

Community report

People living with HIV accessing NSW Aged Care Services



Dedication

In memory of the Australian people who lived with HIV in earlier years and who did not have the opportunity to survive into old age. On their shoulders we now stand!

Acknowledgements

Positive Life NSW would like to thank the people living with HIV (PLHIV), their partners and caregivers, including the HIV service providers in NSW who took the time to participate in the consultation and share their thoughts and fears about PLHIV growing older with HIV and aged care.

Author: Lance Feeney, Senior Policy Consultant to Positive Life NSW

Editor: Craig Andrews, Communications Manager, Positive Life NSW

Reviewers: Bella Bushby, Health Promotion Officer, Positive Life NSW. Jane Costello, CEO, Positive Life NSW. Liz Sutherland, Senior Policy Officer, Positive Life NSW

Positive Life NSW would like to acknowledge and thank the following academics, clinicians, and individuals for their contributions to this study:

- Leo Barreto, Program Manager, HIV Outreach Team
- Dr Lucette A Cysique, Senior Lecturer, University of New South Wales
- Neil Fraser, Deputy Chief Executive Officer, Positive Life NSW
- Dr Richard Gray, Senior Research Fellow, Surveillance, Evaluation, and Research Program, Kirby Institute, University of New South Wales
- Ruth Hennessy, Psychology Unit Manager/Senior Clinical Psychologist, the Albion Centre
- Dr Eva Jackson, Clinical Director, Nepean Blue Mountains Sexual Health & HIV Clinics
- Associate Professor Limin Mao, Centre for Social Research in Health, University of New South Wales
- Associate Professor Kathy Petoumenos, Biostatistics and Database Program, Kirby Institute, University of New South Wales
- Dr Jennifer Power PhD, Senior Research Fellow, Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne
- Dr John Rule, National Research Manager, National Association of People with HIV Australia.

Further Information

For further information on this community survey report, please contact:

Email: contact@positivelife.org.au Phone: (02) 9206 2177

Images used in this publication are sourced stock photography and are used for illustrative purposes. They do not imply any particular HIV status, sexuality, attitudes, or behaviours

Contents

Executive Summary	2
Summary of key findings from NSW-based respondents to the consultation	4
Health Burden for PLHIV 50 years and older	4
Stigma and Discrimination in Aged Care	4
PLHIV and Access to Aged Care	5
Aged Care Service Model	5
Aged Care Quality Standards	6
Recommendations	7

Methods	9
----------------	----------

Respondents	10
PLHIV aged 50 to 64 years who reside in NSW	12
PLHIV aged 65 years and older who reside in NSW	17
Partners, carers, and family members of PLHIV in NSW	21
HIV specialist services in NSW	24

PLHIV and Aged Care	27
Accessing and using Aged Care	31
Aged Care for PLHIV with HAND or HAD	36
Aged Care Information and Application Support	40

Conclusions	43
--------------------	-----------

Executive Summary

Since the introduction of modern highly active combination antiretroviral therapy (ART) in 1996¹, death from Acquired Immune Deficiency Syndrome (AIDS) has declined significantly. By the beginning of the new millennium, HIV organisations were noting an increase of older PLHIV, many of whom were ageing with serious physical and mental health conditions. In response to these observations, in 2010 the National Association of People with HIV Australia (NAPWHA) commissioned the Kirby Institute to investigate patterns of demographic shifts and trends in the Australian HIV-positive population. The core objective of the Kirby Institute research was to build an evidence base to inform future policy development and planning within the national and jurisdictional HIV responses. The research concluded that the population of Australian PLHIV was expected to change substantially over the coming years, and predicted that by 2020, nearly half (44.3%) of the PLHIV population will be over 55 years of age.²

This finding alerted policy makers and HIV service staff to start advocating for the future service needs of an ageing PLHIV population. Since that time, there has been additional Australian research into the issues ageing PLHIV are faced with. This research has been largely conducted by the Kirby Institute at the University of NSW, the Centre for Social Research in Health (CSRH) at the University of NSW, and the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University, Melbourne.

In 2018, the Royal Commission into Aged Care Quality and Safety (Royal Commission) was established following media coverage of abuse of residents in aged care facilities. Positive Life NSW (Positive Life) recognised this was a unique opportunity to advocate for the current and future health care and support needs of PLHIV, both in NSW and around Australia and consulted with PLHIV, their caregivers, partners and family/friends, as well as HIV service providers who reside in and operate within Australia using an anonymous electronic and paper-based survey between 20 May and 15 July 2019.

Findings formed part of the evidence presented in a submission by Positive Life to the Royal Commission in December 2019³ with nine principal recommendations (page 7) regarding the use and acceptability of aged care services by Australian PLHIV.

The following issues of importance were investigated during the national consultation:

- Uptake and utilisation of aged care services
- Health conditions faced by PLHIV and their partners/carers
- The levels of physical functional limitations of PLHIV and their ability to perform activities of daily living
- Whether aged care services met the needs of PLHIV and their partners/carers
- Levels of satisfaction with aged care services being received
- How aged care services could be improved
- Gaps in aged care services (i.e. whether there were PLHIV who needed services, but were ineligible)
- Examples of mistreatment, abuse, or neglect of PLHIV by staff delivering aged care services
- How aged care services should be provided to PLHIV with HIV-Associated Neurological Disorder (HAND), HIV-Associated Dementia (HAD), and non-HIV related psychiatric conditions
- Preferences about where and how aged care services are provided to PLHIV
- Preferences about how PLHIV receive information about aged care and linkage to aged care services.

This consultation was the first in Australia to investigate PLHIV's uptake of and satisfaction with aged care services. It also investigated attitudes to aged care and whether Australian PLHIV believed the aged care service system can meet their particular care needs.

Conclusions highlighted the reality that despite many PLHIV living alone with chronic physical and mental health conditions, and with physical functional limitation and impairment, there were low rates of aged care service utilisation among PLHIV (particularly home-based care).

Many PLHIV are fearful of engaging with aged care and want to access information and support about aged care from peers. PLHIV who identify as LGBTIQ want to receive services from LGBTIQ people in their own home. This preference is based on fears of encountering stigma and discrimination from aged care service staff and other people who are unaccepting of homosexuality, gender diversity, drug use, or HIV.

Though the survey consultation was a national one, and all survey responses were utilised in the submission into the royal commission, this community survey report is reporting back on NSW-specific findings. For findings and analyses relating to other states and territories please see the submission to the Royal Commission into Aged Care Quality and Safety, Feeney, L. *Australian People Living With HIV & Aged Care*. Positive Life NSW, Sydney, 2019.

Summary of key findings from NSW-based respondents to the consultation

Survey Respondents

251 respondents from NSW are included in this data analysis, including:

- 201 PLHIV respondents over 50 years,
- 27 respondents who identified themselves as partners/family members and carers of PLHIV living in NSW, and
- 23 representatives from HIV specialist services operating within NSW.

Health Burden for PLHIV 50 years and older

- The health burden and other factors contributing to the need for support are similar in both PLHIV aged 50 to 64 years and those aged 65 years and older.
- More than half (62, 51.7%) of PLHIV aged 50 to 64 years have another chronic health condition besides HIV, while two-thirds of PLHIV aged 65 years and older have a chronic health condition in addition to HIV.
- There appears to be a strong case for reducing the aged care eligibility requirements to include PLHIV aged 50 to 64 years, due to their health and physical functional limitation. This would prevent premature deterioration in physical and mental health, reduce admissions to hospital and/or relocation to a residential aged care facility following misadventure or prolonged illness, as well as support their independence and participation in the community.
- One third of the 17 respondents who were partners, carers, or family members who answered to the question (6, 35.3%) reported they also experience serious health conditions that may impact on their ability to provide future care and support to the PLHIV. About a quarter of the 25 carers/partners who responded to the question (6, 24%) were also living with HIV and ageing themselves.

- More than half (53.12%) of the partners, carers, or family members caring for the PLHIV were fearful of not being able to care for their partner in the future.
- Overall, health and independence could be substantially improved if PLHIV and their partners, carers, and family members were encouraged and supported to apply for and receive aged care services, particularly home-based care.

Stigma and Discrimination in Aged Care

- High levels of fear were expressed by PLHIV (60.9%) about ageing with HIV and the potential for discrimination, abuse, and neglect from aged care services and from other residents in residential aged care facilities. Many expressed limited to no trust in the aged care sector to provide them with non-discriminatory services.
- 338 PLHIV respondents who identified as LGBTIQ expressed fears they would not be treated with respect by aged care providers who had limited understanding of the LGBTIQ community, and the long-term effects of HIV physically, mentally, and socially.
- PLHIV and HIV specialist service providers expressed considerable concerns about the risk of stigma and discrimination for PLHIV in aged care facilities, and the ability of the current mainstream aged care services to provide non-discriminatory care of PLHIV.
- HIV specialist services highlighted concerns, observations, and specific incidents about substandard care of PLHIV, lengthy waiting lists, and issues of abuse and neglect of PLHIV including HIV stigma and discrimination by aged care service providers.

PLHIV and Access to Aged Care

- Many PLHIV respondents (58%) have no partners, friends, or family members to help navigate the aged care service system.
- 54 (43.2%) of the 125 PLHIV aged 50 to 64 years plan to apply for aged care at some time in the future, while 19 (15.2%) reported they would not apply.
- 47 (55.3%) of the 51 PLHIV aged 65 and older planned to apply for aged care at some time in the future, while five participants (10.6%) reported they would not apply for any aged care services at any time in the future.
- Uptake of aged care by PLHIV eligible for aged care (aged 65 years and older) was low, with only 11 (21.6%) reporting receiving aged care services. There appears to be a significant under-utilisation of aged care services by PLHIV who are being formally and informally cared for by a partner, friend, or family member.
- Three quarters (18, 75%) of partners, carers, or family members caring for PLHIV were older than 50 years of age and none of them reported the PLHIV they cared for receiving aged care services.
- More than three quarters (13, 76.5%) of the 17 HIV specialist services who responded to the question reported having clients living with HIV who receive aged care services. All received some form of home support, followed by 71.4% received short-term support/respite care after an illness or stay in hospital.
- More than half of the seven responding HIV specialist services (4, 57.1%) said the current aged care services did not meet the needs of PLHIV. Reasons for this included lengthy wait times, lack of understanding of the impacts of social isolation and poverty on PLHIV physical and mental health, and lack of understanding of HIV generally, including HIV transmission.

Aged Care Service Model

- There was general agreement across all respondents that mainstream aged care services are not equipped to deal with PLHIV with HAND and HAD, and that without adequate training of aged care staff, cases of stigma and discrimination are likely.
- PLHIV, their carers, and HIV specialist services agreed that mainstream aged care staff will need specialist training to provide culturally and medically appropriate care to PLHIV with HAND or HAD.
- HIV specialist services called for specific training to all aged care staff to understand the health and social issues associated with HIV, including transmission risks, to help mitigate the impacts of stigma and discrimination.
- Of the 185 PLHIV, their partners and carers, and HIV specialist services who responded to the question, most (148, 80.0%) agreed that PLHIV prefer to receive aged care information and application support face-to-face, followed by a community website (77, 41.6%).
- The majority of PLHIV, their partners, carers, and family members indicated a preference for LGBTIQ aged care providers, followed by PLHIV aged care providers.
- There may be a role for HIV community and peer-based organisations like Positive Life to provide services to PLHIV, and also in educating aged care services about the impacts of stigma and discrimination on the physical and mental health of older PLHIV.
- The majority of PLHIV preferred a person-centred service approach where information is tailored to their needs by staff who can assist with assessments and service provider linkages and negotiations, operated by other PLHIV, due to fears of stigma and discrimination.

