

*“Ageing and aged care  
are not exciting  
prospects for anyone.  
It is likely to be a worse  
experience when living  
with HIV”*

(PLHIV consultation participant)

# Australian People Living with HIV & Aged Care

December 2019

**PositiveLifeNSW**  
the voice of people with HIV since 1988

## DEDICATION

*In memory of the Australian men and women who lived with HIV from earlier years who did not have the opportunity to survive into old age.*

*On their shoulders, we now stand!*

## ACKNOWLEDGEMENTS

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- Living Positive Victoria
- Positive Life South Australia
- Queensland Positive People
- Positive Organisation Western Australia

## ENDORSEMENTS

The following organisations support the statements and recommendations provided to the Royal Commission into Aged Care Quality and Safety in this Positive Life NSW submission: the National Association of People with HIV/AIDS (NAPWHA), Queensland Positive People, Living Positive Victoria, Positive Women Victoria, Positive Life South Australia, Positive Organisation Western Australia, Health Consumers NSW, the AIDS Council of NSW (ACON), and the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM).



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## THIS SUBMISSION

This submission is made by Positive Life NSW (Positive Life). Positive Life is the non-government peer-led organisation representing people living with HIV (PLHIV) in NSW.

### OBJECTIVES OF THE SUBMISSION

The objectives of this submission are to:

- Respond to the Royal Commission into Aged Care Quality and Safety (the Royal Commission) Terms of Reference with direct input from PLHIV, their care givers, partners and friends, and HIV service providers
- Respond to the Royal Commission's Terms of Reference by citing relevant Australian research on the Australian HIV epidemic and its impacts
- Provide recommendations for how aged care can better meet the diverse and evolving needs of Australian PLHIV.

This submission responds to Terms of Reference that Positive Life is qualified to answer; i.e. they directly impact upon the lives of ageing PLHIV. The Terms of Reference responded to are:

- The quality of aged care services provided to Australian PLHIV, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and the actions that should be taken in response;
- How best to deliver aged care services to 1) people with disability (in this particular instance, PLHIV), and 2) the increasing number of Australian PLHIV living with dementia (i.e. people with HIV-associated neurological disorder [HAND] and people with HIV-associated dementia [HAD]); and
- The future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including 1) in the context of changing demographics and preferences in particular people's desire to remain living at home as they age; and, 2) in remote, rural and regional Australia.

### BACKGROUND

While the health and wellbeing of younger PLHIV has markedly improved, concerns about ageing PLHIV are increasing. Concerns about ageing PLHIV have been increasing since the mid-2000s, however, the issue of ageing PLHIV came more starkly into focus when NAPWHA commissioned the Kirby Institute to investigate patterns of demographic shifts and trends in the Australian HIV-positive population in 2010. The core objective of the Kirby Institute research was to investigate the issues and build an evidence base to inform future policy development and planning within the national and jurisdictional HIV responses. The research found that the population of PLHIV had aged substantially. It predicted by 2020, nearly half (44.3%) of PLHIV would be 55 years and over. This finding alerted policy makers and HIV services to start advocating for the future service needs of an ageing PLHIV population. Since that time, there has been further Australian research into the issues of ageing PLHIV, and this submission has utilised this research to address various questions posed by the Royal Commission's Terms of Reference.

## RESEARCH QUESTIONS FOR THIS SUBMISSION

In developing this submission, the following questions have guided the gathering of data and the consultation with PLHIV, their care givers, and HIV services:

1. What are the demographic characteristics of Australian PLHIV (2019 and beyond)? How do these characteristics impact on the current and future aged care needs of older Australian PLHIV?
2. What are the rates of chronic physical and mental health conditions in ageing PLHIV? Do these physical and mental health conditions result in functional limitation and to what extent do they limit activities of daily living?
3. How do the social determinants of health compound and impact on physical and mental health outcomes and contribute to functional limitation and the need for support services?
4. Do aged care services meet the current and future needs of PLHIV? If not, what would improve service provision, safety and quality, and make aged care services more responsive to the needs of PLHIV?
5. Are there gaps in aged care services and the system in general? For example, are there PLHIV who need support services but are ineligible because they do not meet eligibility requirements?
6. Is there mistreatment, abuse and/or discrimination of PLHIV by aged care service staff, and if so, what kinds of abuse, neglect and/or discrimination are experienced?
7. How should aged care services be provided to PLHIV with neurological or psychiatric conditions?
8. How will aged care services be provided to ageing PLHIV with complex care needs?
9. What are PLHIV's preferences about where and by whom aged care services are provided?
10. What help do PLHIV need to navigate and engage with aged care services and how can that information/support be optimally provided?

## SPECIAL NOTES

This submission deals with Australian people living with diagnosed HIV. It does not include people living with undiagnosed HIV. In 2017, there were an estimated 2,899 people (11% of all PLHIV), living with HIV who were unaware of their HIV status (undiagnosed), (Kirby Institute 2018). The proportion of undiagnosed PLHIV was estimated to be higher in females (13%), than males (10%), and higher in Aboriginal and Torres Strait Islander people (14%), than in the Australian-born non-indigenous population (10%), (Kirby Institute 2018). People born in Southeast-Asia had the highest proportion of estimated undiagnosed HIV (27%), compared with people born in sub-Saharan Africa (13%), and other countries (10%), (Kirby Institute 2018).

## RECOMMENDATIONS

### PREFACE

The provision of quality non-discriminatory aged care services to PLHIV in home care or residential settings presents a unique health and care challenge for the Australian Government. The recommendations in this submission provide a pathway based on evidence to assist the Commonwealth and the aged care service sector to:

- a) Increase the quality of and access equity to aged care services by Australian PLHIV; and
- b) Ensure and enable aged care services meaningfully engage with and meet the Australian Aged Care Quality Standards (ACQS) in relation to PLHIV.

### A NOTE ON AGED CARE QUALITY STANDARDS

The recommendations in this submission relate to our understanding of the ACQS, which are briefly:

- a) Standard 1: Dignity and respect
- b) Standard 2: Partnership
- c) Standard 3: Safe and correct care
- d) Standard 4: Independence
- e) Standard 5: Feeling safe and comfortable with services
- f) Standard 6: Being able to give feedback or make a complaint
- g) Standard 7: Knowledge of service staff
- h) Standard 8: Services are accountable

### RECOMMENDATIONS:

- 1) **Mandatory education and awareness training for aged care services (to meet ACQS 1, 3, 5, and 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;
  - HIV and other blood borne viral transmission risk and prevention procedures;
  - privacy and confidentiality requirements for aged care service staff;
  - HIV-associated stigma and discrimination and its impacts on physical and emotional health;
  - cultural awareness on the diversity of populations with HIV, sexual identity, gender dysphoria, and recreational drug use; and
  - 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 increased 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 of Australia 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 comorbidity;
  - 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; and
  - fly-in/fly-out s100 prescribers to manage HIV and non-HIV related health conditions for PLHIV.
- 6) **Improving access to and uptake of aged care services (to meet ACQS 2, 3, and 4)** - In view of the low rates of aged care service uptake by PLHIV, their partners and carers (identified in the consultation), 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 LGBTI 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); and
  - remove structural and compliance barriers preventing not-for-profit (NFP) organisations (such as Positive Life NSW) to become accredited care providers of home-based care services to PLHIV.
- 7) **Increase funding for home-based support services (to meet ACQS 4)** - to 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 away from for-profit providers, for both home-based aged care services and residential aged care services. For-profit providers will be more inclined to operate in an environment where profit margins are maximised at the expense of care recipients. This needs to change. Religious institutions and for-profit corporations are not always best placed to provide quality aged care services to PLHIV and other ageing Australians. NFP organisations should be considered on merit and qualitative measures, rather than primarily quantitative measures.
- 9) **The role of community organisations (to meet ACQS 1, 3, 4, 5, and 7)** - Community organisations which are peer based (like Positive Life NSW) are uniquely positioned to offer

patient-centred, peer-based training components. PLHIV understand the health and social issues faced by other PLHIV and the potential contexts in which stigma and discrimination can occur. Positive Life NSW and other jurisdictional PLHIV organisations 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).

## EXECUTIVE SUMMARY

### ABOUT THIS SUBMISSION

This submission by Positive Life NSW (Positive Life), uses Australian HIV research and findings from a 2019 national consultation of people living with HIV (PLHIV), their partners, carers and family members, as well as specialist HIV services, to respond to the Royal Commission's inquiry into Aged Care Quality and Safety (the Royal Commission) Terms of Reference.

### BACKGROUND

The introduction of highly active combination antiretroviral therapy (ART) in Australia (1996) significantly improved the prognosis of PLHIV. The early drugs were ineffective and produced a range of serious and debilitating side-effects, however, over time, the efficacy and tolerability of ART improved. Modern ART has very few side-effects and the vast majority of PLHIV are able to reduce the amount of HIV virus in their blood to very low levels and prevent HIV disease progression. This means that PLHIV who take ART, no longer go on to develop AIDS and are unable to sexually transmit HIV, if their viral load is below 200 copies per ml.

The reduced mortality rates in PLHIV after the introduction of ART in 1996, led to an increasing Australian population of PLHIV. For example, even if the number of people infected with HIV significantly decreases over the coming decade (due to the impacts of ART and pre-exposure prophylaxis on transmission), the population of Australian PLHIV will exceed 30,000 by 2027. The PLHIV population is also ageing. In 2017, 25.51% of PLHIV were 55 years and over (n=6290) and 10.75% were 65 years and over (n=2650). By 2025, these proportions will have increased to 33.98% of PLHIV 55 years and over (n=10940) and 16.98% of PLHIV 65 years and over (n=5467). It is worth noting that the proportions of PLHIV in older age brackets will continue to increase, which will lead to an increasing demand on aged care services by this population.

### DISTRIBUTION OF PLHIV IN AUSTRALIA

The Australian PLHIV population density varies significantly across Australia. Currently, states with the largest populations of PLHIV in 2017, were New South Wales (9,475), Victoria (6,559) and Queensland (4,865). Western Australia (2,136) and South Australia (1,292) had smaller populations of PLHIV. Tasmania, the Australian Capital Territory and the Northern Territory have very small populations of PLHIV (less than 370 respectively). Most PLHIV live in major capital cities (Sydney, Melbourne, Brisbane, Perth and Adelaide - in that order). There are small populations in rural and regional areas (generally less than 20%), except in Queensland where about half of the PLHIV population live in regional, rural and remote areas. Providing quality aged care to PLHIV with complex care needs in metropolitan areas, will challenge aged care services. However, the provision of aged care to PLHIV with complex care needs in regional, rural and remote areas of Australia, will be even more difficult. Small populations are spread over large geographic areas and access to HIV specialist clinical care, is often extremely limited.

## CULTURAL CHALLENGES FOR AGED CARE SERVICES AND PLHIV

There are cultural challenges ahead for aged care services providing home-based and residential aged care to PLHIV. The majority of older PLHIV are gay, bisexual or other men who have sex with men (GBMSM). Many grew up in a time when homosexuality was illegal, where GBMSM were routinely socially marginalised, often bullied or bashed. They sought safety and freedom of expression in an international community of other GBMSM. The advent of HIV/AIDS in the early 1980s, decimated these communities and left many GBMSM in a fragile and vulnerable mental and physical state. Many died from AIDS, and those that survived still carry the physical, emotional and financial scars from that time.

HIV remains a highly stigmatised disease, even in the current era. Despite ART reducing the risk of mortality and HIV sexual transmission, many people continue to hold prejudices around homosexuality and drug use. While GBMSM can, to some degree, shelter from the worst cases of stigma and discrimination within their communities, heterosexual men and women living with HIV often must deal not only with HIV stigma, but also with stigma associated with drug use and sex work. Heterosexual men living with HIV endure the presumption that they are gay or an injecting drug user. Heterosexual women living with HIV are often discriminated against and assumed to be a sex worker or an injecting drug user. Trans and gender diverse PLHIV live with multiple layers of stigma and discrimination. The effects of stigma on PLHIV (gay, heterosexual, bisexual and trans) have been profound. The provision of non-discriminatory aged care to PLHIV will challenge aged care services who employ staff who hold deeply held fears and prejudices about homosexuality, illicit drug use, sex work, gender dysphoria, and by association, HIV.

