', 'employment', 'happiness', 'enough money', 'lower stress', 'stay up to date', 'brain exercise', 'intimacy', 'don't give s dc', 'give up smoking', 'honour', 'enjoyment', 'stable housings', 'food', 'good sleep', 'meditation', 'humour', 'hot-sex', 'healthy food', 'laughter', 'elder abuse', 'hobbies', 'dignity', 'self love', 'socialise', 'practice', 'dv family violence', 'healthy relationship', and 'pride'. The words are color-coded: blue for 'connection', 'exercise', 'diet', 'social connection', 'friends', 'eat well', 'acceptance', 'love', 'pets', 'sex', 'information', 'pride', 'employment', 'happiness', 'enough money', 'lower stress', 'stay up to date', 'brain exercise', 'intimacy', 'don't give s dc', 'give up smoking', 'honour', 'enjoyment', 'stable housings', 'food', 'good sleep', 'meditation', 'humour', 'hot-sex', 'healthy food', 'laughter', 'elder abuse', 'hobbies', 'dignity', 'self love', 'socialise', 'practice', 'dv family violence', 'healthy relationship', and 'pride'.

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Brent Clifton, Positive Life Board Director and Kirby Project Officer in the HIV Epidemiology and Prevention Program, presented data titled *Ageing with HIV* provided by Jennifer Power, Senior Research Fellow at the Australian Research Centre in Sex, Health and Society. The presentation drew on data from the eighth survey of PLHIV in Australia, the HIV Futures Survey, which has been repeated every 2–3 years since 1997.

The data quickly establishes the fact that from 1997 to 2015, there has been both a steady increase of PLHIV in Australia as well as a steady increase in the group of PLHIV aged 50 years and over. This also highlights the steady increase in the length of time people have been living with a daily treatment regimen of antiretroviral drugs.

HIV Futures 8

- Data for HIV Futures collected between July 2015 and June 2016
- Survey completed online or hardcopy
- Study advertised through PLHIV organisations, PLHIV networks, clinics and other services, online (social media, website advertising)
- 895 participants.



Ageing population of PLHIV



The presentation unpacked attitudes to ageing by PLHIV, questions of the impact of co-morbidities associated with ageing and the impact of financial stress on PLHIV engagement with healthcare.

Health, wellbeing and aging

		<35 years	35-49 years	50-64 years	65+ years	Total
		%				
Overall sense of wellbeing	Excellent/ good	61.8	58.8	58.5	69.9	60.7
	Fair/poor	38.2	41.2	41.5	30.1	39.3
Physical Health	Excellent/very good	69.9	61.3	47.6	51.6	55.2
	Good	19.4	26.6	28.6	25.8	26.5
	Fair/poor	10.7	12.0	23.8	22.6	18.3

Support and wellbeing

- Higher levels of perceived social support were linked to **greater emotional wellbeing**, **higher resilience** and **better physical health**
- PLHIV aged 65 years or older reported the *highest* levels of perceived social support of all age groups (significantly higher than people aged 45-64)
- The reasons for this are unclear

Older PLHIV (the 50-64 age bracket) were unsurprisingly more likely to report poorer physical health compared to younger PLHIV (the 35-49 age bracket). Despite this, PLHIV aged 65 and older reported a higher overall sense of wellbeing than any other group and reasons for this remain unclear. This is in keeping with the general Australia population that even though physical health may decline, people tend to become happier with age.

Aging and co-morbidities

	Ever been diagnosed		Currently receiving treatment	
	Aged <50 (N=377)	Age 50 or over (N=485)	Aged <50 (N=377)	Age 50 or over (N=485)
	%(n)			
Hypertension	7.7 (29)	27.2 (132)	5.8 (22)	25.1 (122)
Arthritis	6.6 (25)	26.6 (129)	2.4 (9)	12.8 (62)
Hepatitis B	3.2 (12)	20.8 (101)	1.1 (4)	3.1 (15)
Cardiovascular disease	2.4 (9)	17.7 (86)	1.3 (5)	15.3 (74)
Asthma	17.5 (66)	17.1 (83)	8.8 (33)	11.3 (55)
Hepatitis C	10.6 (40)	13.2 (64)	2.6 (10)	2.3 (11)
Cancers				
Prostate cancer	<1 (1)	2.3 (11)	0	1.0 (5)
Breast cancer	0	<1 (1)	0	0
Other cancer	4.5 (17)	14.6 (71)	1.3 (5)	1.2 (6)

Financial stress

- Participants aged over 50 years were significantly more likely to report experiencing significant financial stress than those under 50
- Financial stress is associated with poorer health and lower levels of social support.
- Participants who had experienced significant financial stress were 'more likely' than those reporting low or no financial stress to report:
 - difficulties 'traveling to places they need to go'
 - difficulties 'paying for specialist medical services'
 - having experienced 'long waiting lists' when accessing specialist services
 - having 'experienced discrimination' in a healthcare context
 - feel 'less capable of engaging actively with healthcare providers' and have lower capacity to navigate the healthcare system.