Aged Care Quality Standards

In 2019, the Australian Government endorsed new aged care quality standards (ACQS).⁴ They apply to all Australian Government subsidised aged care services and must be complied with by aged care services before accreditation can be granted. These standards cover the following areas of compliance:

Standard 1: Consumer dignity and choice

Standard 2: Ongoing assessment and planning with consumers

Standard 3: Personal care and clinical care

Standard 4: Services and supports for daily living

Standard 5: Organisation's service environment

Standard 6: Feedback and complaints

Standard 7: Human resources

Standard 8: Organisational governance

Positive Life made the following nine recommendations to the Royal Commission as part of our submission⁵, offering a pathway based on evidence to assist the Commonwealth and the aged care service sector to: increase the quality of and access equity to aged care services by Australian PLHIV; and ensure and enable aged care services meaningfully engage with and meet the Australian Aged Care Quality Standards (ACQS) in relation to PLHIV.

Recommendations

1. Mandatory education and awareness training for aged care services (to meet ACQS 1, 3, 5, 7)

Aged care services who provide care to PLHIV must be required (as part of accreditation) to undertake yearly education and awareness training on:

- the clinical management and treatment of HIV and other blood-borne viruses (BBVs)
 - transmission risk and prevention procedures for HIV and other BBVs
 - privacy and confidentiality requirements for aged care service staff
 - HIV-associated stigma and discrimination and its impacts on physical and mental health
 - cultural awareness on the diversity of populations living with HIV, including sexual identity, diverse genders, and recreational drug use
 - the dangers of polypharmacy, non-adherence to HIV and other medications, and the misuse of prescribed and non-prescribed medicines, including illicit drugs.
-

2. Clinical management of HIV, multimorbidity, and polypharmacy (to meet ACQS 3 and 7)

Aged care services with PLHIV in residential care must initiate and maintain shared clinical care arrangements between the residential aged care facility doctor and an HIV specialist doctor (s100 practitioner) to ensure appropriate clinical management and treatment of HIV and other chronic health conditions.

3. Re-evaluating aged care service eligibility restrictions for PLHIV with physical functional limitations and clinical indicators, who are aged less than 65 years (to meet ACQS 4)

PLHIV aged 50-64 years are to be assessed for aged care services on the basis of clinical indicators, levels of physical functional impairment, and other factors such as living alone and/or without familial support.

4. PLHIV with HIV-associated neurological disorder (HAND) and HIV-associated dementia (HAD) (to meet ACQS 3 and 7)

Aged care of PLHIV with HAND and HAD is to be conducted in coordination with HIV specialist neurology services at centres of excellence (such as St Vincent's Hospital, Sydney), with appropriate additional resource allocation for the increase workload this will require for these specialist services. The Commonwealth Government should consider funding specialist HIV services that manage PLHIV with HAND and HAD to provide training to aged care service staff (including clinical staff) who care for clients with these disorders.

5. Aged care for PLHIV in regional, rural, and remote Australia (to meet ACQS 4)

The Commonwealth Government must adequately resource:

- community transport services in regional, rural, and remote areas of Australia to transport PLHIV from rural and remote areas to HIV specialist clinical care in regional centres and metropolitan cities. This would include free transport to city-based centres with multidisciplinary hospitals and experience in the clinical management of PLHIV with comorbidities
- home-based and residential aged care services in regional, rural, and remote areas proportional to the challenges that extensive geographical area coverage entails
- incentives for GPs in regional, rural, and remote Australia to access s100 prescriber training and certification
- additional fly-in/fly-out s100 prescribers to manage HIV and non-HIV related health conditions for PLHIV in rural and remote areas.

6. Improving access to and uptake of aged care services (to meet ACQS 2, 3, 4)

In view of the low rates of aged care service uptake by PLHIV, their partners and carers, the Commonwealth Government should:

- redesign, with an emphasis on co-design principles and practices, the aged care service system to enhance navigation, access, and uptake
- resource HIV sector and LGBTIQ sector community organisations to provide programs that assist and support PLHIV to overcome personal and systemic barriers to a) access and utilise aged care services and, b) make a complaint about poor quality or inappropriate aged care services (particularly PLHIV with physical, neurological, and mental health impairment)
- remove structural and compliance barriers preventing not-for-profit (NFP) organisations to become accredited care providers of home-based care services to PLHIV.

7. Increase funding for home-based support services (to meet ACQS 4)

Increase access and reduce wait times, facilitate improved shared-care arrangements, service coordination, continuity and streamlining, as well as recognition of social support as an integral component of aged care service delivery. This includes but is not limited to provision of these support services by NFP organisations.

8. Future funding patterns (to meet ACQS 5)

The Commonwealth Government must increase support to NFP aged care service providers and consider reducing support to for-profit providers for both home-based aged care services and residential aged care services. For-profit providers may be cost-cutting and reducing quality to maximise profit margins at the expense of their care recipients. This is untenable. Religious institutions and for-profit corporations may not always be best placed to provide quality aged care services to and meet the needs of PLHIV and other ageing Australians.

9. The role of community organisations (to meet ACQS 1, 3, 4, 5, 7)

Community organisations which are peer-based (such as Positive Life NSW) are uniquely positioned to offer peer-based training components. Accordingly, they should receive resourcing from the Commonwealth Government to provide education and awareness training to aged care services and their staff (as outlined in Recommendation 1).

Methods

From May to July 2019 Positive Life conducted a national consultation of PLHIV, their partners, carers, and family/friends, HIV service providers, and aged care service providers. The research tool was an anonymous online survey distributed to the targeted population groups by state and territory PLHIV organisations (Queensland Positive People, Living Positive Victoria, Positive Life South Australia, and NAPWHA). It was also posted out to all Positive Life Members across NSW. The survey was open between 15 May to 20 July 2019 with most responses received during the months of June and July 2019.

Quantitative data were analysed and reported by number and percentage. Qualitative data were analysed by theme and selected participant quotes were included to provide context and strength of emotion.

For the purposes of this community report, 251 respondents from NSW are included in this data analysis. They are made up of 201 PLHIV respondents over 50 years, 27 respondents who identified themselves as partners/family members and carers of PLHIV living in NSW, and 23 representatives from HIV specialist services operating within NSW. For the purposes of this report, we did not conduct analyses on data from the 102 PLHIV residing in NSW aged less than 50 years.

Respondents

Consultation participants from NSW are presented in three main groups:

- PLHIV living in NSW (n=201)
- Partners/family members and carers of PLHIV living in NSW (n=27)
- HIV specialist services operating within NSW (n=23)

To enable a more thorough comparison, the 201 PLHIV from NSW were subdivided into two groups, those aged 65 years and older (n=51) and those aged 50 to 64 years (n=150). This data was then compared with responses from the partners/family members and carers of PLHIV. The rationale for this division was to enable comparisons between each group of participants.

Analyses included:

- The demographic characteristics of each group
- The rates of uptake of aged care services in each group
- The rates of satisfaction/dissatisfaction for those who were receiving services in each group
- Factors impacting on the need for aged care in each group including rates of comorbidity, physical functional limitations, and whether PLHIV lived alone or had limited or no support to perform activities of daily living
- Whether PLHIV and their partners/carers intended to apply for aged care services at a future time, and if not, why this was so
- What would improve aged care services.

Data from the 23 HIV specialist services operating in NSW were analysed. Analyses included:

- The types of HIV specialist services providing feedback
- The uptake of aged care services by their clients
- The levels of satisfaction/dissatisfaction with aged care services
- How difficult it was for HIV services to assist their clients with aged care
- Whether these services had the necessary knowledge and capacity to effectively assist their clients
- Recommendations to improve aged care service provision for PLHIV.

Finally, PLHIV, their partners and carers, as well as HIV services, were asked to provide information on:

- How aged care should be provided to PLHIV with HAND, HAD and other psychiatric conditions
- Experiences of substandard care, mistreatment, neglect, and abuse of PLHIV by aged care services
- Preferences about where aged care services were provided, and by whom
- Preferences about how information about aged care is provided, and by whom
- Their thoughts and fears of ageing with HIV.

251 respondents from NSW are included in this data analysis, including 201 PLHIV respondents over 50 years.

PLHIV aged 50 to 64 years who reside in NSW

150 PLHIV from NSW aged 50 to 64 years participated in the consultation. The vast majority were assigned male at birth (143, 96.6%) and five (3.4%) were assigned female at birth. Two respondents skipped this question. 16 (10.9%) identified as trans or gender diverse (their gender assigned at birth was different to their gender identity). Most (119, 79.9%) identified as gay male/homosexual, nine (6%) as straight/heterosexual, eight (5.4%) as queer, seven (4.7%) as bisexual, and six (4%) as 'other', which included a range of unspecified identifiers. One person skipped this question. Most of the 147 respondents to the question of country of birth reported being born in Australia (108, 73.5%). Most of the 144 respondents to the question of language spoken at home spoke English at home (140, 97.2%). Three (2%) identified as Aboriginal.

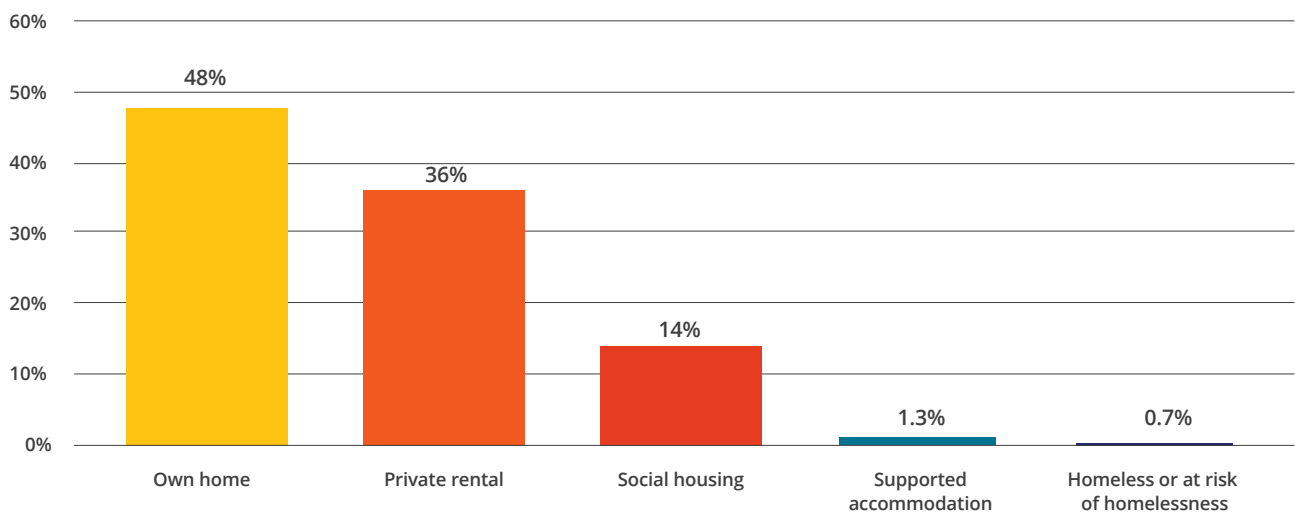
Three quarters (115, 76.7%) lived in a metropolitan area and the remainder (35, 23.3%) lived in a regional or rural area. Of the 124 who responded to the question, 22 (17.7%) reported planning to relocate from a city to a regional or rural area, and 34 (27.4%) were unsure whether they would relocate at some time in the future (depending upon circumstances).