## CLINICAL CHALLENGES FOR AGED CARE SERVICES INVOLVED IN THE CARE OF PLHIV

The clinical management of HIV can only be conducted by accredited practitioners (s100 prescribers), who are specialists trained in the clinical management of HIV. If the aged care facility doctor is not an accredited s100 prescriber (which is unlikely), it will be necessary for aged care facilities to organise an s100 prescriber to share care with the facility GP, or for an s100 prescriber to visit the facility and provide specialist HIV care. Unfortunately, availability of s100 prescribers outside major metropolitan areas is extremely limited. The provision of HIV specialist clinical care for PLHIV in facilities located in regional areas, will be difficult to arrange, and may require facilities organising fly-in/fly-out specialist clinical care. Ageing PLHIV who live independently in remote and rural areas will also challenge aged care services, particularly transport services. As PLHIV become increasingly immobile and unable to transport themselves (drive) to medical appointments (both for the management of HIV and other chronic health conditions) there will be calls for aged care services to assist these individuals. This may involve services travelling long distances and, in some cases, transporting PLHIV from a regional, rural or remote area to a specialist in a capital city and back again.

The clinical management of other chronic health conditions in PLHIV, will additionally challenge care teams in residential aged care facilities. All PLHIV experience comorbidity at higher rates than the general population. For example, HIV positive gay men experience comorbidity at two to three times the rate of HIV-negative gay men and at substantially higher rates than the general population. They also experience a significantly increased number of comorbidities. Conditions can include thrombosis, diabetes, heart disease, HIV-associated neurological disorders, impaired renal function, osteoporosis, non-AIDS related cancers, and mental health conditions. Comorbidity will result in poorer health and reduced physical function, particularly in relation to performing activities of daily living (bending, stooping, kneeling, walking etc). Functional limitations will increase the demand for

home-based aged care services, but also for residential aged care, when PLHIV can no longer maintain independent living arrangements.

### DANGERS OF POLYPHARMACY

The increased prevalence of multimorbidity in combination with HIV, means that older PLHIV will generally be prescribed multiple medicines for the treatment of HIV and other chronic health conditions. Adherence to prescribed medicines will be crucial in preventing further disease progression and premature death. However, PLHIV experiencing mental health conditions, illicit drug and alcohol misuse, overuse of prescribed narcotic analgesics, sleeping pills, as well as the impacts of HIV-associated cognitive impairments, may be at increased risk of non-adherence, health care disengagement, falls, fractures, overdose, admission to hospital, and premature death. In circumstances where PLHIV live alone with limited support, visiting home-based aged care service staff may be the only people able to identify and prevent misadventure and premature death from non-adherence to prescribed medicines, or drug-to-drug interactions and overdose. Concerns have also been raised about aged care service staff who hold prejudices around misuse of medicines and use of illicit drugs, behaving in inappropriate ways to clients with HIV. PLHIV deserve to be treated with dignity and respect by aged care service staff, irrespective of their decisions.

### IMPAIRMENT IS NOT ALWAYS DIRECTLY RELATED TO CHRONOLOGICAL AGE

It should be noted that Australian HIV research (APPLES and HIV Futures) have identified that PLHIV aged 55-64 years report poorer overall health than any other age group, including those aged 65 years and over. The principal concerns in this group are poor physical health, poor mental health, reduced social connection and support, financial insecurity, and the need to manage serious multiple complex health conditions. More than a quarter (26%) of PLHIV aged 55 years and over also report moderate physical limitations, and 13% report severe physical functional limitation. Physical functional limitation is characterised by reduced capacity to undertake activities like stooping, bending, kneeling, carrying, and walking or climbing stairs. PLHIV who experience physical functional limitation and live independently are more likely to require home-based assistance to maintain activities of daily living. If home-based services are unable to be provided, due to age restrictions and ineligibility, PLHIV with physical functional limitation will experience premature health deterioration and premature admission to hospital, and then an aged care facility.

### SOCIAL FACTORS AFFECTING OVERALL HEALTH AND FUNCTION

There are a range of social factors that have negatively impacted on the lives and health of PLHIV. These social factors are experienced by older PLHIV, who were diagnosed in the pre-ART era and have survived into the current era. Many not only deal with their own health issues but lost multiple partners and extensive social networks to AIDS. They were forced to leave employment and became reliant on welfare. Consequently, many now live in poverty, in public housing, and have never had the opportunity to amass savings, superannuation or assets. In addition, they have faced down HIV-related stigma from the general community. It is no wonder that many express fears about their future, their increasingly poorer health, losing independence, losing cognition, and dealing with loneliness and potential discrimination from people in aged care services who may hold deeply held prejudices about homosexuality and HIV. The recent media coverage of physical and emotional abuse by aged care service staff has intensified concerns by PLHIV, that they will be treated without dignity and respect.

## THE USE OF AGED CARE SERVICES BY PLHIV

In our consultation,<sup>1</sup> only 23% of PLHIV aged 65 years and over, use aged care services. The outcome was surprising, considering the prevalence of multiple debilitating chronic health conditions in this group, the levels of physical functional impairments, and the finding that 40% live alone and have no partner to assist them with activities of daily living. While 40% intended to apply for services in the future (predominantly home care services) and a third were currently unsure whether they would apply or not, more than one in ten reported they would not apply. This was primarily due to fears they would be stigmatised and discriminated against by aged care service staff, who hold prejudices about homosexuality, drug use, and gender dysphoria.

38.8% of PLHIV aged 50-64 years, reported receiving support services. We were unable to assess what proportion of support services were provided by HIV community health organisations and what proportion were provided by aged care services. As previously stated, this group experience the poorest physical and mental health of any PLHIV age group, including those aged 65 years and over. The impact of multiple debilitating chronic health conditions means that many PLHIV in this age group experience physical functional limitations which affects their ability to perform activities of daily living and take care of routine household responsibilities. Some even reported difficulty washing and dressing themselves. In addition, more than half (56.2%) live alone. Consideration should therefore be given to easing eligibility restrictions and assessing these PLHIV according to levels of physical functional limitations, as well as other presenting health and social factors. Denying PLHIV (in the 50-64 age group) services, will only exacerbate premature physical and mental health deterioration and lead to unnecessary hospital admissions or premature relocation into a residential aged care facility.

The proportion of PLHIV who were being cared for by a partner or family member and received aged care services was very low (3%). This was despite a high proportion of the partners/carers being themselves aged and living with multiple chronic health conditions including HIV. Many partners/carers felt extremely vulnerable to a generally worsening situation where they would no longer be able to care for their loved one and be forced to split-up. For the minority who did receive aged care, most were satisfied, however there were complaints, principally about the lack of service coordination and poor quality of home-care service staff.

Three quarters of HIV services had clients living with HIV who were receiving aged care. Most received home-based services. This implies that PLHIV who are connected to these HIV specialist services, are more likely to apply for and receive aged care packages. Many services, however, thought aged care did not meet the needs of their clients. They reported a lack of available services, excessive waiting times for aged care assessments, poor levels of understanding of HIV, treatment and transmission dynamics.

## SUBSTANDARD CARE, MISTREATMENT, NEGLECT AND ABUSE OF PLHIV

There were complaints about substandard care. These were primarily in relation to poor service coordination and the quality of services provided. A significant number of complaints were about aged care service staff being poorly trained, being rude and unhelpful, and in some cases, patronising and disrespectful. There were also complaints about poor communication skills, the need for better service coordination and the need to reduce long waiting times for services.

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<sup>1</sup> A national consultation of PLHIV, their partners, care givers and HIV specialist services, conducted by Positive Life NSW for this submission in 2019.

We received reports of discriminatory behaviour by staff who have no or limited knowledge of HIV. Some feared they would be infected. There were also examples reported of discrimination by workers who were homophobic. Acts of discrimination ranged from being ignored, shamed and silenced, to outright refusals to provide service. Abuse and neglect primarily resulted from ignorance and fear on the part of aged care service staff about HIV, HIV treatment, and the negligible risk of transmission to staff or other residents. Some of these reports were reminiscent of abuse and neglect during the very early days of the HIV epidemic in Australia. At that time, hospital staff refused to enter rooms, due to fears of HIV transmission. Food was left on trays outside doorways, and patients were neither showered nor cared for. The potential for abuse by aged care service staff who hold prejudices is of real concern. Education about HIV will be needed to ensure that services are provided in a respectful and non-discriminatory manner. Peer-led organisations such as Positive Life NSW are best placed to provide HIV education to aged care services, and need to be resourced to do so

### PROVIDING AGED CARE TO PEOPLE WITH HIV-ASSOCIATED NEUROLOGICAL DISORDER [HAND] AND HIV-ASSOCIATED DEMENTIA [HAD]

The prevalence and future impacts of HAND and HAD are yet to be fully understood. There are, however, significant numbers of older PLHIV who are thought to be at risk of HAND, particularly those who were diagnosed in the pre-ART era and who lived for extended periods of time with very low CD4 cell counts. Some researchers believe that the impacts of HAND will not be fully apparent until a significant proportion of PLHIV are aged 60 to 70 years and over. If HAND progresses to more severe forms of dementia, the clinical management of people with HAND and HAD will challenge aged care providers, particularly in regional and rural areas of Australia, where access to specialist knowledge and treatment is non-existent. Currently, clinical centres of excellence in HAND and HAD are restricted to inner Sydney, Melbourne, and to some extent, Brisbane.

There were calls for specialist HIV services that manage PLHIV with HAND and HAD to provide training to staff who care for clients with these disorders. There were also significant concerns expressed about the overlap between homophobia, illicit drug use, HIV, HAND and the potential for acts of abuse, neglect and discrimination of clients with HAND and HAD. Acts of abuse and neglect could remain hidden and unreported for long periods of time because people with HAND and HAD would not necessarily be aware they were being abused. Services in regional, rural and remote areas of Australia, who don't have access to centres of excellence in the clinical management of HAND and HAD will struggle to provide appropriate and high-quality treatment and care.

### PREFERENCES ABOUT WHERE AGED CARE SERVICES ARE PROVIDED AND BY WHOM

An overwhelming majority of PLHIV (95%) wanted to remain living in their home until it became impossible for them to manage any longer. They wanted to receive services from LGBTIQ people or other people living with HIV. The primary reasons were due to a deep and abiding distrust and loathing of faith-based institutions and their acts of marginalisation and discrimination against LGBTIQ people, particularly older gay men. Many reported having no confidence they would be cared for in a respectful and dignified way by faith-based services. Some reported they would rather suicide than be cared for by a religious/faith-based organisation.

## PREFERENCES WHERE INFORMATION ABOUT AGED CARE SERVICES ARE PROVIDED AND BY WHOM

A clear majority of PLHIV wanted to receive information about aged care services via a peer-run face-to-face service. Older PLHIV preferred a face-to-face service model, because they believed they would receive reliable, targeted, high quality information and support, and be treated with understanding and respect. There was limited support for websites. Many older PLHIV are technophobic or do not engage with or have access to the internet. Similarly, phone services were not popular because many older PLHIV have hearing impairments.

## IMPROVING QUALITY, SAFETY, CHOICE AND ENGAGEMENT WITH AGED CARE SERVICES BY PLHIV

Considering the extent of disengagement by PLHIV aged 65 years and over, the lack of uptake of aged care services, and fears about mistreatment and abuse by aged care service staff, there are ethical and practical reasons why community not-for-profit organisations (like Positive Life in NSW and other HIV organisations in other states and territories) should provide aged care services to PLHIV. There are, however, structural, compliance and financial disincentives that prevent participation. The Commonwealth Government could improve the long-term utilisation of the aged care service system by reviewing the process for becoming an accredited My Aged Care provider and making it less onerous for community not-for profit organisations to provide high quality and responsive home-based care to their identifying communities – in this case, PLHIV (one of the most stigmatised groups in Australian society).