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The data shows significant increases of PLHIV aged 50 or older diagnosed with one or more health conditions. Hypertension, arthritis and chronic Hepatitis B are the top three comorbidities affecting PLHIV, followed closely by cardiovascular disease, asthma and Hepatitis C. Financial stress impacts PLHIV aged 50 and over by reducing access to specialist health services, both in terms of paying the bills and meeting travel expenses. PLHIV aged 50 and over who experience financial stress also reported they feel 'less capable of engaging actively with healthcare providers', experience discrimination in clinical environments and feel they have a lower capacity to navigate the healthcare system.

Jennifer's presentation showed that HIV impacts PLHIV through ageing, financially, socially and across healthcare needs. PLHIV diagnosed prior to 1996/1997 are likely to experience more negative impacts on their financial security as well as their long-term health, given the previous lack of effective treatments. Stigma, especially within clinical settings, impacts our access to timely appropriate healthcare intervention and supports, and negatively affects the health of ageing PLHIV. Evidence from HIV Futures studies suggests that PLHIV experience ageing challenges due to the social impact of living with HIV, rather than HIV directly, an observation supported by accounts shared in the forum so far.

After conclusion of this research component, Craig continued to facilitate discussion between participants. Discussion focused on the reality that 'one size does not fit all' and reflects how different groups of PLHIV demonstrate considerably different reactions and responses to living with HIV, depending on era of diagnosis, length of time lived with HIV and length of time living with HIV before starting treatment. Participants discussed the anomaly between ageing, poorer physical health and increased wellbeing, and how this might be explained beyond perspective and maturity. Attendees reflected on the fact that some PLHIV '*don't wear it so heavily*' as others. Some are part of a resilient group of PLHIV and are well informed, have the luxury of living and/or working in the HIV sector, and experience little to no stigma, while others remain unaware of the social networks, live with increasing HIV-associated neurocognitive disorders (HAND), impairment or social isolation as well as declining mental health. Questions were raised around the profile of the health of women living with HIV (WLHIV) in HIV Futures, and it was discussed that WLHIV experience higher rates of mental ill-health, such as depression or anxiety.

Participants suggested greater awareness and strategies to overcome fears of connecting and attending social events. One participant said, “*I didn’t go to a HIV thing for 13 years*”. There was a general discussion of the various networks and partners already engaged with Positive Life and the positive community, along with suggestions for overcoming barriers and hurdles of reach and funding limitations. Bella posed the third interactive Menti Meter question: *What will help you age well?* Again, participants were invited to anonymously submit, without restriction, as many times as they liked, into the word cloud. 24 responses were received in all.



Discussion ranged from the perceived pressures around today's narrative of HIV, the trauma of being diagnosed young with HIV and the fears of rejection. The benefits of being diagnosed today compared to 15-25 years ago were also emphasized; 'we get over it – been through the worse'. Participants shared personal impacts of poverty, which reduces the opportunity to connect with other PLHIV, including travel to access medical care. The power of personal stories was resoundingly acknowledged by participants as a strategy to raise awareness, not only about living with HIV with a broader audience, but within the communities of PLHIV to raise awareness of the wide range of experiences we have across factors like gender, cultural and ethnic, socio-economic, geographical location, age of diagnosis, length of time living with HIV, and more. Participants reflected on the benefits of distance from grief and the strength of developing resilience, a positive attitude, humour and social connections, compared to the fears and stigma of mainstream society, especially for those diagnosed late, who have been living with the long-term effects of HIV without diagnosis and treatment.

In closing, participants commented on a range of strategies to growing older with HIV along the lines of *"adjusting to letting go"*, and *"reaching out to each other in the community"*. Craig clarified that the notes and word clouds will become part of the forum report and will be distributed to community, that the Silver Warriors program will soon be finalised and that the Ageing Survey will also be shortly finalised and launched across Australia. Forum participants unanimously agreed that Positive Life should lobby for PLHIV to the Commonwealth for early/priority access to Aged Care due to multi-morbidities, pre-mature ageing, and so forth. Positive Life is immensely thankful for the people who attended and supported the forum, in particular, our brave peers who shared their stories and strategies to maintain our independence as we age with HIV.

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Appendix A

Mentimeter questions:

1. Described your concerns about ageing with HIV?
2. How do you age well?
3. What will help you age well?

Forum prompts or questions

Individual experience and feedback:

1. What is your understanding of ageing with HIV?
2. How does ageing with HIV impact on you? What is your experience? Health, relationally, socially, psychologically, culturally, spiritually etc.
3. How do you maintain your self-determination and self-esteem in the face of HIV and ageing?
4. How do you cope with and respond to HIV and ageing? (solutions, options)
5. How we remain socially active and connected as we age?
6. As an older person, what will you need to live a quality life as you age?

Health system and contextual:

7. Does ageing make it harder to access, navigate and remain engaged in the HIV treatment and care? Please tell us about your story or experience? What has been your experience?

Discussion:

8. What is your experiences of elderly abuse, HIV stigma and discrimination, trauma, grief, multi-morbidities, aged care options reality and experience?
9. Have you experienced any hurdles or barriers living with HIV as you age? How have you dealt with these? What are your strategies to navigate or overcome these?
10. Can you share how you remain socially active and connected with HIV as you are aging? How does this impact your life?

Forum participants unanimously agreed
that Positive Life should lobby for PLHIV, for
early/priority access to Aged Care.



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PositiveLifeNSW
the voice of people with HIV since 1988