Figure 1 (below) shows the proportions of PLHIV aged 50 to 64 years by reported accommodation situation. Most were living in their own home (72, 48%) or private rental accommodation (54, 36%), and 21 (14%) lived in social housing. There were two (1.3%) who lived in supported accommodation, and one (0.7%) reported being homeless or at risk of homelessness. More than half of the 123 PLHIV who answered the question (aged 50 to 64 years) did not have a partner, friend, or family member to help and support them to navigate the aged care system (65, 52.9%).

Regarding main source of income, about half (77, 51.7%) were employed, 40 (26.9%) received the Disability, Aged or Carers Pension, 21 (14.1%) received income from a range of sources, including superannuation, investments, income protection, and being self-employed, nine (6%) reported receiving unemployment benefits, and 2 (1.3%) reported being supported by a partner, spouse, or friend.

Few reported being religious (16, 10.9%). Approximately half (76, 51.4%) described themselves as a 'spiritual person'.

Figure 1: Participants' Accommodation – PLHIV Aged 50 to 64 Years



Chronic health conditions

More than half (62, 51.7%) of the 120 PLHIV aged 50 to 64 years who answered the question had been diagnosed with a chronic health condition (comorbidity) other than HIV. The most reported conditions were mental health conditions, diabetes, hypertension, cancer, HAND, metabolic disorders, osteoarthritis, osteoporosis, and cardiovascular disease.

Participants also reported a range of issues they thought may impact on their ability to remain engaged in healthcare. These issues included:

- Increased morbidity associated with HIV and other chronic health conditions
- Reduced mobility and difficulty travelling to medical appointments
- Living in a rural area
- Limited healthcare services in the area they lived in
- Limited aged care services in regional/ rural areas.

Functional limitations

18.5% of the 122 PLHIV aged 50 to 64 years who answered the question experienced mild physical functional impairment, 9.8% experienced moderate physical functional impairment, and 5.4% experienced extreme physical functional impairment, as represented in Table 1 (below).

The numbers in red show higher than average proportions of PLHIV experiencing mild, moderate, and extreme physical functional impairment over a range of activities, impacting their ability to take care of themselves and meet their daily household responsibilities. These include difficulties taking care of household responsibilities, standing for 30 minutes, and walking a kilometre. Significant proportions of PLHIV in this age group also report difficulty joining in community events, maintaining friendships, and undertaking work/study activities. This may also indicate some level of neurocognitive decline and mental health impacts.

Table 1: Difficulty Performing a Range of Common Activities – PLHIV Aged 50 to 64 Years

Activity	Mild	Moderate	Extreme
Standing for 30 minutes	18.3%	14.2%	6.7%
Taking care of household responsibilities	15.6%	9.8%	7.4%
Learning a new task	15.1%	6.7%	2.5%
Joining in community activities	19.7%	9.0%	8.2%
Emotionally dealing with health conditions	24.8%	19.0%	9.1%
Concentrating for 10 minutes	23.8%	6.6%	3.3%
Walking one kilometre	18.3%	10.0%	9.2%
Washing your body	7.4%	6.6%	0.8%
Getting dressed	11.6%	5.0%	1.7%
Dealing with people you do not know	24.2%	8.3%	5.0%
Maintaining friendships	19.7%	12.3%	6.6%
Work/study activities	23.0%	9.8%	4.1%
Overall Average	18.5%	9.8%	5.4%

Accessing and using aged care

11 (9.2%) of the 119 PLHIV aged 50 to 64 years who answered the question reported needing aged care services but were ineligible due to the age restrictions. Eligibility is restricted to people aged 65 years and older, or 50 years and older for Aboriginal and Torres Strait populations.⁶ Most reported needing help with home care responsibilities, such as cleaning, gardening, shopping, and transport to get to a doctor or specialist.

A small number of PLHIV aged 50 to 64 years reported currently or previously receiving aged care services (14, 9.3%), despite being aged less than 65 years and being generally ineligible for aged care. Of those who did receive services, six (4%) received help at home, seven (4.7%) received short-term help after an illness or stay in hospital, and one (0.7%) received care in a residential facility.

While ten (40%) of those who received services were either satisfied or very satisfied, nine (36%) were neither satisfied nor dissatisfied with the services provided. Four (16%) were unsatisfied, and two (8%) were very dissatisfied. The principal reasons for dissatisfaction were:

- Service costs
- Unhelpful service providers
- Feeling judged by service providers
- Service providers being unable to provide the requested service
- Poor service coordination by the provider.

Participants thought the following would improve the quality of aged care services:

- A reduction in the long waiting list for care packages
- More reliable community transport services
- Employing workers who were not patronising, and treated PLHIV with respect
- Employing workers who were keen to help, adequately trained, and not judgemental
- Employing workers who could communicate effectively with clients.

54 (43.2%) of the 125 PLHIV aged 50 to 64 years who answered the question planned to apply for aged care at some time in the future, and 52 (41.6%) were unsure if they would apply or not. Of those who said they would apply (with multiple responses allowed), most (88, 71.5%) reported they would need help at home, and one third (41, 33.3%) thought they would need help after a stay in hospital or during an illness. One in five (26, 21.1%) thought they would need care in an aged care facility at some future time. In total, 19 (15.2%) reported they would not apply.

The reasons for not applying varied. Some were unsure about the quality of service they would receive, others thought they would not qualify because of assets, while some stated they would prefer to die before they needed go into care. The following quotes illustrate their sentiments:


- *"I'm not sure I want to live that long"*
- *"Will die before I need aged care"*
- *"When the time comes, I want to die by any means possible"*
- *"Don't trust aged care service providers"*

There appears to be a strong case for decreasing the aged care eligibility requirements to include PLHIV aged 50 to 64 years.

Conclusions

Given the health burden experienced by PLHIV in the 50 to 64 years of age group, the proportions who have no partner, carer, or family/friend to support them with the aged care system (52.9%), and the proportions with moderate (9.8%) and extreme physical functional limitations (5.4%), there appears to be a strong case for decreasing the aged care eligibility requirements to include PLHIV aged 50 to 64 years.

The provision of aged care (particularly home-based care) to PLHIV aged 50 to 64 years who have limited support, and experience multimorbidity and physical functional limitations would assist them to remain living independently and to participate in the community. It would also significantly contribute to them being able to look after themselves, prevent further premature deterioration in physical and mental health, admissions to hospital and/or relocation to a residential aged care facility following misadventure or prolonged illness.



Positive Life recognised a unique opportunity to advocate for the current and future health care and support needs of PLHIV.

PLHIV aged 65 years and older who reside in NSW

51 PLHIV aged 65 years and older who lived in NSW participated in the consultation. The majority (49, 96.1%) were assigned male at birth and two (3.9%) were assigned female at birth. There was one respondent (2%) who identified as trans and/or gender diverse. Most respondents identified as gay male/homosexual (40, 78.5%), seven (13.7%) as straight/heterosexual, two (3.9%) as bisexual, and two (3.9%) as queer. None identified as Aboriginal or Torres Strait Islander. Most were born in Australia (35, 68.6%) and spoke English at home (49, 96%).

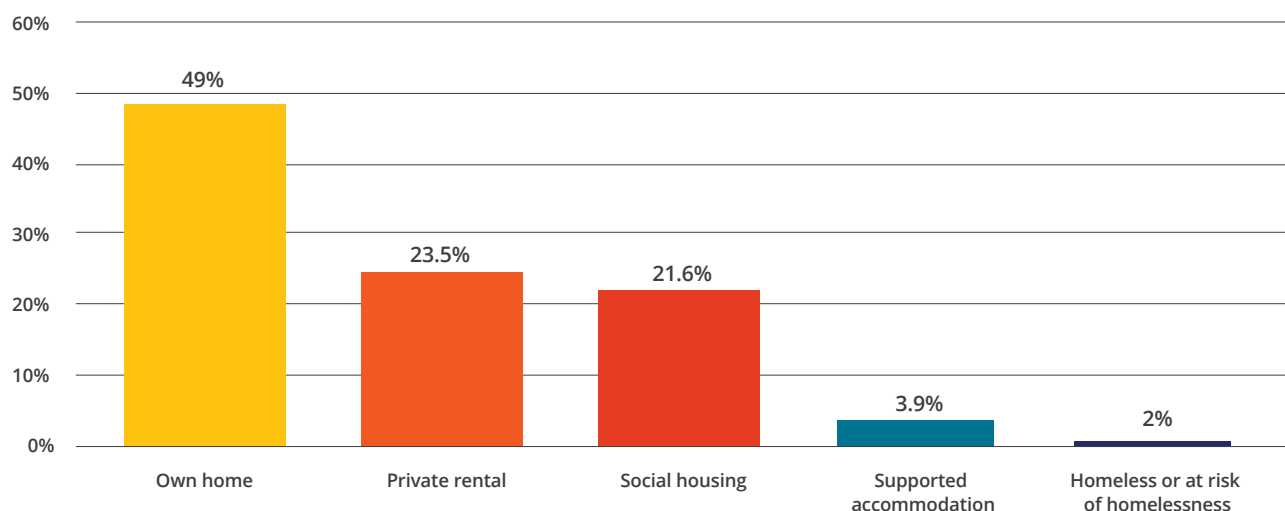
The majority (32, 64%) lived in metropolitan areas, and about a third (18, 36%) lived in a regional or rural area. Only one respondent planned to relocate to a regional or rural area in the future (2.9%), however, nearly a quarter (8, 22.9%) reported they were unsure whether they would relocate to a regional or rural area sometime

in the future. Nearly half (25, 49%) owned their home, 12 (23.5%) were renting privately, and 11 (21.6%) were living in social housing. Two (3.9%) reported being homeless or at risk of homelessness, and one (2%) lived in supported accommodation (Figure 2). Participants ages ranged from 65 to 86 years.

Of the 51 participants aged 65 and older, the main source of income was cited by nearly two thirds (33, 64.7%) as the disability, aged, or carers pension. A small proportion were employed (7, 13.7%), and 11 (21.6%) reported another source of income, primarily superannuation or investments.

One quarter of respondents (13, 25.5%) described themselves as religious, and nearly half (24, 47%) described themselves as a 'spiritual person'.

Figure 2 Participants' Housing - PLHIV Aged 65 Years and Over



Chronic health conditions

Analysis of the 45 PLHIV aged 65 years and older who provided information on comorbidity conditions revealed that two-thirds (30, 66.7%) had been diagnosed with chronic health conditions in addition to HIV. Conditions included epilepsy, cardiovascular disease, liver disease, cancers, osteoporosis, osteoarthritis, HAND, kidney disease, heart attack, stroke, metabolic disorders, endocrine disorders, and mental health conditions. In addition, just over half (26, 56.5%) of the 46 respondents to the question had no partner, friend, or family member to help them navigate the aged care system.

Functional limitations

When questioned about their ability to engage in daily activities, a fifth of PLHIV aged 65 years and older (20.6%) reported mild physical functional impairment, 11.4% (overall) reported moderate physical functional impairment, and 6.4% (overall) reported extreme physical functional impairments (see Table 2).

Table 2: Difficulty Performing a Range of Common Activities – PLHIV aged 65 Years and Over

Activity	Mild	Moderate	Extreme
Standing for 30 minutes	20.0%	20.0%	11.11%
Taking care of household responsibilities	20.0%	17.8%	4.4%
Learning a new task	24.4%	13.3%	2.2%
Joining in community activities	13.3%	15.6%	15.7%
Emotionally dealing with health conditions	24.4%	15.6%	11.1%
Concentrating for 10 minutes	17.8%	6.7%	4.4%
Walking one kilometre	13.3%	6.7%	20.0%
Washing your body	8.9%	6.7%	2.2%
Getting dressed	25.6%	7.0%	0.0%
Dealing with people you do not know	35.6%	11.1%	2.2%
Maintaining friendships	20.0%	6.7%	6.7%
Work/study activities	23.8%	9.5%	2.4%
Overall Average	20.6%	11.4%	6.9%

Accessing and using Aged Care

Only two (4.4%) of the PLHIV aged 65 years and older who answered the question reported currently needing aged care services but were ineligible. They reported needing help with home care responsibilities, such as cleaning, gardening, and maintenance.