## METHODOLOGY

This submission preferences Australian HIV research before international HIV research. This is because the Australian HIV epidemic is different to the HIV epidemic in other parts of the world (for example Africa, the United States of America, Europe or Asia). We have therefore drawn evidence from a range of peer-reviewed Australian literature published by the following research institutions:

- Kirby Institute (University of New South Wales)<sup>2</sup>
- Centre for Social Research (University of New South Wales)<sup>3</sup>
- Australian Research Centre in Sex, Health and Society (La Trobe University, Melbourne)<sup>4</sup> and,
- Other publications (individually listed).

Where no Australian research was available, international research has been referenced.

### PRINCIPAL RESEARCH PUBLICATIONS USED IN THIS SUBMISSION:

#### Epidemiology

HIV is a notifiable disease in each Australian state/territory health jurisdiction. All new HIV diagnoses are reported by doctors and laboratories to state/territory health authorities. The *2018 Annual Surveillance Report* (Kirby Institute) is the 22<sup>nd</sup> annual review of Australian HIV health surveillance data and includes the proportions of PLHIV in Australia.

#### Demographic shifts among Australian PLHIV

Older PLHIV, aged 50 years and over, present a unique population that requires special care. In 2010, NAPWHA commissioned the Kirby Institute to estimate the current and future size, age and location of PLHIV in Australia. The study (*Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*) estimates population changes at a statistical regional level, trends in HIV and gender, and age distribution. This work has recently been reviewed and updated by the Kirby Institute (*Ageing of the HIV Population in Australia: A Modeling Study*) (2018). The study estimates the number of diagnosed men and women in Australia between 1986 and 2026, by five-year age groups, if current notification rates continue and if rates decline.

#### The health, socio-economic, and geographic contexts of Australian PLHIV

The Australian Research Centre in Sex, Health and Society (ARCSHS) (La Trobe University) conducts the *HIV Futures* studies. There have been eight *HIV Futures* reports between 1996 and 2016. The most recent iteration being *HIV Futures 9* which is due to report. The study provides invaluable information on the health and wellbeing of Australian PLHIV, including data on physical and mental health, access to health and other support services, the social world of PLHIV, and trends in accommodation, employment, finances, and discrimination.

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<sup>2</sup> The Kirby Institute (UNSW) is a leading global research institute dedicated to the prevention and treatment of infectious diseases including HIV.

<sup>3</sup> The Centre for Social Research in Health (UNSW Arts and Social Sciences) undertakes social and behavioural research in health that inform and strengthens knowledge, policy and practice.

<sup>4</sup> The Australian Research Centre in Sex, Health and Society (ARCSHS) is a centre for social research into sexuality, health and the social dimensions of human relationships. It works to produce research that advances knowledge and promotes positive change in policy, practice and people's lives.

*Futures 8* was completed by approximately 900 Australian PLHIV. The sample is made up of 84.3% GBMSM, with 56.3% aged 50 years or over. While not necessarily representative of the Australian PLHIV population generally, *HIV Futures* provides an invaluable data set for older male PLHIV.

#### HIV and clinical care

*The Australian HIV Observational Database (AHOD)* (Kirby Institute) is an observational cohort study of more than 4,000 HIV-positive Australians receiving routine clinical care. It was established in 1999 to monitor treatment uptake and outcomes. Since its inception, AHOD has provided the best available surveillance data on trends in antiretroviral treatment uptake and use in Australia and has a central role in State and Commonwealth Health Departments planning HIV care.

#### The prevalence of self-reported comorbidities in Australian PLHIV

*The Australian Positive and Peers Longevity Evaluation Study (APPLES)* (Kirby Institute) is a prospectively recruited cross-sectional sample of 228 HIV-positive and 218 HIV-negative gay and bisexual men (GBM) aged 55 years and over. The study investigates the prevalence of age-related comorbidities and risk factors among these two cohorts and provides our most accurate data on the rates of comorbidity in PLHIV and the rates of physical limitations associated with poorer health outcomes.

### ADDITIONAL DATA REQUESTS MADE TO KIRBY INSTITUTE AND ARCSHS PRINCIPAL INVESTIGATORS

Additional data was requested from principal investigators of some studies listed above. The data requests were as follows:

- Kathy Petoumenos (Principal Investigator of APPLES). Assess the degree (prevalence) and risk factors for physical functional limitations within the APPLES cohort and compare results between HIV-positive and HIV-negative GBM aged 55 years and over
- Jennifer Power (Principal Investigator of *HIV Futures*). Investigate the relationship between ageing and physical health/physical functioning in PLHIV. What factors support physical health/physical functioning among PLHIV aged 55-64 years and 65 years and over? What is the relationship between ageing and mental health in PLHIV? What factors support good mental/emotional health among PLHIV aged 55-64 years and 65 years and over?
- Richard Gray (Senior Research Fellow in Surveillance, Evaluation and Research, Kirby Institute). Provide up-to-date data on the numbers of Australian PLHIV at various time intervals (2010, 2017, 2025 and 2030). The analysis also included providing population estimates for Australian states and territories at each time period.

In addition, we requested expert opinion from Lucette A Cysique, on HAND and HAD and the future impacts on aged care.

### GATHERING EXPERIENTIAL DATA ON AGED CARE SERVICES

No published literature could be found on the experiences of PLHIV using Australian aged care services. To address the deficit, Positive Life developed a national anonymous electronic survey. The survey targeted PLHIV, their care givers, partners and family/friends, HIV service providers, and aged care service providers. Participants were asked a series of open-ended and closed questions. These included questions on:

- Health
- Participants ability to perform activities of daily living

- Experiences with aged care services and whether aged care services met needs
- Levels of satisfaction with aged care services and suggestions about how services could be improved
- Gaps in aged care service provision (i.e. ineligible PLHIV who needed services)
- Examples of mistreatment, abuse or neglect of PLHIV using aged care services
- Suggestions about how aged care services could be provided to people with HAND and psychiatric conditions
- Preferences about where and how aged care services are provided to PLHIV
- Preferences about how PLHIV receive information about aged care services.

## AGEING AUSTRALIAN PLHIV – THE EVIDENCE

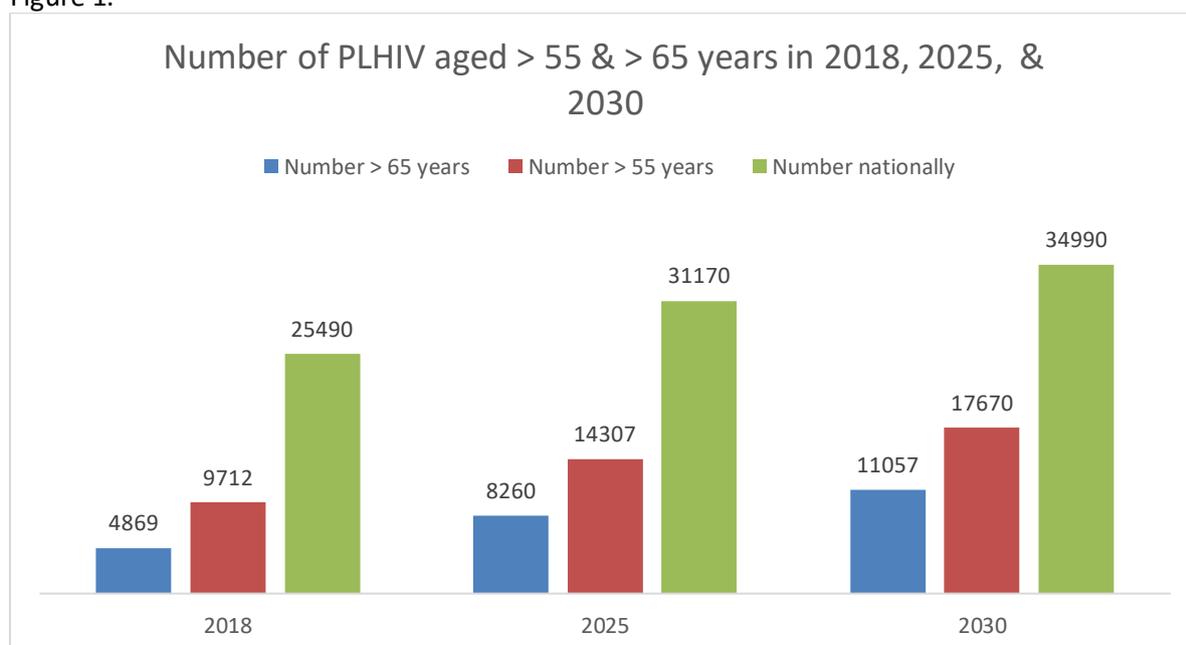
### AN AGEING PLHIV AUSTRALIAN POPULATION

The first Australian cases of HIV and AIDS were diagnosed in Sydney in 1984. The introduction of antiretroviral therapy (ART) in 1996 vastly improved survival of PLHIV by preventing HIV disease progression and death from AIDS. Consequently, the Australian PLHIV population is increasing. In 2010, there were 17,960 Australian PLHIV. In 2018, this number had increased to 25,490, and will further increase to 31,170 in 2025 and 34,990 by 2030 (Gray 2019).

The Australian PLHIV population is also ageing. In 2010, 12.0% of PLHIV were aged 65 years and older. In 2018, the proportion had increased to 19.1%. By 2025, the proportion of PLHIV aged 65 years and older is estimated to be 26.5%, and by 2030, it is estimated to be 31.6%. Similarly, the proportion of PLHIV aged 55 years and older, is also increasing (Gray 2019).

Figure 1. shows the numbers of Australian PLHIV aged 55 years and older, 65 years and older, and the total Australian PLHIV population at time periods, 2010, 2018, 2025 and 2030.

Figure 1.



## Significance

There is an increasing number of PLHIV, who are, or will be, aged 65 years and older, and eligible for aged care over the next 10 years, (4,869 in 2018, 8,260 in 2025, and 11,057 in 2030). In addition, there is a growing number of PLHIV aged 55 years and older, who will become eligible for aged care (during the next 10 years), as they reach age 65.

## THE DISTRIBUTION OF AUSTRALIAN PLHIV IS NOT UNIFORM

The population density and distribution of ageing Australian PLHIV varies substantially for states and territories. Table 1. below, provides the overall estimates and proportions of PLHIV nationally, and in each Australian jurisdiction - overall, and for PLHIV aged 55 years and older, and 65 years and older. The estimates were created by the Kirby Institute (2019), using the HIV cascade methodology (Gray 2019).

Table 1.

State/Territory	2018		2025		2030	
	Number of PLHIV	% All	Number of PLHIV	% All	Number of PLHIV	% All
National	25,490	100%	31,170	100%	34,990	100%
New South Wales	9,640	37.1%	11,250	35.7%	12,330	35.0%
Victoria	6,760	26.0%	8,630	27.4%	9,870	28.1%
Queensland	5,040	19.4%	6,230	19.8%	7,010	19.9%
Western Australia	2,200	8.5%	2,670	8.5%	2,990	8.5%
South Australia	1,320	5.1%	1,540	4.9%	1,690	4.8%
Australian Capital Territory	380	1.5%	420	1.3%	450	1.3%
Tasmania	360	1.4%	460	1.5%	520	1.5%
Northern Territory	260	1.0%	290	0.9%	320	0.9%

NSW has the largest PLHIV population, with 9,640 PLHIV in 2018. Although the total number of PLHIV in NSW will increase to 11,250 in 2025, and 12,330 in 2030, the overall proportion will slightly decrease, from 37.1% in 2018 to 35.0% by 2030. Victoria has the next largest PLHIV population, with 6,760 in 2018, increasing to 8,630 in 2025, and 9,870 in 2030. Victoria will have a slightly increasing PLHIV population proportion (26.0% in 2018, increasing to 28.0% in 2030). Western Australia's PLHIV population was 2,200 in 2018, and will increase to 2,670 in 2025, and 2,990 in 2030. The proportion remains static at 8.5%. South Australia's PLHIV population was 1,320 in 2018 and will increase marginally to 1,540 in 2025, and 1,690 in 2030. The remaining states and territories (Australian Capital Territory, Tasmania and Northern Territory) have small PLHIV populations (380, 360, 260, respectively in 2018). These interstate estimates use ABS interstate population movement data for the general population, which may not reflect the movement of PLHIV. For instance, the number of Victorian PLHIV may be slightly underestimated, and the number of Queensland PLHIV, may be slightly overestimated. This is due to population movements which are somewhat different to the general population.

Table 2. provides estimates of the number of PLHIV older than 55 years and 65 years in each Australian state and territory at time periods 2018, 2025 and, 2030.

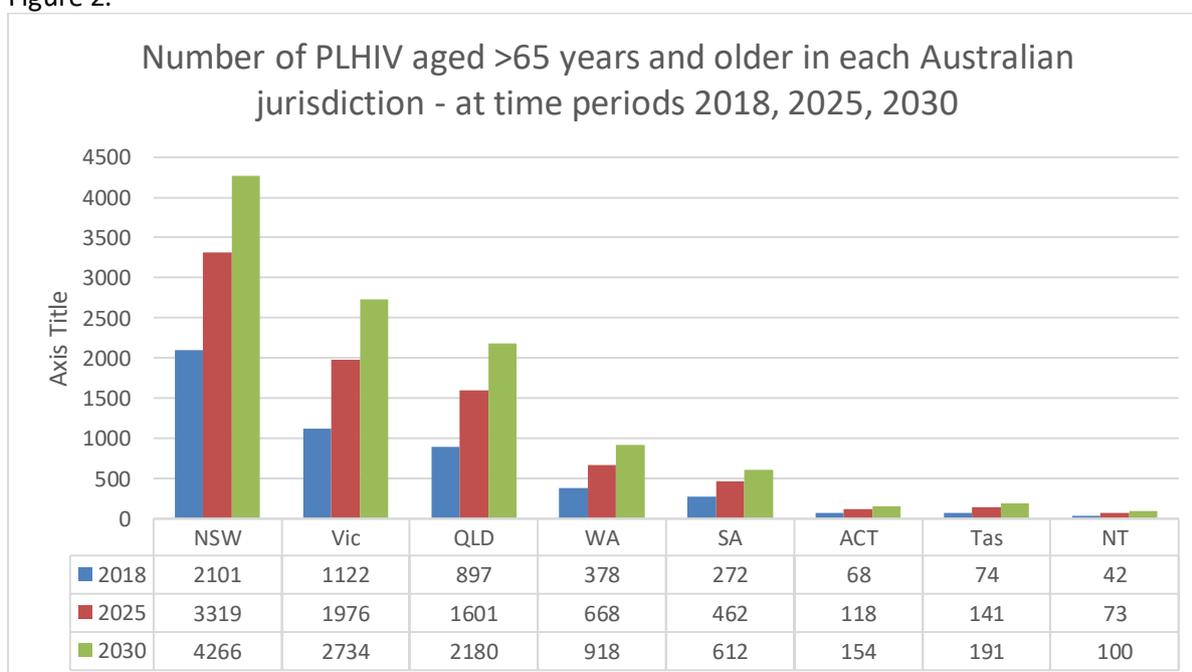
State/Territory	2018		2025		2030	
	Number of PLHIV >55	Number of PLHIV >65 years	Number of PLHIV >55	Number of PLHIV >65	Number of PLHIV >55	Number of PLHIV >65

## AUSTRALIAN PEOPLE LIVING WITH HIV & AGED CARE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

National	9,712	4,869	14,307	8,260	17,667	11,057
New South Wales	4,039	2,101	5,558	3,319	6,597	4,266
Victoria	2,319	1,122	3,599	1,976	4,590	2,734
Queensland	1,875	897	2,847	1,601	3,533	2,180
Western Australia	774	378	1,196	668	1,503	918
South Australia	531	272	776	462	948	612
Australian Capital Territory	140	68	197	118	234	154
Tasmania	149	74	235	141	294	191
Northern Territory	89	42	138	73	170	100

Figure 2 (below), shows the jurisdictional populations of PLHIV, aged 55 years and older and 65 years and older at time periods 2018, 2025 and 2030. NSW has, and will continue to have, the largest number and proportion of PLHIV (aged 55+ and 65+), followed by Victoria, Queensland, Western Australia and South Australia. The ACT, Tasmania and Northern Territory, have small populations of ageing PLHIV.

Figure 2.



### Significance

Ageing PLHIV (65 years and older and eligible for aged care), have specific clinical and social support needs. These needs and contexts are dealt with in detail later in this section of the submission. Servicing increasing numbers of older PLHIV will challenge aged care services (both home care and residential), particularly in NSW, Victoria and Queensland where the numbers of PLHIV are substantial and increasing.

### AUSTRALIAN PLHIV POPULATION DISTRIBUTION – CAPITAL CITIES VS. REGIONAL AND RURAL AREA

The Australian PLHIV population distribution varies significantly between major capital cities and regional and rural areas. Table 3 shows the numbers and proportions of PLHIV in capital cities and

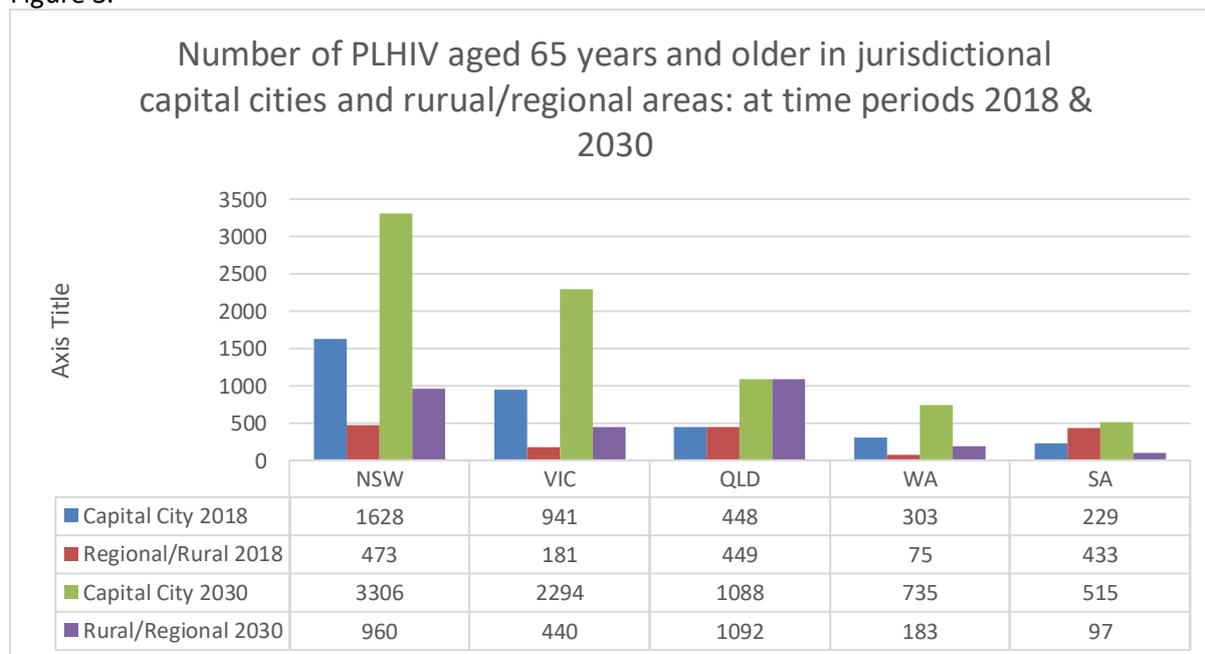
regional and rural areas. The breakdown for the Australian Capital Territory, Tasmania and the Northern Territory are unavailable (Gray 2019).

Table 2.

2020 PLHIV Population – City and Rural - by number and percentage					
State/Territory		Number	% of state/territory	Number	% of state/territory
		City		Regional/Rural	
NSW	Sydney	9,082	77.5%	2,638	22.5%
Victoria	Melbourne	5,841	83.9%	1,118	16.1%
Queensland	Brisbane	2,697	49.9%	2,710	50.1%
WA	Perth	1,623	80.1%	403	19.9%
SA	Adelaide	1,218	84.1%	231	15.9%
Tas, NT, ACT		Populations too small to differentiate			

Figure 3 shows the estimated number of PLHIV aged 65 years and older residing in a capital city versus a regional/rural area in NSW, Victoria, Queensland, Western Australia, and South Australia.

Figure 3.



### Significance

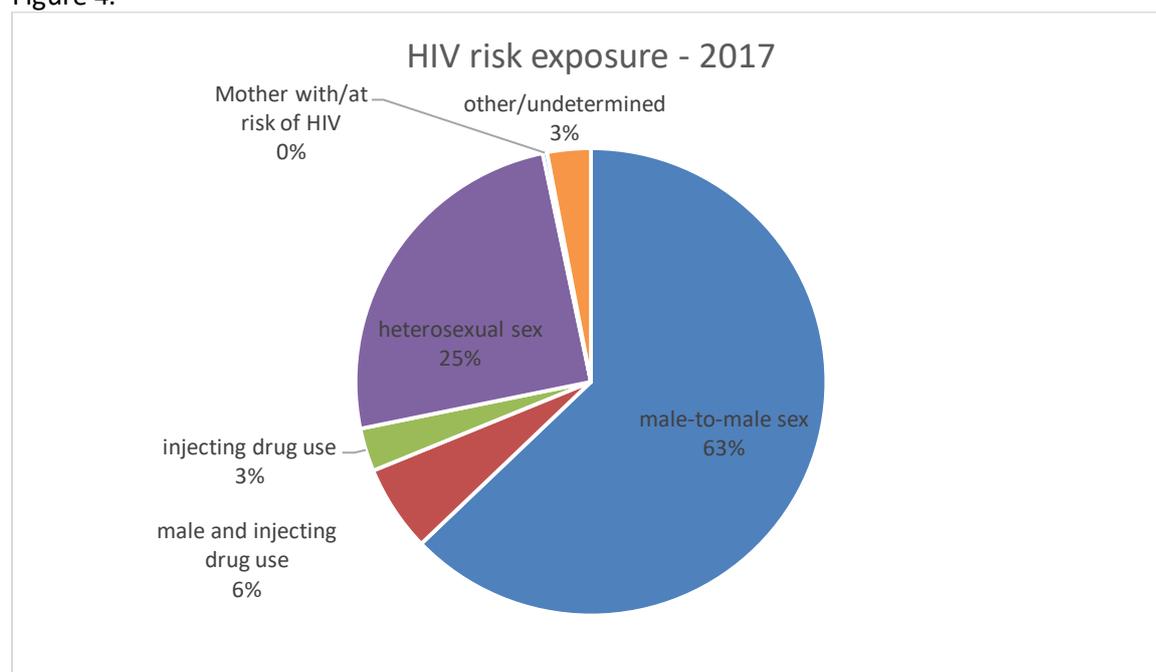
Most PLHIV live in and will continue to live in, capital cities (Sydney, Melbourne, Brisbane, Perth and Adelaide). Between 15.9% and 22.5% however, live in regional and rural areas, except for Queensland, where the PLHIV population is about evenly split between Brisbane and rural and regional Queensland (Gray 2019). The population of aged PLHIV (65 years and older), will more than double in Sydney and regional and rural NSW, by 2030. Nearly 1,000 PLHIV (aged 65 years and older) will live in regional and rural NSW, where access to HIV specialist clinical care and aged care is limited. The situation will be even more challenging in Queensland, where more than 1,000 PLHIV aged 65 years and older will live in a regional/rural area. The population will be spread thinly over an extensive geographical area, making the provision of appropriate aged care services extremely difficult - both for residential and home-based aged care service providers. Many older PLHIV will

increasingly experience poorer physical and mental health, and will require transportation over long distances, to receive routine specialist treatment and care for HIV and other chronic health conditions. It will be necessary to transport PLHIV to multidisciplinary tertiary services, in Sydney, Melbourne, Brisbane and Adelaide, when specialist care is necessary.