The uptake of aged care by PLHIV aged 65 years and older was low. Only 11 (21.6%) reported currently or previously receiving aged care services. Most of these (8, 15.7%) received help at home. The remainder (3, 5.9%) received short term help after an illness or stay in hospital. None reported being a resident in an aged care facility.

Most who received aged care services were satisfied with the service (6, 54.5%) or neither satisfied nor unsatisfied (2, 18.2%). However, three (27.3%) were very unsatisfied. When questioned about why they were unsatisfied, reasons varied, but were mainly about poor service coordination by provider agencies and staff.

The three responses below describe the reasons for dissatisfaction:

- *“The service was appalling. They would change the time on the day and never notify me... told me when I queried them that they didn't have time to ring clients to change times. When I cancelled a service for that week, they never contacted the home care person and they would turn up to find me not there...unsurprisingly as I had cancelled. On most occasions I was still charged. Finally, when they had a stuff-up with their accounting system I didn't receive a bill for 6 months. I cancelled the entire service. The call centre staff were rude, and the supervisors/managers NEVER returned phone calls.”*

- *“I was about to undergo Radiation therapy due to a Squamous cell carcinoma. I contacted an organisation. Two guys from the organisation came to my home to interview me. They said we can supply such and such. All I asked for was someone to come once a week and help me with the shopping. They said they would contact me once my Radiation therapy started. I've not heard from them since. So, no I didn't rely on them and did everything myself during my five weeks of Radiation therapy.”*
- *“I needed home care services after heart surgery, but despite trying, was unable to make any arrangements until I was in hospital recovering. It would have given me greater peace of mind if a preliminary arrangement was in place before the surgery.”*

26 (55.3%) of the 47 PLHIV aged 65 years and older who answered the question planned to apply for aged care at some time in the future, and about a third (16, 34%) were unsure if they would apply or not. 35 respondents to a follow up question (with multiple responses allowed) (74.5%) intended to apply for help at home, and about a quarter (13, 27.7%) thought they would need short-term help after a stay in hospital or illness.

Interestingly, only about a quarter (11, 23.4%) thought they would apply for residential aged care services in the future. We were particularly interested why five participants (10.6%) reported they would not apply for any aged care services at any time in the future. Some thought they could look after themselves or were presently managing to remain independent. Some were going to ask a partner, family member, or friend for assistance when they could no longer manage. Other respondents (16, 34%) were unsure what services were available or how to access services.

The following quotes illustrate why some PLHIV were dubious or would not apply for aged care:

- *"It depends on the quality of services they offer as to whether I'll apply for Aged Care Services. Also, if they're not HIV friendly I won't bother – I don't need the hassle of needlessly perpetuated stigma from ignorant people"*
- *"I plan to apply for euthanasia before I need to go into care"*
- *"As an aged care worker I know my medication would be exposed to all nurses and I don't want that. I would be rejected because there's not enough education about HIV"*
- *"Not sure I want to live that long"*
- *"Do not trust aged care service providers"*
- *"I don't want to be in aged care out of a metropolitan area. Too much chance of stigma"*
- *"Sort of hoping I don't live to old age, and need to"*
- *"I tried but found it too difficult"*
- *"I'd rather commit suicide than go into and aged care home. Your quality of life is appalling!"*
- *"Being dependant on people who probably think you are low life! That's not an option for me"*

Conclusions

Considering the compounding issues of living with HIV (100%), comorbidity (66.7%), physical functional impairment of a moderate and extreme level (11.4% and 6.4% respectively), and the high proportion of PLHIV aged 65 years and older who do not have a partner/carer to help them with the aged care system (56.5%), these figures demonstrate a strong need for aged care services by this cohort of ageing PLHIV with increasing physical impairments. Only 5.9% of survey respondents received home-based care, while 15.7% received short-term care after an illness or stay in hospital. Almost a quarter (10, 22.2%) of the 45 respondents to the question had moderate difficulty or extreme difficulty taking care of household responsibilities.

Concerns from this group of PLHIV aged 65 years and older highlight a range of fears that are commonly held by older PLHIV, many of whom are gay men who have experienced stigma associated with their sexual orientation and living with HIV, or discrimination based on sexual orientation from healthcare providers. Many expressed limited to no trust in the aged care sector to provide them with non-discriminatory services. It appears there may be a role for HIV community and peer-based organisations like Positive Life to ensure services provide appropriate quality care to PLHIV, and also in educating aged care services about the impacts of stigma and discrimination on the physical and mental health of older PLHIV.

As PLHIV continue to age and their health conditions likely become more serious and protracted, physical function will likely decrease and they will struggle to perform routine activities of daily living like looking after themselves or being able to maintain independent living arrangements. Increasing uptake of aged care services, particularly home-based care, would help older PLHIV to remain independent, maintain a clean and orderly living environment, improve their quality of life, and prevent hospital admissions and premature death.

Partners, carers, and family members of PLHIV in NSW

There were 27 participants from NSW who reported being a partner, carer, or family member of a PLHIV. Most 19 (76%) lived in metropolitan areas, and six (24%) lived in regional or rural NSW. Two did not answer the question. Of the 24 participants who provided information on age, 14 (58.3%) were aged 50 to 64 years, and four (16.7%) were aged 65 years and older.

Of the 25 who responded, 18 (72%) described themselves as not religious, and slightly less than half (12, 48%) described themselves as 'a spiritual person'.

None of the partners, carers, or family members of a PLHIV reported the PLHIV receiving aged care services. Some partners, carers, or family members had physical issues that could or would impact on their current and future ability to provide care and support to the PLHIV. One third (6, 35.3%) reported serious health conditions of their own that may impact on their ability to provide future care and support. These health conditions included aggressive arthritis, diabetes, cardiovascular disease, mental health conditions, eye problems, stroke, neurological conditions, and cancers. About a quarter (6, 24%) of the 25 respondents to the question were also living with HIV. Additionally, of the 24 who responded to the question, 14 (58.3%) were aged 50 to 64 years, and four (16.7%) were aged 65 years and older.

Chronic health conditions

About a quarter (5, 27.8%) of the PLHIV being cared for by a partner or family member also had chronic health conditions in addition to HIV, out of the 18 responses to the question. These conditions included combinations of chronic hepatitis B and C, depression, anxiety, cardiovascular disease, liver and kidney disease, cancer, stroke, HAND, heart attack, and blindness.

Functional Limitations

Rates of physical functional limitation for PLHIV being cared for by a partner, carer, or family member are listed in Table 3 below. There were 16.5% of PLHIV being cared for who reported mild physical functional limitations, 8.4% reported moderate physical functional impairments, and 6.2% reported extreme physical functional impairment. These percentages are the averages across a range of activities for each of the categories of impairment (mild, moderate, and extreme). The figures in red represent above average proportions. Of note is the proportion of participants who experienced moderate difficulty taking care of household responsibilities, however, social activities were also significantly affected (i.e. joining in community activities, emotionally dealing with health conditions, dealing with people they did not know, and maintaining friendships etc.).

Table 3: Difficulty Performing a Range of Common Activities – PLHIV Being Cared for by a Partner, Carer, or Family Member

Activity	Mild	Moderate	Extreme
Standing for 30 minutes	11.1%	11.1%	0.0%
Taking care of household responsibilities	16.7%	11.1%	5.6%
Learning a new task	5.6%	5.6%	5.6%
Joining in community activities	11.1%	16.7%	5.6%
Emotionally dealing with health conditions	33.3%	16.7%	16.7%
Concentrating for 10 minutes	22.2%	0.0%	5.6%
Walking one kilometre	11.1%	11.1%	11.1%
Washing your body	11.1%	5.6%	0.0%
Getting dressed	22.2%	5.6%	0.0%
Dealing with people you do not know	23.5%	0.0%	11.8%
Maintaining friendships	29.4%	5.9%	5.9%
Work/study activities	11.8%	11.8%	5.9%
Overall Average	16.5%	8.4%	6.2%

Many PLHIV reported holding deep fears of engaging with existing mainstream aged care service, and want to access information and support about aged care from peers.

Accessing and using Aged Care

Three quarters (18, 75%) of partners, carers, or family members caring for PLHIV who answered the question were older than 50 years of age. Coupled with the burden of health conditions of themselves and the PLHIV they are caring for, it is surprising that none of these couples reported receiving aged care services.

More than half (53.12%) of the partners, carers or family members caring for the PLHIV were fearful of not being able to care for their partner in the future. The following responses illustrate their concerns:

- *"I won't be able to care for him"*
- *"The care we need will not be available, because we live in a regional/rural area"*
- *"The amount of support I can give to my partner will decline"*
- *"In the future when I am older, I may not be able to offer assistance"*
- *"I may become too sick, because of my chronic diseases. I may not be able to take care of myself and my partner who has HIV"*
- *"I have concerns about my ability to provide emotional support, concerns about future health issues, and access to aged care services"*
- *"I need aged care training for me to better support my partner at home"*
- *"Uncertainty about my health and therefore my ability to support my partner in the future"*
- *"Caring for someone who is constantly unwell and disabled is draining"*

Of the 21 respondents to the question, 11 PLHIV being cared for by a partner/carers (52.4%) reported intending to apply for aged care services at some future time, and six (28.6%) were unsure if they would apply or not. Four (19%) reported they would not apply for aged care. The primary reasons were that they were either too young to be eligible or their current health status would preclude eligibility. Of those who reported they would apply in the future (with multiple responses allowed), 11 (52.4%) thought they would need help at home, and nine (42.9%) thought they would need short-term help after an illness or stay in hospital. One third (7, 33.3%) thought they would need care in a residential aged care facility. One participant (5.3%) out of 19 respondents thought the PLHIV they cared for needed aged care services now but were ineligible. The services needed were help with shopping and cleaning.

Conclusions

There appears to be a significant under-utilisation of aged care services by PLHIV who are being formally and informally cared for by a partner, friend, or family member. Many of these partners, carers, or family members are also experiencing their own chronic health conditions including also living with HIV, and are ageing. As both individuals age and health conditions worsen, their ability to remain living independently will reduce. Aged care services will then be required for one or both individuals.

Overall, health and independence could be substantially improved if PLHIV and their partners, carers, and family members were encouraged and supported to apply for and receive aged care services, particularly home-based care.

HIV specialist services in NSW

23 HIV specialist services in NSW participated in this consultation. While this may seem low in size, services were asked to nominate staff with the most experience to consult with their team and provide feedback on behalf of a number of colleagues. The types of services included:

- Mental health, counselling, and psychology services
- HIV health promotion, education, and peer support services
- HIV self-management services for PLHIV aged 50 years and older
- HIV clinical care services
- Allied health services
- Pharmacy services
- Community pastoral services to PLHIV and carers
- Social work services
- Community care and support
- Nursing
- Social support and respite care
- Hospital HIV specialist clinics
- HIV testing and monitoring
- Case management services

Over a quarter of HIV specialist services (6, 26.1%) operated in a regional/rural area. The remainder (17, 73.9%) operated in the Sydney metropolitan area.

Need and use of aged care

More than three quarters (13, 76.5%) of the 17 HIV specialist services who responded to this question reported having clients living with HIV who receive aged care services. The aged care support services received were mostly home support (100%), followed by short-term support/respite care after an illness or stay in hospital (71.4%), and then residential aged care (42.9%) (multiple options were available).

The HIV specialist services who answered this question in NSW (7) were either 'satisfied' (4, 57.1%) or 'neither satisfied nor unsatisfied' (3, 42.9%) with the quality of aged care services received by their clients. When asked if aged care services met the needs of their PLHIV clients, less than half (3, 42.9%) said 'yes'. However, more than half (4, 57.1%) said they did not meet the needs of PLHIV.

Some examples of reasons why aged care services did not meet their clients' needs are:

- *"Once the short-term services have finished, there is a gap in time until they can access other services, up to 18 months for home care if they have had an ACAT assessment"*
- *"The clients are still socially isolated, and services do not have a great awareness of support services for people living with HIV"*
- *"At times when speaking to client's, the services do assist them, however, their needs are greater than the capacity of the service"*
- *"Service provision is too limited"*
- *"Waitlist for high level aged care packages are too long. Once the cap is met with level four aged care package, the only options is residential aged care (for those who cannot afford private services at minimum \$50 dollars per hour of support)"*
- *"Staff are not trained to support people living with HIV, and LGBTIQ people"*
- *"Stigma is an issue"*

Many HIV specialist services thought there was a need for more services to be available, so wait times could be reduced. There were also calls for aged care services to have a better understanding of HIV, including an understanding of HIV transmission and that HIV cannot be transmitted by PLHIV who are being successfully treated with ART as well as an understanding of the impacts of social isolation and poverty on PLHIV physical and mental health. Cost of services was reported to be an issue for some older PLHIV who were financially disadvantaged.

HIV specialist services who responded to the question (7) reported that 100% of their clients living with HIV will need home support services in the future. They also reported that 85.7% will need short-term help after a future illness or admission to hospital, and 71.4% will eventually need residential aged care. More than half (57.1%) of HIV services reported the need for more community engagement and social groups to reduce social isolation and loneliness, and appropriate dementia services to allow more dignified care for those PLHIV with dementia.

HIV specialist services were asked how difficult it had been to organise aged care for their clients living with HIV, with seven responding. None (0%) of the HIV specialist services reported it being 'easy' or 'very easy', two (28.6%) said it was 'neither easy nor difficult', more than half (4, 57.1%) said it was 'difficult', and one (14.3%) said it was 'very difficult'. There were a range of reasons contributing to reported difficulty. Reasons included:

- Delays in getting ACAT assessments and then receiving services
- Issues surrounding the clinical management and treatment of PLHIV with comorbidities and resultant drug reactions/interactions for PLHIV in aged care facilities
- Problems with management of PLHIV in aged care facilities with HAND and HAD
- Wait times for packages to be approved
- Aged care staff being unaware of transmission risks
- Inappropriate disclosure of HIV status and the use of stigmatising language
- Difficulties navigating the My Aged Care service portal and waiting for assessments, particularly for higher level packages.

When asked if their service had the necessary knowledge, skills, experience, and time to help older PLHIV to engage with aged care services, seven aged care services responded, with most (5, 71.4%) reporting that they did. About a quarter (2, 28.6%) thought they did not have the knowledge, skills, and time to assist. In these circumstances, HIV specialist services referred onto another service.

Finally, the following suggestions were made by the HIV specialist services in relation to improving aged care service provision for PLHIV:

- *“A good assessment process and referrals to good agencies (service providers)”*
- *“Provide specific training to aged care and home care staff so they understand the health and social issues faced by PLHIV, including the impacts of stigma and discrimination. Training should be provided by community HIV services and include transmission risks”*
- *“Providing more dignified accommodation for PLHIV with dementia. Some PLHIV with HAND are currently accommodated in locked mental health units”*
- *“Specific training for services caring for PLHIV with HAND”*
- *“Initiate care plans for PLHIV prior to age 65 years. This would allow PLHIV to have a proactive role in the decision-making process. The care plan should be formulated with all parties involved in the care of the PLHIV, including the PLHIV”*

Conclusions

PLHIV who are clients of specialist HIV services appear to have a significantly higher rate of engagement with, and access to, aged care than those who are not connected to these HIV specialist support services. This may be due to the complexity, disease burden, and levels of physical functional limitation for those PLHIV who are clients of these specialist services; however, it may also be due to HIV services recognising the need for aged care and demonstrating a willingness to support PLHIV through the complex application process.

PLHIV who are clients of specialist HIV services appear to have a significantly higher rate of engagement with, and access to, aged care.

PLHIV and Aged Care

Media coverage of physical and emotional abuse of residents in aged care facilities has doubtless contributed to PLHIV, partners, carers, and family members, and HIV specialist services concerns about the ability of mainstream aged care services to provide non-discriminatory aged care to PLHIV. Many people during this consultation told Positive Life that they have little hope of being treated with dignity and respect if and when they are in the aged care system. As one PLHIV told us: *"If members of the general population can be treated in this manner, what hope does a gay man with HIV have of escaping abuse and humiliation."*

During the consultation, remarks and specific complaints by respondents were made about substandard care by aged care service providers. Most of these complaints were made by HIV specialist services who care for and provide case management/case coordination services to PLHIV in NSW. They included:

- Aged care service staff being unhelpful, patronising, disrespectful, and lacking empathy to PLHIV
- Aged care service staff being unfriendly, impolite, and not listening to the requests of PLHIV
- Aged care service staff lacking training and not being able to carry out tasks satisfactorily
- Aged care service staff not being able to communicate effectively in English
- Services being too costly
- Services being too rigid
- Services not turning up as arranged. There were specific complaints made about community transport services in regional areas cancelling service on the morning of medical appointments, despite being booked up to six months in advance
- Poor coordination of aged care services
- Long waiting lists for aged care services and the need for more services.

Participants were asked if they had any knowledge or experience of acts of discrimination against PLHIV receiving aged care. The following quotes highlight a range of issues reported:

- *"I have had some services pull out, using varied excuses and the PLHIV believes it was about their HIV status. Also, the way workers have cleaned their home (very quickly) as if to get out asap"*
- *"Yes. A client was living in a care facility due to his dementia. He was also Aboriginal. Staff perceived him as a threat and the police were called, leaving him bruised and not knowing why the police had come. The second time he was removed from the facility and is now in a locked hospital ward, awaiting another placement"*
- *"Yes, the patient had reported being in the shower by aged care staff, I was concerned, the patient had presented smelling of urine, further to my concern, I was aware the client had a recent stroke and from a past visit had appeared to have deteriorated. I flagged my concerns with the medical officer and found the client was missing essential medication for their epilepsy and had lost engagement with key specialist e.g. neurologist"*
- *"I have many examples of PLHIV having experienced discrimination, abuse and/or neglect. For example, a client being humiliated by workers discussing his HIV status and the lack of correct information. The PLHIV had to educate the service provider and the agency. They continue to argue in defence of the worker that it's necessary for full HIV disclosure"*
- *"Agency staff members who have been unaware of HIV/AIDS, and communication issues with client's when their HIV status has been disclosed; 'can I drink from this cup', 'why wasn't I told about your status before accepting this service' etc."*
- *"I work in an aged care facility. The client with HIV was shamed and silenced"*
- *"I am helping a friend who got verbally abused about both his sexuality and HIV status in an aged care service. The complaints procedure is full of obstacles and there is little interest from the provider in addressing the problem. But I will persist and escalate as necessary, depending on my friend's permission to do so"*
- *"Yes. I have witnessed homophobia by facility staff"*
- *"A 90-year-old mother of a gay son was told after a fall that caused both ankles to break, it was because God was punishing her because her son was gay"*
- *"Heard staff say he's probably got AIDS when it was non-related cancer"*
- *"I have acquaintances working in aged care who discuss residents by name, gossip about residents personal and medical situations and describe interactions with them that are disrespectful and degrading, especially when the aged person also has Dementia"*
- *"An HIV-positive gay man was discharged from an inner-Sydney hospital to recover in an aged care facility. The facility staff refused to care for him and eventually he became very weak and was transferred back to the hospital after falling out of bed. He died some-time after"*

The following qualitative responses received in the survey highlighted commonly held thoughts and fears of ageing PLHIV:

- *“Living in a regional area of Australia and having to use mainstream (non-LGBTIQ) services who may discriminate or not maintain confidentiality of my HIV status. This would result in discrimination from members of the general community who are intolerant of people with HIV”*
- *“I hope I don’t have to deal with abuse, neglect or nastiness from homophobic church-based aged care providers. I would probably decide to do without the services altogether if that happened. Sometimes I can be quite fragile mentally and physically and can’t deal with conflict and abuse”*
- *“I don’t believe it will be the HIV itself that will be an issue - but more the mental understanding that we are living with HIV as we age. I never really took seriously that I would grow old, as I did not expect to reach that age where I would have to. Adjusting my frame of mind to believe in that and to accept that is where I am are my biggest concerns”*
- *“It’s going to be hard. I gave up work 2 years ago. My super has gone now and I’m not sure what’s going to happen to me”*
- *“I’m only just starting the process and my first experience has been with Centrelink. If Centrelink’s unhelpful, bombastic and negative attitude is indicative of government agencies, then god help us all, HIV or not”*
- *“I will try to plan so I never have to enter residential aged care. My experience (aged/dying mother) and knowledge (ex-RN) of it is not good, but the risk is my plans do not work well – wish me luck!”*
- *“I don’t feel like I can talk about it at all. I sometimes wonder if it would be better to have cancer because we talk about that (we, being society). We never talk about HIV”*
- *“Governments need to start planning for populations ageing with HIV. No one really knows how HIV affects the body long-term and what the future needs of long-term survivors will be”*
- *“Perhaps, suicide”*
- *“Hoping to die before it gets much worse”*
- *“It would be great if there were group accommodation for people with HIV. Preferably units etc. where we could support each other. We need to feel safe. I think being together in a small community of PLHIV would be more secure and we could live the rest of our life in safety”*
- *“There is a point where I have seen many decide that enough is enough, and they peacefully and with dignity, end their life”*
- *“I’m starting to feel that I should have done my duty and died earlier!”*
- *“Abuse is a major issue I’m aware of. Will it be worse because I have HIV?”*
- *“Ageing and aged care is not an exciting prospect for anyone. It is likely to be a worse experience when living with HIV. Dealing with barely literate care givers who hold stigmatising attitudes, organisations that only want profitable residents”*
- *“It’s going to be very expensive, very lonely and frightening. I was used to being in control of my life and that control is slipping away. I am truly scared”*
- *“It scares the life out of me to realise that I will end up in an aged care facility. I have no family here. The stories are generally not good”*

Conclusions

Considerable concerns were expressed by PLHIV and HIV specialist service providers about the risk of stigma and discrimination for PLHIV in aged care facilities, and the ability of the current mainstream aged care services to provide non-discriminatory aged care to PLHIV. HIV specialist service providers shared observations and concerns about substandard care, lengthy waiting lists, or issues of abuse and neglect of PLHIV by aged care service providers.

Considerable concerns were expressed by PLHIV and HIV specialist service providers about the risk of stigma and discrimination for PLHIV in aged care facilities.