### THE AUSTRALIAN PLHIV POPULATION BY RISK EXPOSURE CATEGORY AND SUBPOPULATION

Transmission of HIV in Australia continues to occur primarily between GBMSM, through male-to-male sexual contact. 63% of HIV notifications were attributed to male-to-male sex in 2017, a 7% decrease from 70% in 2016. Heterosexual sex accounted for 25% of notifications, an increase from 21% in 2016. In 2017, other risk exposures were: male-to-male sex and injecting drug use for 6% of notifications, and injecting drug use for 3% of notifications (Kirby Institute, 2018). It is difficult to exactly specify the proportions of PLHIV who identify as GBMSM and heterosexual. In general, it is broadly agreed that approximately 80% of Australian PLHIV are GBMSM, and 20% identify as heterosexual. The 20% of heterosexual PLHIV are approximately evenly split between men and women.

Figure 4.



Within these three risk exposure categories are people from different cultural backgrounds and countries of birth. For example, over the past 10 years, the number of HIV notifications in Australian-born men with male-to-male sex as an exposure risk has decreased by 21%. Conversely, the proportion who were born in Asia (Southeast Asia, Northeast Asia, and Southern and Central Asia) has increased over the past 10 years from 28% in 2008, to 52% in 2017. The number of HIV notifications in men born in countries other than Asia has remained stable between 2013 and 2017 (Kirby Institute, 2018).

### Significance

The provision of non-discriminatory aged care to GBMSM, will challenge providers who employ and retain staff with prejudices about homosexuality, illicit recreational drug use, sex work, and gender dysphoria. Aged care staff may associate with religious and cultural belief systems that are intolerant of homosexuality, drug use and by association, HIV infection. If ageing PLHIV are to receive quality non-discriminatory aged care, and not be marginalised and neglected, attitudes and prejudices by aged care staff will need to change. The potential power imbalance between aged care workers and PLHIV will also threaten to undermine legitimate requests for appropriate non-discriminatory aged care. Stigma associated with homosexuality, illicit drug use and HIV, will likely result in PLHIV feeling a need to hide their homosexuality, HIV, and illicit drug use. They may also not speak out about poor service or make complaints about poor care, for fear of repercussions from staff.

### HIV TREATMENT AND CLINICAL CARE

In Australia, HIV clinical care and the prescribing of HIV treatment (ART) can only be carried out by an accredited doctor (HIV specialist or s100 prescriber). S100 prescribers can be accredited GPs or HIV specialists working in a hospital or sexual health clinic. The role of the s100 prescriber is to monitor HIV infection, prescribe ART, and ensure ART is effectively suppressing HIV viral replication. PLHIV are routinely prescribed daily dosing of ART. While ART cannot cure HIV, it can prevent HIV destroying the immune system and prevent HIV disease progression to AIDS and death. The main goal of ART is to reduce the amount of HIV virus in the blood to an undetectable level. An undetectable viral load means that the level of HIV in the blood is below 200 copies per ml. People who have an undetectable viral load have no risk of transmitting HIV to others.

There are a limited number of s100 prescribers in Australia. The vast majority of s100 prescribers work in major capital cities and along the Australian eastern seaboard. Access to s100 prescribers in regional and rural settings is often extremely limited, and many PLHIV need to travel from rural and regional areas to a capital city for HIV clinical care. For example, in NSW, there are no private s100 prescribers working west of Orange. PLHIV living west of Orange, can only access HIV clinical care from a Sexual Health Clinic in major regional cities (Dubbo, Tamworth, Armidale, Wagga Wagga etc.) where an s100 prescriber flies in once a month (for 1-2 days) to monitor and treat PLHIV. Appointment availability is limited and s100 prescribers are usually fully booked. Fly-in/fly-out s100 prescribers are also required to manage non-HIV health conditions as well as HIV. This places additional pressure on clinicians and support staff in sexual health clinics to meet the healthcare needs of older PLHIV with multimorbidity.

The map below, indicates the locations of s100 prescribers throughout Australia. If the map is downloaded and increased in scale, it will become apparent that nearly all s100 prescribers are in capital cities. <https://www.ashm.org.au/prescriber-locator/>

## AUSTRALIAN PEOPLE LIVING WITH HIV & AGED CARE ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY



It should be noted that PLHIV in rural and regional areas (with no public transport) often struggle to attend healthcare appointments for the clinical monitoring and treatment of HIV and other chronic health conditions. Some must travel long distances (drive) to a local sexual health clinic to receive treatment and care. As PLHIV age and their health deteriorates, travelling to medical appointments will become even more challenging.

### Significance

The clinical management of HIV, particularly in residential aged care facilities, will challenge aged care facility staff. As explained above, HIV treatment and care can only be conducted by an accredited HIV specialist (usually an accredited GP or hospital specialist). It is unlikely that a residential aged care facility doctor will be accredited. Therefore, a shared care arrangement (between the facility GP and an external s100 prescriber) will be required. While this may be possible in capital cities (where most s100 prescribers are located), it will be increasingly difficult in regional and country areas. Fly-in/fly-out s100 prescribers are usually fully booked during their monthly two-day visits to regional sexual health centres. This means that residential aged care facilities in country areas, will need to arrange for an s100 prescribers to visit their facility and monitor the health of their residents with HIV. While these arrangements may be practical for facilities with many residents with HIV, it will be impractical for facilities with one, or maybe two PLHIV.

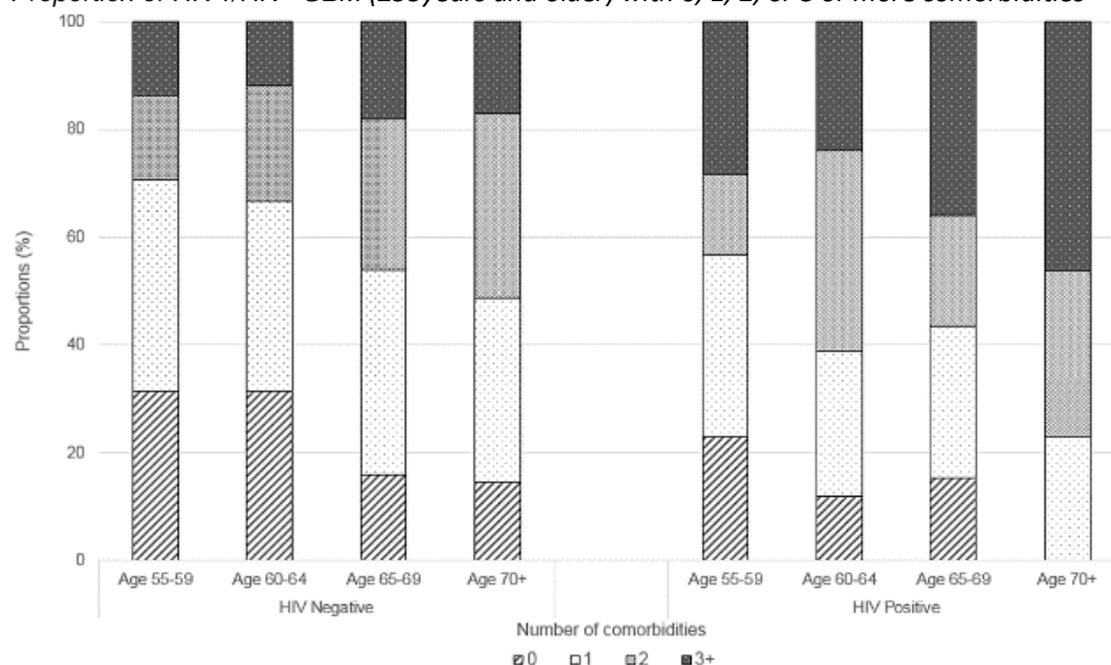
Attending routine medical appointments will also become more difficult for PLHIV who live independently and experience deterioration in their health and ability to drive to a clinic or use public transport. Elderly PLHIV will increasingly need community transport to take them to medical appointments and to collect prescribed medications. The provision of these services will be challenging in rural areas of Australia, where aged care services will be asked to transport PLHIV over long distances to visit an s100 prescriber or hospital specialist in a capital city.

## COMORBIDITIES

PLHIV experience an increased prevalence of comorbidities, when compared to people without HIV. The Australian Positive and Peers Longevity Evaluation Study (APPLES) (Petoumenos, 2017) found that when compared to HIV-negative GBMSM of similar age, HIV-positive GBMSM aged 55 years and over report an increased prevalence of morbidity including thrombosis, diabetes, heart disease, neuropathy, bone disease and non-AIDS related cancers. They also experience a significantly increased number of comorbidities. Figure 5 shows the proportion of HIV-positive and HIV-negative GBMSM (aged 55 years and over) with 0, 1, 2, and 3 or more comorbidities.

Figure 5.

*Proportion of HIV+/HIV- GBM (≥55years and older) with 0, 1, 2, or 3 or more comorbidities*



HIV-positive GBMSM aged 55 years and over, experience comorbidity at two to three times the rate of aged-matched HIV-negative GBMSM. Lifestyle risk factors such as having ever smoked and the use of recreational drugs, are more common among HIV-positive men (Petoumenos K, 2017). These Australian findings are consistent with the international study (AGEHIV), one of few other studies with appropriate age-matched HIV-negative controls. In the AGEHIV cohort, HIV-positive people experienced a significantly greater number of comorbidities compared to HIV-negative controls, as well as a significantly increased prevalence of myocardial infarction, peripheral arterial disease, impaired renal function, and osteoporosis (Schouten J, 2014). The increased prevalence of traditional risk factors among HIV-positive populations (smoking, elevated lipids, hyperglycaemia, altered body composition, alcohol use, and recreational drug use) significantly contribute to the increased risk for many of these non-communicable diseases (Schouten JW, 2012).

It is important to note however, that not all comorbidity risk factors result from lifestyle choices made by some GBMSM with HIV (i.e. smoking, alcohol use, and recreational drug use). Dyslipidaemia for example, is strongly associated with cardiovascular disease and is particularly common among HIV-positive people who have been on continuous ART for long periods of time, and neither smoke nor use recreational drugs.

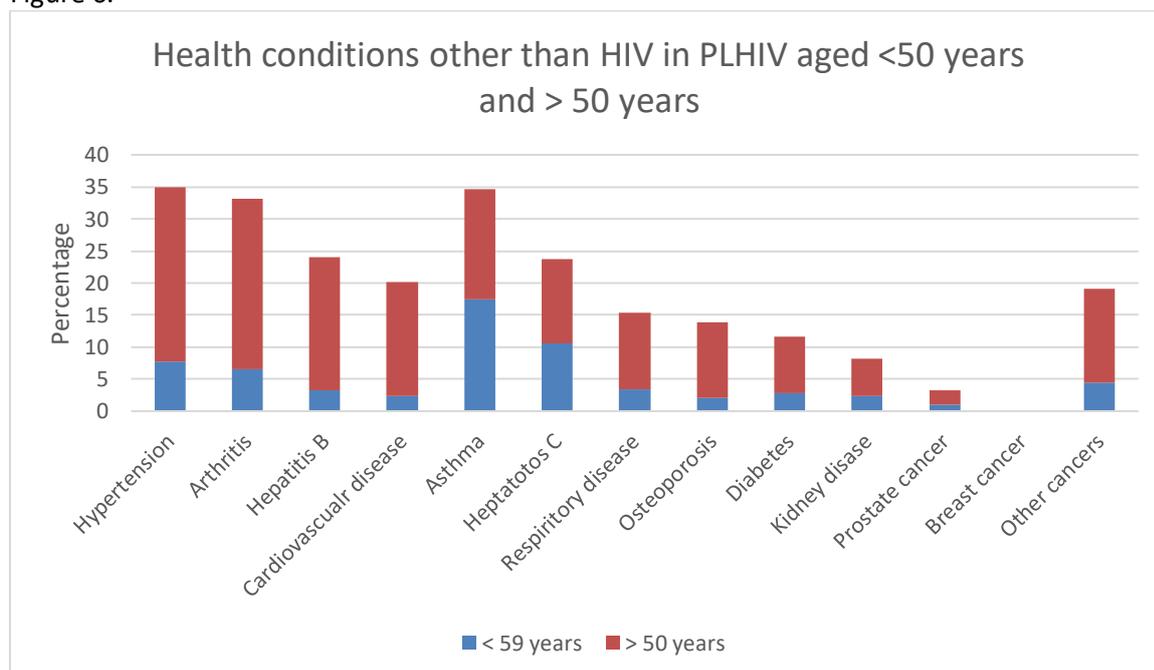
There are well documented associations between dyslipidaemia and the use of HIV drug regimens including protease inhibitors (PIs) and nucleoside reverse transcriptase inhibitors (NRTIs). (Fris-Molier N 2007). In the APPLES study, significantly more HIV positive GBMSM had lower HDL-cholesterol compared to HIV negative GBMSM. HIV infection is associated with low HDL-cholesterol, and low HDL-cholesterol has been identified as an independent risk factor for cardiovascular disease (Di Angelantonio E 2009). Most people who have lived with HIV infection for 20 or more years (generally older PLHIV) would have at some time been prescribed these more toxic earlier generation drugs. Moreover, ART use has been associated with several other age-related comorbidities including hyperglycaemia, cardiovascular disease, thrombosis, diabetes, and bone disease. Cardiovascular and related diseases may be driven in part by increases in lipids, with PI use having the most profound effect on triglyceride and cholesterol levels (Fris-Molier N 2007). The PI tenofovir disoproxil fumarate for example, has been associated with reduced bone density (osteoporosis) and renal disease (Gallant JE 2000).

Results from the Australian HIV Futures studies (1 to 8), illustrate the significantly increased prevalence of self-reported comorbidities in PLHIV aged 50 years and over (Power, 2016). For example, in the Futures 8 report (2016), older HIV-positive people (aged 50 years and over), reported significantly increased rates of chronic health conditions compared to respondents aged less than 50 years. Table 3 illustrates the rates of self-reported morbidities in the two aged groups (aged less than 50 years, and aged 50 years and over).

Table 3.  
*Health conditions other than HIV according to age*

Health conditions other than HIV according to age	Aged <50 %	Aged ≥50 %
Hypertension	7.7	27.2
Arthritis	6.6	26.6
Hepatitis B	3.2	20.8
Cardiovascular disease	2.4	17.7
Asthma	17.5	17.1
Hepatitis C	10.6	13.2
Respiratory disease	3.4	12.0
Osteoporosis	2.1	11.8
Diabetes	2.9	8.9
Kidney disease	2.4	5.8
Prostate cancer	<1.0	2.3
Breast cancer	0	<1.0
Other cancers (including anal cancer)	4.5	14.6

Figure 6.



PLHIV aged 50 years and over are approximately three times more likely to experience hypertension, be diagnosed with cancers, including anal cancer, and experience respiratory disease. They are slightly less than four times more likely to experience arthritis, and six times more likely to experience cardiovascular disease and osteoporosis (Power J 2019).

### Significance

The high prevalence of comorbidities in older PLHIV (i.e. 55 years and older) will result in poorer physical and mental health, and significantly reduce levels of physical function and the ability to perform activities of daily living. Reduced physical function will increase the demand for aged care support services, particularly home-based support services, but also residential aged care, when PLHIV are no longer able to maintain independent living arrangements.

Clinical care for PLHIV with comorbidities in residential aged care will present clinical and communication challenges for facility staff, particularly nursing staff and visiting doctors who have day-to-day responsibility for patients with HIV. Excellent communication between visiting s100 prescribers and facility doctors will be an important factor in ensuring PLHIV receive appropriate clinical care of acute and chronic health conditions, including diagnosis, monitoring and treatment of those conditions.

### MEDICATIONS PRESCRIBED FOR HEALTH CONDITIONS OTHER THAN HIV

Chronic health conditions often require prescribed treatment. Table 4 shows the proportions of PLHIV (aged less than 50 years, and more than 50 years), who report receiving treatment for a range of non-HIV health conditions (Power, 2016).

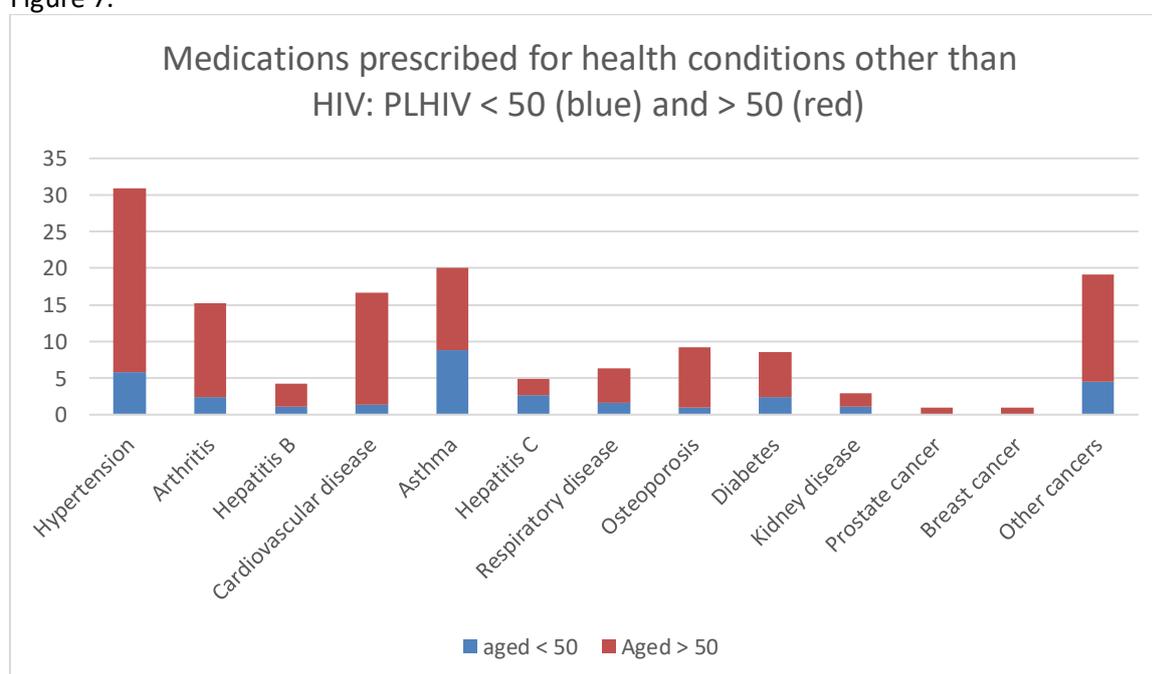
Table 4.

*Health conditions other than HIV where medication is prescribed by age group*

Health conditions other than HIV according to age	Aged <50	Aged ≥50
	%	%

Hypertension	5.8	25.1
Arthritis	2.4	12.8
Hepatitis B	1.1	3.1
Cardiovascular disease	1.3	15.3
Asthma	8.8	11.3
Hepatitis C	2.6	2.3
Respiratory disease	1.6	4.7
Osteoporosis	<1	8.2
Diabetes	2.4	6.2
Kidney disease	1.1	1.8
Prostate cancer	0	1.0
Breast cancer	0	0
Other cancers (including anal cancer)	1.3	1.2

Figure 7.



The table above in Figure 7, shows that PLHIV aged 50 years and over are substantially more likely than their younger counterparts, to be taking medication for hypertension, arthritis, cardiovascular disease, respiratory disease, diabetes and osteoporosis. In fact, they are four times more likely than PLHIV who are younger than 50 years to be taking medication for hypertension and arthritis, nearly twelve times more likely to be taking medication for cardiovascular disease, and more than eight times more likely to be taking medication for osteoporosis.

In addition, PLHIV use a range of prescribed and recreational drugs for non-medical purposes. HIV Futures 8 found that a relatively high number of PLHIV reported occasional or regular use of prescription drugs (pain killers/narcotic analgesics and tranquilisers/sleeping pills) for non-medical purposes. There was also a relatively high percentage reporting the use of marijuana, methamphetamine, and other recreational drugs (Power, 2016). Table 5 provides further detail on non-medical drugs used in the past 12 months by PLHIV (Power, 2016).

Table 5.

Drugs used for non-medical purposes		
	Used occasionally	Used regularly
	%	%
Pain killers/analgesics	22.4	8.6
Tranquilisers/sleeping pills	13.7	6.1
Marijuana	10.6	10.6
Methamphetamine	7.1	3.9
Inhalants (amyl nitrite)	5.7	1.5
GBH	3.0	0.9
MDMA/ecstasy	3.8	0.2
Steroids	1.4	0.8
Opioids (morphine, oxycodone)	1.2	1.1
Ketamine	1.1	<1
Cocaine	<1	<1
Heroin	<1	<1
Synthetic cannabis	<1	<1
Hallucinogens	<1	0

These results are consistent with the APPLES study, where 41.9% of HIV-positive GBMSM aged 55 years and over, reported recreational drug use (Petoumenos K H. R., 2017).

### Significance

There are increasing concerns about PLHIV and polypharmacy. The risk of harms associated with polypharmacy increase with the number of medications prescribed and taken (Edelman, 2013).

Common problems associated with polypharmacy include:

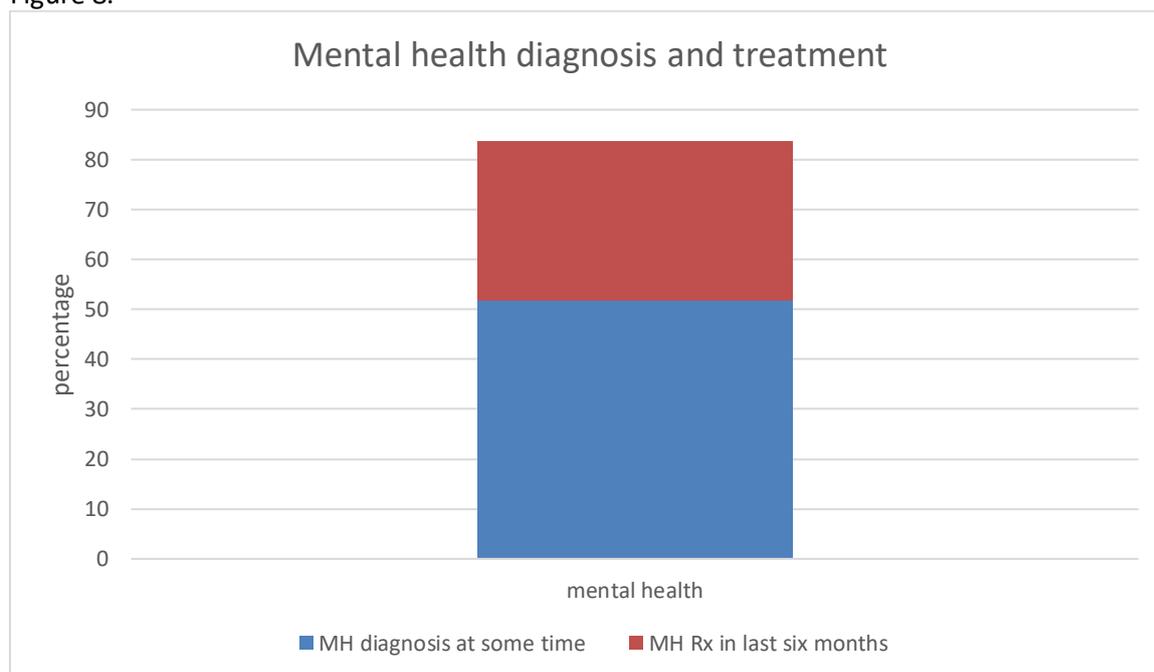
- Inappropriate medication use, including decreased medication adherence, and difficulties managing medication, especially when multiple prescribers are involved
- Adverse drug events, including drug-drug interactions, drug toxicity, and mortality
- Delirium, falls, and fractures from medications like sleeping pills and narcotic analgesics
- Impaired elimination and/or drug accumulation linked to loss of the optimal functioning of the liver or kidneys, which may decrease with age (Edelman, 2013).