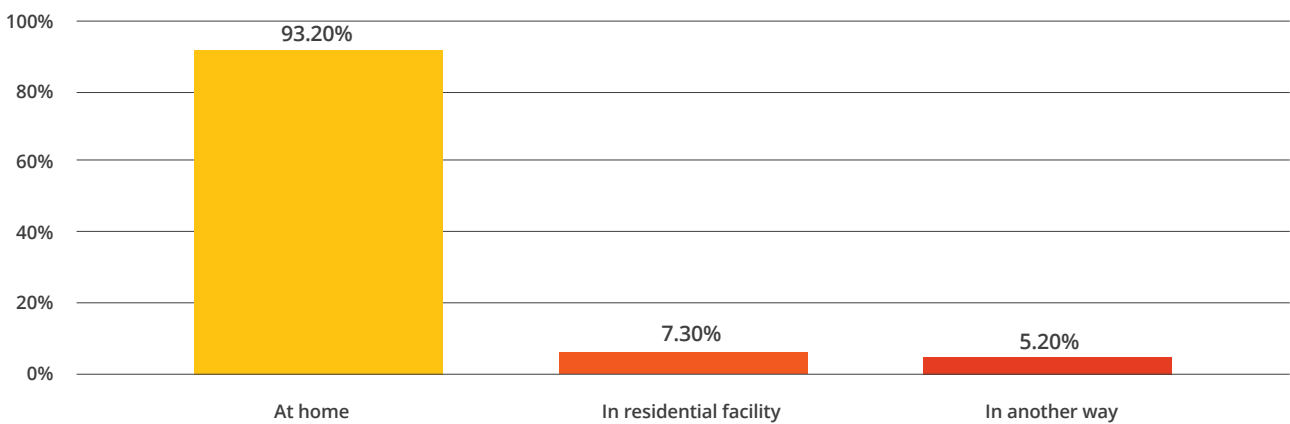


Accessing and using Aged Care

A majority of the 191 PLHIV and partners, carers, and family members who expressed a preference about where aged care services are provided to them, reported a clear preference to remain living in their own home until such time as they could no longer manage (178, 93.2%). A small proportion (14, 7.3%) preferred to receive care

in a residential facility, and a few (10, 5.2%) nominated 'in another way' (including gay retirement home, purpose-built facility for PLHIV, shared private housing, or in the company of peers). Figure 3 illustrates the preferences of participants where aged care services should be provided to them. Multiple options were available.

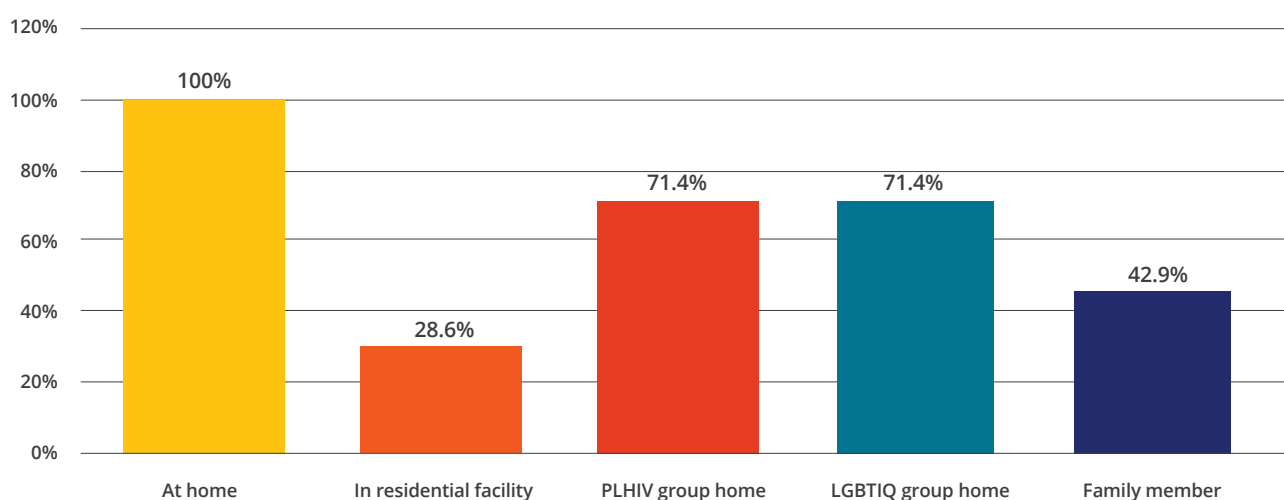
Figure 3: Where Participants Would Prefer to Receive Aged Care



We also asked HIV service providers where they thought PLHIV would prefer to receive aged care (Figure 4), of which seven provided responses. Multiple options were available. Seven (100%) thought they would prefer to receive services in their own home. This was followed by five HIV services who thought PLHIV would prefer to

receive services in a group home together with other PLHIV (71.4%), and in a communal home with other LGBTIQ people (71.4%). Three (42.9%) thought they would prefer to be cared for by a family member. Only two services (28.6%) thought PLHIV would prefer a residential aged care facility.

Figure 4: Where HIV Service Providers thought PLHIV Would Prefer to Receive Aged Care

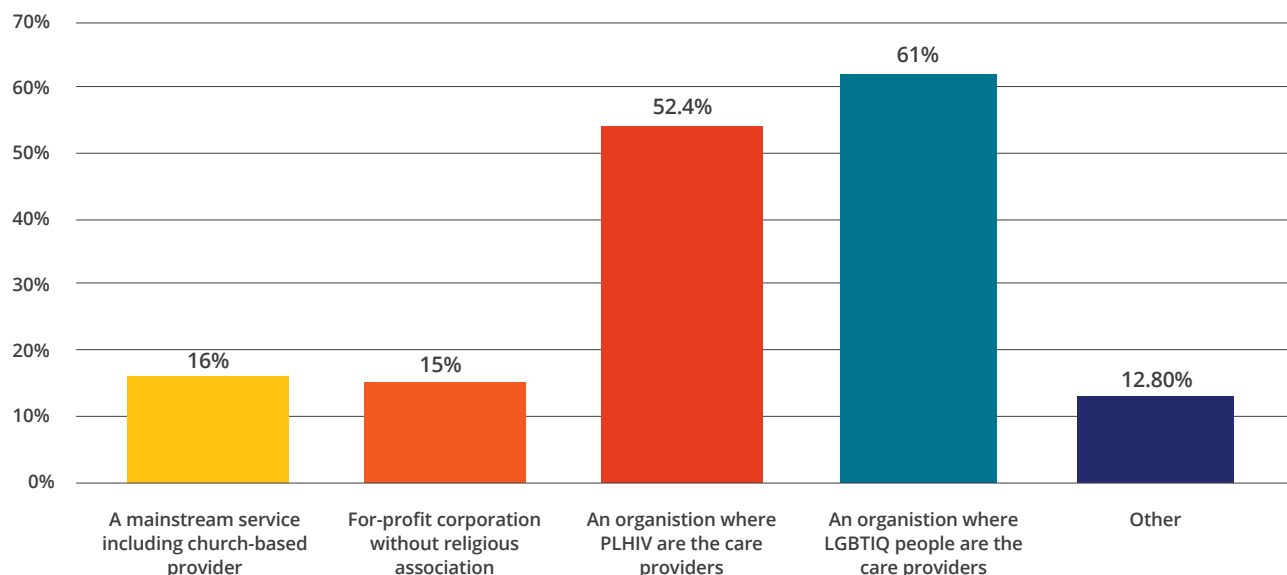


PLHIV, their partners, carers, and family members were asked who they would prefer to provide aged care services to them, with 187 providing responses. The majority (114, 61%) wanted LGBTIQ people to be the care providers, followed by 98 (52.4%) preferring PLHIV to be the care providers. There were 28 (15%) respondents who nominated a for-profit organisation without religious associations, and 30 (16%) nominated a mainstream service provider, including a church-based provider. The remaining (24, 12.8%) nominated a range of other options. These options included:

- *“Any service who will treat me with respect”*
- *“Non-Government Organisation without religious association and preferably with some workers who understand PLHIV or are PLHIV”*
- *“A non-religious not-for-profit organisation”*
- *“Having PLHIV staff would be a bonus”*
- *“An organisation that works in the HIV and LGBTIQ space and understands the need for good training of staff”*
- *“An organisation with appropriate attitude and approach to ensure provision of highly qualified, highly skilled appropriate care, that is respectful and non-judgmental”*

Figure 5 (below) shows the proportional preferences of participants by service provider type. Multiple options were available.

Figure 5: Participants' Preferences on Type of Aged Care Service Provider



PLHIV, their partners and carers were asked why this preference was important to them, of which 162 provided information. Many expressed significant concerns about being cared for by faith-based organisations and this may be due to the large proportion of respondents who identified as LGBTIQ (180, 89.6%). Persecution and discrimination by religious institutions was provided as a reason for this by LGBTIQ people who had personally experienced or witnessed vilification and discrimination by church clergy and members of church congregations.

The following comments illustrate the levels of concern, suspicion, and mistrust of faith-based organisations/services and their ability to provide non-discriminatory care to PLHIV and LGBTIQ people:

- *"The church has caused such damage and pain. I would not want a church-based provider to look after me"*
- *"Profits and Christianity are not a good mix"*
- *"Having done home care for people with AIDS in the 90s, and coming from a Catholic upbringing, I don't want or need the judgment or preaching"*
- *"I am not religious and do not want religious ideology affecting my care later in life"*
- *"I would never feel safe in a religious or faith-based association ever again. Similarly, I would feel uncomfortable with mainstream service providers profiteering from my likely premature ageing"*
- *"I fought too hard for gay rights to be forced back in the closet when I'm old"*
- *"I think religion is evil and I would hate to have to rely on any religious organisation for care in my old age"*

- *“Church based phobia I don’t want or need”*
- *“I’m an atheist and don’t want to deal with discrimination from religious institutions”*
- *“I feel threatened by the religious right who preach tolerance and respect yet demonstrate hatred and persecution”*
- *“Don’t want church people looking after me”*
- *“Organised religion, in my personal opinion based on many years’ of experience of receiving stigma and discrimination from such bodies, is a system that has its very principles based in exclusionary practices and I want nothing to do with any “health” organisations built on such a belief system when it comes to my own wellbeing. I recognise they have done a lot for our communities over the years and do not want to take that away from religious organisations and it’s not to say I wouldn’t want to receive care from, or even care for, an individual who is religious, just that I do not want the policies and behaviour/support to be guided by institutions that have dogmatically and relentlessly campaigned for the mistreatment of people like me who are same-sex attracted or gender diverse and/or religions that promote unhealthy sex practices (such as banning condoms), especially in developing countries which contributes to the miseducation of millions of vulnerable people and probably makes them absolutely responsible for millions of deaths worldwide to this day. I consider spirituality to be different to organised religion, but again, I’m not sure my first choice would be a “spiritual” care home either. I would first hope to fulfil other markers when considering a care facility such as; are there LGBTIQ people there, am I going to get along with the residents and staff, are they open minded in terms of the use of alcohol and other drugs and the people who use them, are there interesting activities, etc.”*

Of the 180 LGBTIQ respondents who completed the survey, many expressed fears they would not be treated with respect by care providers who had limited understanding of the LGBTIQ community. Many respondents wanted to be cared for by others living with HIV (peers), or at least by members of the LGBTIQ community. The following comments illustrate the range of concerns:

- *“I want to be treated with empathy and understanding and not patronised”*
- *“I identify as a gay man with HIV. I would prefer my caregivers identify with that to some degree, so I don’t feel as though I have to de-gay my home”*
- *“I’ve worked as a carer for people with AIDS and I would prefer an organisation with people with HIV and LGBTIQ people providing care. I feel they would have a better understanding”*
- *“Peers understand needs and experiences without explanation”*
- *“Better appreciation of the community values and non-judgmental to my lifestyle”*
- *“Having people living with HIV and LGBTIQ could imply empathy, people who really care”*
- *“I want people who understand the long-term effects of HIV on the body, soul and mind. Also, a queer space to be free to express my sexuality into my old age”*
- *“To be looked after by people from the same community. Respect and dignity”*
- *“It would make me feel more confident if the home care person was gay or gay friendly”*
- *“Peers supporting peers”*
- *“I don’t want to be surrounded by ‘straight people’”*
- *“To be able to express myself without having to hide”*
- *“They would have to understand the needs of gay men”*
- *“To feel comfortable. Be around my own tribe so to speak”*

- *"I fought too hard for gay rights to be forced back in the closet when I'm old"*
- *"As PLHIV age and become more vulnerable, it intensifies the need for PEER SUPPORT programmes and service delivery. HIV and AIDS has been highly specific health phenomenon and this is my experience caring for my mother for the last 5 years of her life meant I had a lot of interactions with home care and aged care residential services and staff. I witnessed behaviours and attitudes that made it very clear to me that a significant percentage of staff held homophobic beliefs and I have concerns at the prospects of being in the care of such individuals"*

Finally, HIV specialist services were asked who they thought their clients living with HIV would prefer to receive aged care service from, with seven answering the question. Multiple options were available for participants to choose. All services thought their clients would prefer to receive services from an organisation where PLHIV were the care providers (7, 100%) or an organisation where LGBTIQ people were the care providers (7, 100%). This was followed by a non-church-based corporation (6, 85.7%), and a church-based provider (5, 71.4%). Three HIV services (42.9%) thought their clients would prefer to receive services in another way. These ways included:

- *"Just a good provider full stop. Some of our clients like church-based, and others are wary or indifferent. It varies"*
- *"It all depends upon the person's personal beliefs, all agencies would be relevant, also multicultural services"*
- *"I feel this question is not for me to answer. I have selected services that would represent a majority of patients who access the service I work in"*

HIV services thought these preferences were important to PLHIV for the following reasons:

- *"I think they just want to feel supported and not isolated"*
- *"Safety and the ability to be themselves is very important in care. Without fear of discrimination"*
- *"To reduce stigma and discrimination, to ensure the service provider has the ability to understand their needs"*
- *"There is an eclectic mix of LGBTIQ PLHIV in our organisation and all options for aged care services would be sought"*
- *"Our demographic of clients is diverse. It's impossible to generalise"*

Conclusions

The majority of the 198 respondents, including PLHIV, carers/partners, and service providers, expressed a clear preference to remain living in their own home for as long as possible (185, 93.4%). When asked who they would prefer to provide aged care services, the majority indicated a preference for LGBTIQ care providers, followed by PLHIV care providers. Significant concerns remained about faith-based organisations as care providers.

Aged Care for PLHIV with HAND or HAD

During the consultation we asked participants if they had suggestions about how aged care could best be provided to PLHIV with HIV-Associated Neurological Disorder (HAND) and HIV-related Dementia (HAD). No partners, carers, and family members of PLHIV provided responses. There were 61 PLHIV aged 50 years and older in NSW who provided feedback.

The views of respondents broadly fell into two groupings. The first group thought that aged care services needed specialist training to be equipped to provide culturally and medically appropriate care to PLHIV with HAND and HAD. They thought cultural training should be provided by community organisations (who were providing services to PLHIV), and medical training should be provided by specialist support services such as Adahps (formally the AIDS Dementia and HIV Psychiatry Service, located in inner Sydney). The second group thought that aged care for PLHIV with HAND and HAD should be provided by specialist services only, and by specialist services who employ PLHIV with an understanding of these conditions. There was general agreement that mainstream aged care services are not currently equipped to deal with PLHIV with HAND and HAD and that cases of stigma and discrimination are likely without adequate training of aged care staff. Many PLHIV expressed fears that they would not be treated with dignity and respect and they would be trapped in a situation beyond their control.

Significant concerns were reported about the overlap between LGBTIQ lifestyle issues, HAND/HAD, and the potential for acts of discrimination and abuse by aged care staff who hold prejudices about homosexuality, diverse genders, drug use, and HIV. There were calls for person-centred models of care. Concerns were also raised that PLHIV with HAND or HAD may not be able to identify when they are being neglected, abused, discriminated against, or report abuse. Many felt the confluence of these issues would contribute to conditions where abuse and neglect remained hidden for extended periods of time and un- or under-reported.

Concerns were also raised about the provision of aged care to PLHIV with HAND and HAD who reside in rural and regional areas of NSW. Centres of specialist expertise in the clinical management of PLHIV with HAND and HAD are located only in Sydney. Aged care services will therefore need to liaise with centres of clinical excellence (such as St Vincent's Hospital, Sydney) to ensure that PLHIV who experience HAND and HAD receive appropriate clinical treatment, care, and support.

PLHIV with HAND who responded to the survey expressed a desire to be cared for in their own home for as long as possible, by members of the PLHIV and LGBTIQ community. This was primarily due to fears about aged care staff and other residents not understanding their condition and displaying prejudices. Group homes for PLHIV with HAND and HAD were also suggested, the rationale being that several PLHIV could be co-located and receive specialist care simultaneously, thereby providing appropriate care in an economical way.

The following quotes further illustrate these points:

- *"Through home care. I don't want to go into aged care. Also, assistance by a family member (carer)"*
- *"My concern is how these services can be sensitively and privately delivered in a small town with a big gossip environment"*
- *"By aged care service staff being appropriately trained in dealing with HIV, HAND and HAD"*
- *"Sensitivity and reflective of the experience and memory of their life – without judgement"*
- *"With care and support from peers in the community; cared for by people who either live with HIV or are impacted by HIV and are LBGTIQ allies... That our sexuality and our desire is not limited by prejudiced ideas of HIV... or of our gender or that of our partners"*
- *"Ideally have one person I can 'report' issue to instead of several...one on one"*
- *"There needs to be a lot more training with the nursing staff... Younger people with aged care experience, not overseas staff who just want a job. HIV care should be just like any other aged care, but staff need an understanding of HIV"*
- *"A specialised place"*
- *"Residential aged care is already having great difficulty providing adequate training for staff and guaranteeing appropriate care for dementia affected residents"*
- *"Through community groups and NGOs that are part of our communities"*
- *"Through friends and family"*
- *"Partnerships between trained service providers and Adahps"*
- *"Just need to be accepting and inclusive, even if you disagree with choices. You never know the back stories and why should anyone have to explain themselves"*
- *"Specialist 24-hour care. Person centred care"*
- *"...mental health deterioration frightens me more than physical deterioration. Not being able to control your health care and being at the mercy of other's decision making is threatening to me"*
- *"Training for staff to understand behaviours of LGBTIQ people that differs from heterosexuals. This may include hyper sexualisation of people of the same gender, confusion for trans people who have transitioned but have no memory of the transition and regressed to consider themselves as being their birth gender"*
- *"A separate aged care nurse division specifically to deal with PLHIV would be helpful... Stigma is still the single biggest factor out there"*
- *"People with mental illness of neurocognitive impairments will find it difficult to navigate the bureaucracy. Increasingly causing them more harm, or to drop out of the system altogether"*
- *"An existing community-based service organisation in partnership with trusted medical units"*
- *"I think this area is poorly handled. Dementia whether HIV-related or not, use of medication and restraints are not always needed. There needs to be an independent monitor to look at individuals with HAND and HAD. Aged care facilities should not make decisions by themselves"*
- *"Not really but I will avoid it at all costs, they can't force you into car, it is seen as a breach of civil liberties. I will die in my home from neglect before I will go into care. I have written my own enduring guardianship and I will not allow others to make medical decisions for me. Its just another bloody industry"*

Six HIV specialist services in NSW provided similar feedback on how the Australian Government can best deliver aged care services to PLHIV with mental health, HAND, or HAD.

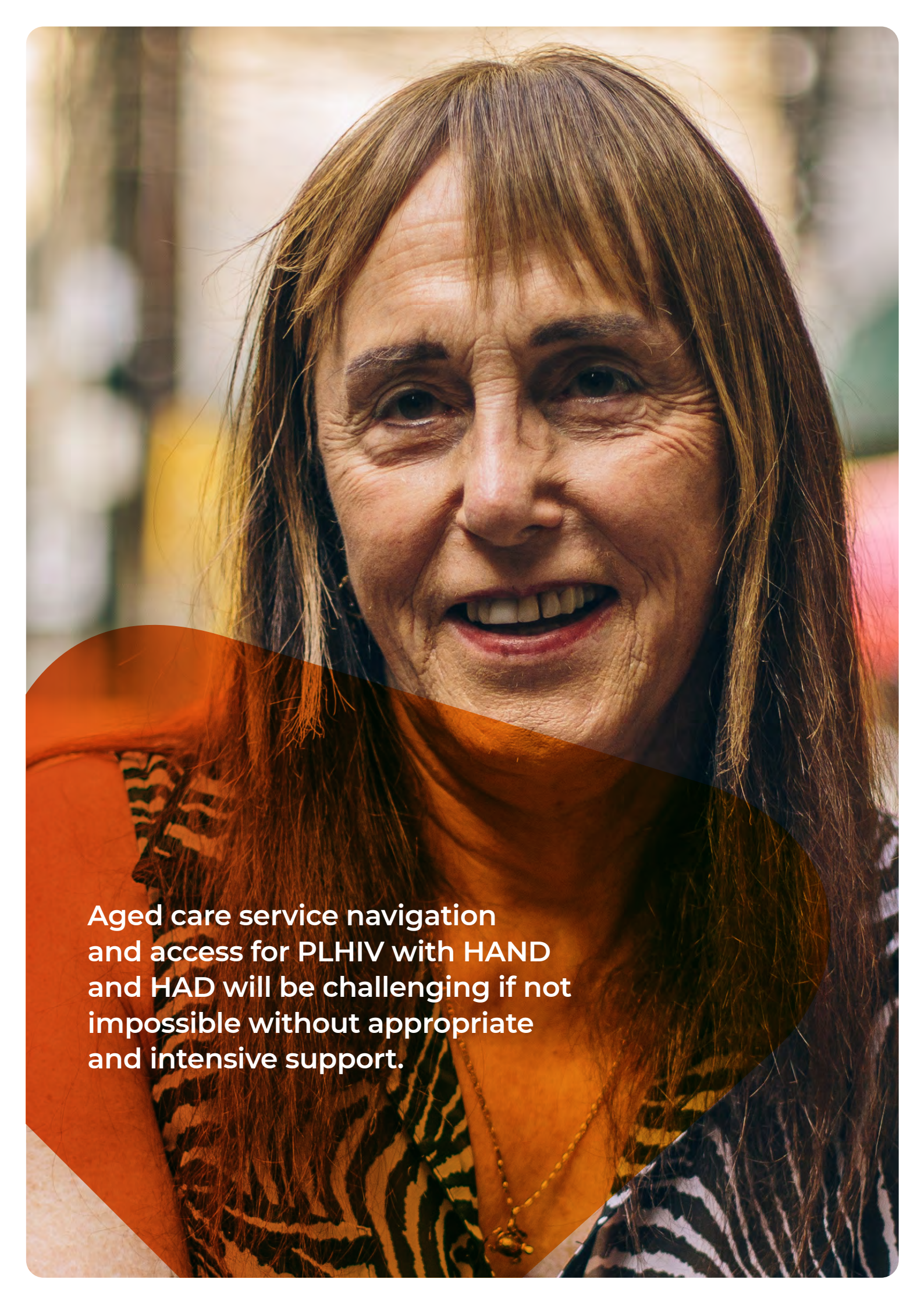
The following quotes illustrate these points:

- *“Good assessment processes and referrals to good agencies”*
- *“Specific training for aged care and home care staff about these issues. Mentoring program with these support staff so that nursing and allied HIV specific health professionals can support workers how to provide additional care (paying the community HIV services to do this)”*
- *“Have a more dignified way in which to support people rather than them walking aimlessly around locked mental health units. Care similar to Yarralla that provides holistic care” (Yaralla House (Dame Eadith Walker House) is a specialist residential care facility for PLHIV with HAND and HAD in Sydney)*
- *“Educate the age care sector to ensure PLHIV are not stigmatised by age care staff relating to their HIV status. Further education to educate the age care sector on issues surrounding ageing, in particular, social isolation”*
- *“Initiate plans prior to aged 65 years allowing clients to have a proactive role in decision making”*
- *“More training for aged care staff. HAND presents differently in each person. Creating communication plans/one-page profiles for clients and their chosen support services”*

Conclusions

There was general agreement across all respondents that mainstream aged care services are not equipped to deal with PLHIV with HAND and HAD and that cases of stigma and discrimination are likely without adequate training of aged care staff. Aged care services will need specialist training to provide culturally and medically appropriate care to PLHIV with HAND or HAD. Aged care service navigation and access for PLHIV with HAND and HAD will be challenging if not impossible without appropriate and intensive support.