PLHIV taking ART, medications for multiple chronic health conditions, and illicit drugs for non-medical purposes (including pain killers, sleeping pills and illicit drugs), will challenge aged care services, both home-based and residential. Older PLHIV, who live alone and experience mental ill-health or HAND, may be at an increased risk of decreased medication adherence, or forgetting to attend medical appointments for routine clinical care and the renewal of prescriptions. Non-adherence to medication will increase the risk of HIV and non-HIV disease progression, illness and even premature death. The misuse of sleeping pills and narcotic analgesics may result in falls, fractures, admissions to hospital, and premature death. Long-term interventions to supervise medication adherence, may then be required. The challenge for home support services and residential aged care facilities, will be to observe the potential negative impacts of polypharmacy and prevent worsening health outcomes, hospital admissions, and premature deaths due to poor adherence/overuse and drug-to-drug interactions. Misuse of prescribed and illicit drugs will also challenge aged care service staff who consider these practices unacceptable. PLHIV may hide illicit drug use to limit unwanted criticism and/or prosecution. The hiding of drug use by PLHIV may further exacerbate the risk of serious harm, accident, and death.

## MENTAL HEALTH AND THE EMOTIONAL STATE OF AUSTRALIAN PLHIV

Assessing the mental health of older PLHIV is complex. While more than half of respondents to the HIV Futures 8 study (51.8%), indicated they had been diagnosed with a mental health condition at some point in their life, overall, only one third (31.9%) had taken medication for a mental health condition in the past six months. This would infer about a third of PLHIV have active depression and/or anxiety (requiring treatment), as opposed to a historical diagnosed mental health condition. Less prevalent conditions reported included bipolar disorder (4.3%), post-traumatic stress disorder (7.0%), and psychosis (2.8%) (Power, 2016).

Figure 8.



Mental health varied according to age. Interestingly, PLHIV, aged 65 years and over, reported better mental health than those in other age groups, with respondents in the 45-54 age group reporting significantly poorer mental health than those aged 55-64 years, and those aged 65 years and over (Power J 2019).

Futures 8 also assessed the emotional state of PLHIV. The SF-36 'role emotional' subscale was used to measure the extent to which people feel their emotional/mental state affects everyday life. Respondents aged 55-64 years had a mean score of 62.2, and those aged 65 years and over, had a mean score of 71.3 (Power J 2019). A higher score indicates better mental health.

It should be noted that PLHIV have a lower mean SF-36 mental/emotional subscale score (67.3) than the general Australian population (76.0) in the HILDA survey data (2015). This finding is consistent with previous research which indicates that PLHIV may generally experience poorer mental health than the general Australian population (Power, 2016).

When rates of depression and anxiety in HIV-positive and HIV-negative GBMSM aged 55 years and over were compared (APPLES, 2017), HIV-positive GBMSM reported slightly lower rates of depression (37.5%) than their HIV-negative aged-match counterparts (38.1%). They also reported lower rates of anxiety (19.0% HIV-positive, 23.0% HIV-negative) (Petoumenos K, 2017). These results

suggest that depression and anxiety in GBMSM may be associated more with issues related to homosexuality, rather than HIV status.

### Significance

While PLHIV generally have poorer mental health than the HIV-negative general Australian population, older PLHIV (65 years and over) report better mental health than PLHIV aged 45-54 years. Better mental health in older PLHIV may be associated with acceptance of HIV status, lifestyle choices and homosexuality, as well as greater learned resilience. It may also help compensate for factors, such as poorer physical health and impaired physical functioning. However, if older PLHIV encounter stigma and discrimination from aged care service staff, their mental health may significantly decline.

## HIV-ASSOCIATED NEUROCOGNITIVE DISORDERS

HIV-associated neurocognitive disorders are caused by poorly controlled HIV viral replication in the central nervous system and brain. Effective ART lowers HIV viral replication in the blood to undetectable levels, however some older combinations of ART are less effective at crossing the blood/brain barrier and suppressing HIV viral replication. This situation can lead to PLHIV experiencing HIV-associated neurocognitive disorders.

Since the introduction of ART (1996) in Australia, HAD is now relatively rare, with a prevalence of 2%-4% (McArthur, 2004). By contrast, milder forms of HAND (mild to moderate levels of neurocognitive impairment, not severe enough to be characterised as dementia), remain fairly common, with a prevalence varying between 30% for PLHIV who have never had an AIDS diagnosis, to 50% for PLHIV with current AIDS, or a previous historical AIDS diagnosis (Lucette A Cysique, 2017).

In continuously virally suppressed PLHIV, the prevalence of HAND varies between 20% and 30% (Bloch, 2016). However, it should be noted that a majority of older PLHIV are survivors of past long-term immunosuppression (diagnosed prior to 1996 and the introduction of ART), as opposed to treated early and virally suppressed (generally younger PLHIV). The prevalence of HAND in older PLHIV, may therefore be higher.

Symptoms of HAND and HAD vary from individual to individual and are experienced over a spectrum of severity. They include changes in the ability to understand and remember information, changes in behaviour, coordination, and emotions. People may experience slower thinking, trouble learning new things, difficulty remembering what has happened in the past, difficulty concentrating, confusion, depression, feeling irritated, an experiencing an unsteady gait, or difficulty maintaining balance.

### Significance

The impacts of HAND and HAD are yet to be fully understood and researched. There are many unanswered questions about how HAND and HAD will progress in older PLHIV (60 to 70 years and over). Some PLHIV will develop atypical dementia syndrome. PLHIV who were diagnosed with HIV infection in the pre-ART era and had a low CD4 cell nadir, may be at increased risk of HAND and HAD. HAND researchers think HAND may become a much more significant issue when high proportions of PLHIV reach the age of 70 and over. While NSW has specialist services for the clinical management of PLHIV with HAND and HAD, other Australian jurisdictions do not. The absence of specialist clinical support services for PLHIV with HAND and HAD will present a significant challenge for aged care services, both residential and home-based who have PLHIV with HAND or HAD in their

care. It must be noted that prevalence of HAND and HAD in PLHIV is additional to other types of age-related dementias, such as Alzheimer's, etc.

## THE OVERALL HEALTH STATUS OF PLHIV

In the HIV Futures 8 study, PLHIV aged 55-64 years reported poorer general health than any other age group, including those aged 65 years and over (Power J 2019). Poorer general health in the 55-64 and 65 years and over age groups was associated with:

- Living alone
- Lower income, being unemployed, and experiencing financial stress
- Lower levels of social support, and isolation
- Lower levels of resilience
- Poorer health literacy and the inability to navigate the health system
- Having had a mental health diagnosis
- Having three or more comorbidities (Power J 2019).

### Significance

The physical and mental health of PLHIV aged 55-64 years is not significantly different to PLHIV aged 65 years and over. In fact, PLHIV in the 55-64 age bracket report poorer overall health than those aged 65 years and over. This may be due to better mental health in the 65 years and over age group. However, it should be noted that there is a substantial cohort of younger PLHIV who have a significant burden of poor health. In both age groups (55-64 and 65 years and over) the major concerns are poor physical health, poorer mental health, breadth/depth of social connection, financial insecurity, and the need to manage multiple complex physical health conditions. These factors are more likely to predict poorer health and functional decline, than chronological age. This outcome suggests there will be a higher proportion of PLHIV currently aged 55 to 64 years who will need aged care in the years to come. It also suggests that some people in this age group, need support services now.

## ACCELERATED OR ACCENTUATED AGEING

Whether HIV accelerates or accentuates ageing, has long been debated. The answer to the question is possibly organ and disease/condition specific. For many biological processes in PLHIV, there appears to be a pattern of accelerated ageing. This is most clear in the immune system where ongoing immune activation strongly suggests accelerated immune senescence. It is also clear that the development of specific geriatric syndromes is hastened in those with HIV (comorbidity, frailty, and polypharmacy). In specific diseases, it is less clear, but many illnesses appear to be accentuated rather than accelerated. Cardiovascular disease, diabetes, and several other conditions are more prevalent at all ages in those with HIV, suggesting there is an extra 'hit' by HIV and HIV treatment, that is accentuating ageing (Sophia Pathai, 2013).

### Significance

More research is needed in the area to determine whether HIV accelerates or accentuates ageing.

## PHYSICAL LIMITATION AND FUNCTION IN OLDER PLHIV

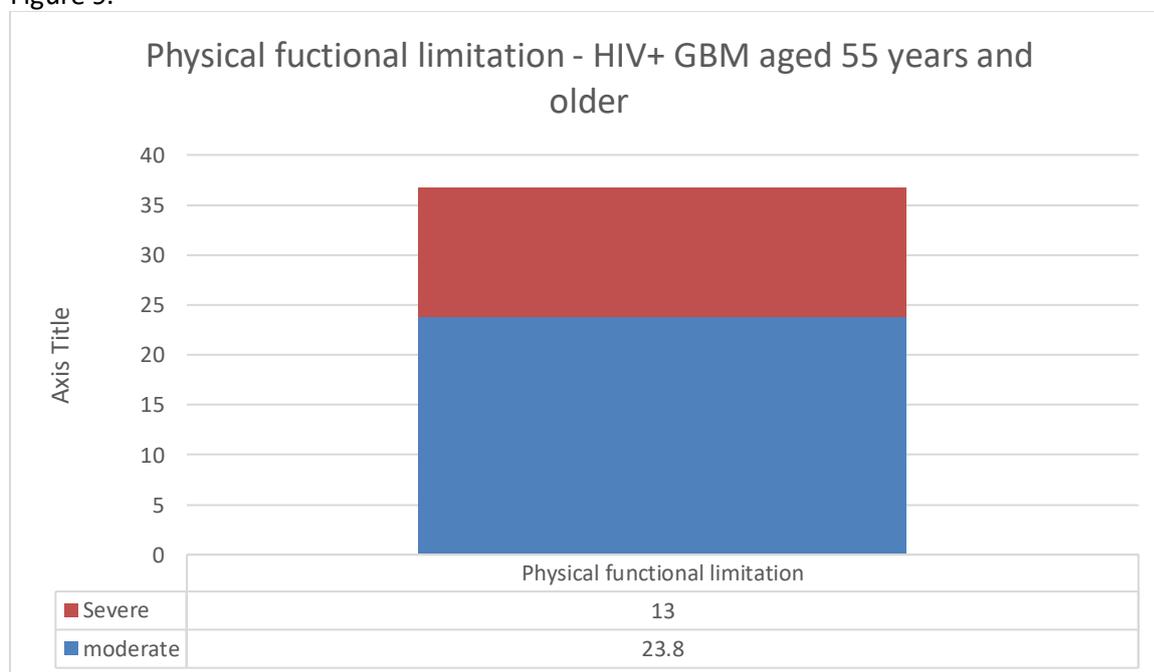
As with the general population, physical function in PLHIV declines with age, with younger PLHIV (aged less than 55 years) having significantly higher levels of physical function than those aged 55 years and over. There is however, no significant difference in the physical functioning of those aged 55-64 years and those aged 65 years and over, although those aged 65 years and over are more

likely to report that their physical condition makes it more difficult to perform activities of daily living (Power J 2019).

In the APPLES study, physical limitation/function was assessed in HIV-positive GBMSM aged 55 years and over using the Medical Outcomes Study – Physical Functioning (MOS-PF) scale (Petoumenos K, 2019). 13.0% of HIV-positive GBMSM aged 55 years and over were found to have severe physical limitation, and 23.8% were found to have moderate physical limitation. The study assessed the extent to which PLHIV’s health, limited their ability to perform daily activities such as:

- Lifting and carrying groceries
- Climbing one/several flights of stairs
- Bending, kneeling or stooping
- Walking various distances
- Bathing or dressing oneself

Figure 9.



Factors associated with severe physical limitation were significantly associated with low CD4 count, hepatitis B co-infection, low income, unemployment, low body mass index, psychological distress, pain killer use, insufficient activity time, number of comorbidities, whether participants needed help with daily activities, and self-reported overall health status. Factors associated with moderate to severe physical functional limitations were significantly associated with living alone, lower income, unemployment, smoking status, body mass index, psychological distress, pain killer use, activity time, number of comorbidities, whether participants needed regular help with daily activities, laboratory measures such as HDL and Glucose level, and older age (70 years and over) (Petoumenos K, 2019).

### Significance

Substantial numbers of PLHIV aged 55 years and over, experience moderate and severe physical functional limitation. Australian studies report 26% of PLHIV aged 55 years and over experience moderate physical limitations and 13% experience severe physical functional limitation. These

proportions extrapolate to approximately 1,263 Australian PLHIV aged 55 years and over having severe physical functional impairment, and 2,525 having moderate physical functional limitation. It is therefore likely that PLHIV who have physical functional limitation will need home-based aged care services at some time in the future. They will also eventually need residential aged care when they can no longer manage to remain living independently.