Concerns about identifying and responding to abuse and neglect of PLHIV with HAND or HAD remain. Questions of access to appropriate aged care for PLHIV with HAND or HAD in regional or rural areas of NSW also remain.



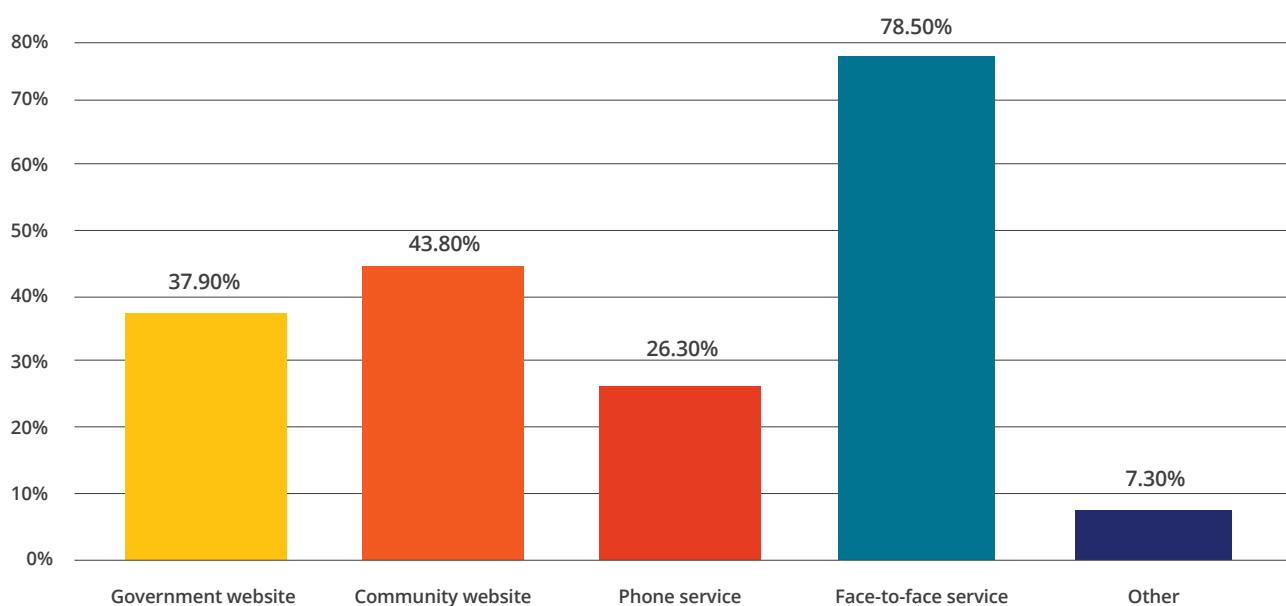
**Aged care service navigation
and access for PLHIV with HAND
and HAD will be challenging if not
impossible without appropriate
and intensive support.**

Aged Care Information and Application Support

There were 185 PLHIV, their partners, carers, and family members who provided feedback about how they would like to get information and support when they needed to apply for aged care services. Respondents could choose more than one option. Most (148, 80%) preferred to receive information face-to-face. This was

followed by a community website (77, 41.6%), a government website (63, 34.1%) and a dedicated phone service (55, 29.7%). 12 participants (6.5%) selected 'other', which included a range of responses such as 'GP', 'HIV-related organisations', 'Email', 'Through case management', and 'Group meetings'. Figure 6 (below) shows the proportional preferences of participants.

Figure 6: PLHIV preference for obtaining Aged Care Information and Application Support



148 PLHIV and their carers provided reasons for these choices. Many thought they would be better informed and better understood by a face-to-face service run by PLHIV, where they could ask specific questions, have issues explained, and the person providing the information would have an understanding of the lived experience and the issues they faced. They thought a peer-run community service would be more empathic to their needs, be more trustworthy, and provide appropriate targeted support. The face-to-face option was even more preferred by older PLHIV,

many of whom reported being technophobic with limited understanding of the internet or ability to access and navigate government or community websites. Many older PLHIV (particularly those over the age of 55 years) also reported not having access to the internet, particularly older rural and regionally located PLHIV. In addition, some reported poor hearing which made phone contact more challenging and difficult. The following responses have been categorised to provide context into PLHIV's reasoning and general preference for face-to-face services.

Lack of computer skills:

- *"My generation generally missed the IT rush, professionally I have never used a computer"*
- *"I'm not a computer person. Too old"*
- *"I have significant problems with computers and technology and my experiences to date, particularly with Centrelink have been frightening"*

Face to face preferences:

- *"I believe to accurately assess a person's needs; it has to be face-to-face"*
- *"Less confusing, greater sense of security, one point of access and not having to repeat yourself"*
- *"I prefer face-to-face as this style is easier, facilitated follow-up questions and is far more personal. As my intellectual capacity weakens, I don't want to have to rely on my ability to navigate around a website"*
- *"Personalised information and support that is relevant to individual needs. We also trust services when we are about to connect to a human or be referred by a peer"*
- *"There should be information and support on government websites. As for a dedicated phone service and face-to-face should exist as does for other ATSI or pensioners"*
- *"I need someone to explain it to me"*
- *"They will have more of an understanding"*

Peer-based preferences:

- *"Government services focus on the public health response, whereas community and peer-based services speak to me as an individual living with HIV"*
- *"Community connection is very important due to the understanding of LGBTQI+ specific issues, this can be done through community websites and face-to-face..."*
- *"Websites can be hard to navigate, but to have someone assist you, A PL advocate, that so much easier"*

- *"As we age, we crave human interaction"*
- *"PLHIV should at least be brokers for services if not providing them. Need face-to-face visit for proper assessment of needs. Need a person with knowledge to advise on what is possible, not rely on guessing"*
- *"It is important that our communities are recognised on government websites as it is usually the first-place people go when considering it. I would go to the community organisation or ring their dedicated phone service to speak to people who identify similarly to me to do a sort of risk assessment; is the service LGBTI friendly, how do they support HIV+ people, are the HIV+ peers employed there, am I going to face discrimination, etc."*

Hearing loss:

- *"I have a severe hearing impediment and go to great lengths to avoid anything on the phone"*
- *"Deafness"*

Accessibility preferences:

- *"They are all important [the different options]. Government websites you access the information and contact details for the phone and face-to-face support"*
- *"I am happy to access information through any avenue that is easy to access and from a reliable source"*
- *"Accuracy of information"*
- *"Easily accessible"*
- *"Support from people who have all the information is imperative"*

Conclusions

Aged care service navigation and access may seem a simple matter to many people, however for PLHIV in poor physical health, with mental health conditions, cognitive impairment, or who do not have anyone to support them, navigating the aged care system can be complex and stressful. This and other consultations Positive Life has conducted, have consistently revealed significant concerns by older PLHIV about where they will go to get information about aged care services and by whom information will be provided. At a time when most government and non-government service information is online, many older PLHIV report government websites difficult to navigate, confusing, and hard to understand. Others don't have access to the internet or choose not to engage with electronic information and mobile devices generally.

Responses indicated that PLHIV prefer a person-centred service approach where information is tailored to their needs by staff who can assist with assessments and service provider linkages and negotiations. It should also be noted that many of the PLHIV respondents have no partners, friends, or family members (53.8%) to help them navigate the aged care service system. This places them in a particularly vulnerable situation. Older PLHIV will need an understanding of support services that can assist them to successfully navigate and apply for aged care services. Many PLHIV respondents indicated they prefer an aged care support service to be operated by other PLHIV, due to fears of stigma and discrimination.

Many of the PLHIV respondents have no partners, friends, or family members to help them navigate the aged care service system. This places them in a particularly vulnerable situation.

Conclusions

The Royal Commission into Aged Care Quality and Safety has provided PLHIV and the organisations representing them (in NSW, Positive Life NSW) with a unique opportunity to inform the Australian Government on how the aged care sector can better meet the diverse and evolving needs of older Australians living with HIV. This survey was the first of its kind in Australia to comprehensively investigate Australian PLHIV's uptake of and attitudes to aged care.

Comparison of PLHIV needs of those aged 65 years and older and those aged 50 to 64 years demonstrated similarly high proportions of comorbidity, having no support, and experiencing moderate and extreme physical functional limitations. The Australian Positive & Peers Longevity Evaluation Study has reported that PLHIV in the 50 to 65 years and older age group experience the poorest health of any age group.⁷ Findings from this consultation identified low rates of aged care service uptake by PLHIV and by their partners, family members, and carers.

Many PLHIV reported holding deep fears of engaging with existing mainstream aged care services. This was because of the potential for acts of stigma and discrimination by aged care service staff who hold prejudicial views about HIV, homosexuality, diverse genders, and drug use. To obviate this risk, many PLHIV reported a preference to receive aged care in their own home from LGBTIQ people who were community attached, or other PLHIV who understood their unique lived experiences and who would not stigmatise or discriminate against them. The preference for aged care services from other PLHIV and LGBTIQ people not only extended to service provision, but also to the seeking and receiving of information about assessment, service availability, and the application processes.

References

1. Antiretroviral Therapy Cohort Collaboration. *Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies*. Lancet. 2008;372:293–299.
2. Jansson, James. and Wilson, David. & Watson, Jo. & National Centre in HIV Epidemiology and Clinical Research (Australia), issuing body. *Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia* National Centre in HIV Epidemiology and Clinical Research Darlinghurst, NSW 2010.
3. Feeney, L. *Australian People Living With HIV & Aged Care*. Positive Life NSW, Sydney, 2019.
4. Commonwealth of Australia, *Quality Standards Consumer Resources*, Aged Care Quality and Safety Commission, 2019, www.agedcarequality.gov.au/consumers/standards/resources accessed 15 October 2020.
5. Feeney, L. *Australian People Living With HIV & Aged Care*. Positive Life NSW, Sydney, 2019.
6. Commonwealth of Australia, *Am I Eligible?*, My Aged Care, n.d., www.myagedcare.gov.au/am-i-eligible accessed 6 April 2020.
7. Petoumenos, K. et al. "Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years-The Australian Positive & Peers Longevity Evaluation Study (APPLES)." PloS one, vol 12(9), e0184583. 8 Sep. 2017, doi:10.1371/journal.pone.0184583



For more information phone 02 9206 2177 or 1800 245 677 (freecall)
or visit www.positivelife.org.au