## HOUSEHOLD INCOME AND POVERTY

Australian research has found around half of Australian PLHIV live on household incomes substantially lower than the average Australian income for all workers including full-time and part-time (\$60,320 per year [ABS, 2016]). The national average annual income for full-time workers in Australia (2016) was \$80,000 per year. By contrast, 27.9% of HIV Futures 8 respondents reported an annual income of less than \$30,000 per year, and 16.0% reported an annual income between \$30,000 and \$49,999 per year (Power et al. 2018). The financial situation of women with HIV is even worse, with 34.2% of HIV-positive women reporting an annual income less than \$30,000 per year (Thorpe 2017).

### Significance

PLHIV who experience financial stress have poorer health, more experiences of HIV-related stigma and discrimination, and lower levels of resilience. Financial security is a key factor determining people's health, wellbeing, and quality of life. A reasonable income enables access to safe housing and other basics, such as food and clothing, and are necessary for survival. A reasonable income also allows for greater choice in how people live their lives, which in turn supports psychological and social wellbeing. By contrast, poverty can be intensely stressful and isolating. Poverty is disempowering and limiting of people's capacity to look after themselves and to demand quality in services such as health care and aged care.

Older PLHIV are particularly vulnerable to poverty. This is due to a combination of factors, including poor physical and/or mental health and being diagnosed in the pre-ART era (1996). PLHIV who lived with untreated HIV, morbidity associated with AIDS-related conditions and opportunistic infections, as well as the side-effects from crude early HIV treatments (AZT), often ceased employment. In some cases, they never resumed employment and became reliant on Commonwealth welfare payments, such as the Disability Support Pension. These PLHIV exhausted superannuation and other savings and were unable to accumulate assets to buffer poverty in old age.

## LIVING ALONE WITHOUT SUPPORT

More than half (58%) of HIV-positive GBMSM aged 55 years and over report being single in the APPLES study (Petoumenos K, 2019). In the Futures 9 study, nearly two-thirds of PLHIV (61.5%) were single (J. A. Power 2019). Many are also estranged from family and had lost multiple partners and friends to AIDS and premature death. HIV-positive GBMSM who live alone are twice as likely to experience severe physical limitations than those in a relationship (65.4% vs. 34.6%). Similarly, nearly two-thirds (65.9%) of those who are not in a relationship experienced moderate to severe physical limitations compared to 34.1% of those who are living with partners. 57.59% of all PLHIV who were consulted for this submission, do not have a partner, friend or family member to care or provide support to them. This percentage is higher in PLHIV aged 65 years and over.

### Significance

As single PLHIV age and their health deteriorates, they will be even more reliant on aged care services than people who have someone to support and assist them with activities of daily living. It

also means that older PLHIV will be more likely to experience social isolation and loneliness. We predict most older PLHIV who live alone will need home support services to hold onto independent living arrangements. If these services cannot be provided, the physical and mental health of older PLHIV will decline and relocation into an aged care facility will become necessary. Living alone without support increases the impact of poverty, social isolation, worsening health outcomes, falls, fractures, admissions to hospital, and premature disability and death.

## HIV-ASSOCIATED STIGMA AND DISCRIMINATION

Despite the improved efficacy and tolerability of modern combination ART to control HIV disease progression and sexual transmission (NSW Ministry of Health, 2015), infection with HIV remains a highly stigmatised condition and has long been recognised as a serious and debilitating feature of the HIV epidemic (Slavin et al., 2012). There are many reasons why HIV is stigmatised, including the fact that it is a serious communicable disease, it disproportionately affects groups who are already marginal in society, and it is linked to behaviours such as drug taking and homosexual sex (Herek, 1999; Herek and Capitanio, 1999). There have been numerous studies of HIV stigma internationally and many attempts to combat it, yet it stubbornly persists. HIV stigma is particularly endemic and difficult for PLHIV who come from CALD, Aboriginal and Torres Strait Islander, or heterosexual communities where HIV and myths about HIV sexual transmission are less well tolerated.

PLHIV report experiencing discrimination in a range of areas. For example, 7.4% reported receiving less favourable treatment in relation to accommodation, 27.6% experienced less favourable treatment at a medical service, and 15.4% experienced less favourable treatment in the workplace as a result of having HIV (J Grierson, 2013).

### Significance

The impact of stigma is particularly felt by PLHIV who are socioeconomically disadvantaged. However, it is also experienced by PLHIV who are from culturally and linguistically diverse backgrounds where homosexuality and drug use are less well accepted. Homosexuality is also less accepted by some sections of Australian society. Many older homosexual PLHIV grew up in an era where homosexuality was illegal. They learnt to hide their sexuality and lifestyle preferences to minimise discrimination and prosecution. If they fear discrimination by aged care service providers, they are likely to hide certain behaviours for fear of persecution. We have concerns that some aged care service staff may hold prejudices against people who are homosexual, who identify as trans or gender diverse, or who use illicit drugs. The challenge for aged care services will be to ensure their staff provide appropriate and non-discriminatory services to all individuals, regardless of difference.

In addition, we consider it likely that some PLHIV, particularly GBMSM with HIV, will be considered socially unacceptable and rejected by some residents. Many people hold fears, prejudices or negative attitudes about HIV and homosexuality. Stigma can result in PLHIV being insulted, rejected, gossiped about and excluded from social activities. At its extreme, stigma can drive people to physical violence. This rejection, as well as fear of rejection, will force some PLHIV to self-isolate from communal activities (such as eating in the communal dining room and attending group social activities run by the facility). We fear they may remain closeted in their room and become socially isolated. Residential aged care facility staff will need to monitor the behaviour of residents. They will need to ensure that stigmatising behaviour and acts of discrimination by residents against PLHIV are immediately addressed and not allowed to become accepted and the norm.



## FINDINGS FROM A NATIONAL CONSULTATION WITH PLHIV, THEIR PARTNERS/CARERS, AND SPECIALIST SERVICES ABOUT AGED CARE

### PREFACE

The information in this part of the submission is sourced from a national consultation with PLHIV, their partners and carers, HIV specialist services, and aged care services commissioned by Positive Life NSW and NAPWHA in 2019.

### CHARACTERISTICS OF PEOPLE CONSULTED FOR THIS SUBMISSION

#### Overall:

522 people participated in the consultation. They included:

- 420 people living with diagnosed HIV (PLHIV)
- 35 partners, carers or family members of a PLHIV
- 25 HIV service providers
- 2 aged care service providers, and;
- 40 respondents who lived outside Australia and were not included in these analyses.

### OVERALL CHARACTERISTICS OF THE 420 PLHIV

Most participants were assigned male sex at birth (93.01%) and 6.99% were assigned female sex at birth. 7.57% reported their gender identity as being different from the one assigned to them at birth, which strongly indicates being trans or gender diverse. In relation to sexual identity, 79.89% identified as 'gay or homosexual', 4.56% identified as 'Queer', 4.02% identified as 'bisexual', and 8.85% identified as 'heterosexual'. 2.16% reported being Aboriginal or Aboriginal and Torres Strait Islander.

Participants were disproportionately from NSW (73.11%). There was an underrepresentation from other states and territories. The proportions from jurisdiction other than NSW, were:

- Queensland (11.75%)
- Victoria (5.99%)
- South Australia (5.10%)
- Western Australia (1.55%)
- Tasmania (0.44%)
- Northern Territory (0.22%) and,
- Australian Capital Territory (0, 0.00%)

Most PLHIV (74.23%) lived in a metropolitan area and about a quarter (25.77%) lived in a regional or rural area. These proportions are consistent with the population distribution of PLHIV in NSW. 15.92% planned to relocate to a regional/rural area in the future. Slightly less than half (44.80%) reported living in their own home, while (40.27%) lived in private rental accommodation. 12.00% lived in social housing. A small number lived in supported accommodation (1.33%), in crisis accommodation (0.27%), or were homeless (1.33%). Slightly more than two-thirds (68.9%) were born in Australia. 12.12% were born in the United Kingdom/Northern Ireland/Republic of Ireland.

Slightly more than half (51.88%) were employed. The remainder received income from the Disability, Aged Care or Carer's Pension (27.69%), Unemployment Benefit (5.38%), or were supported by a

partner, spouse or friend (1.34%). The remainder (13.71%) derived income from various sources including superannuation, income protection or investments.

13.28% described themselves as religious, while a majority were not religious (83.47%), and 3.31% preferred not to disclose. Slightly more than half (50.54%) described themselves as 'a spiritual person'.

We conducted data analysis on several PLHIV subgroups, to allow for multivariate analysis and comparisons to be drawn between different groups. The subgroups included:

- PLHIV aged 65 years and older
- PLHIV aged 50-64 years
- Partners, carers and family members of PLHIV
- HIV specialist services
- Aged care services

#### Aged Care Services

The survey targeted a fourth cohort - aged care services. Only two aged care services responded to the survey. One provided home care and the other provided counselling. One service was in a metropolitan area and the other in a regional area. The limited response from aged care services was disappointing and due to factors unknown. However, it may have been due to PLHIV jurisdictional organisations (who promoted the survey) having limited contact with aged care services.

#### CHARACTERISTICS OF PLHIV AGED 65 YEARS AND OLDER WHO WERE CONSULTED

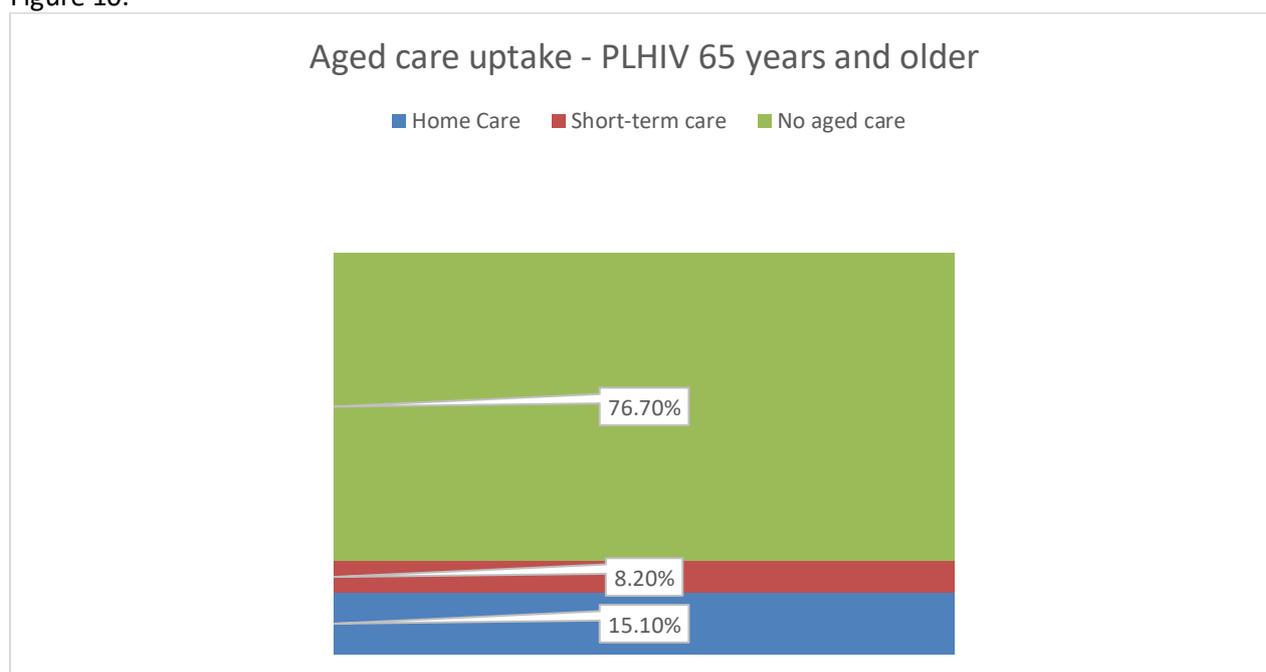
73 PLHIV aged 65 years and over participated in the consultation. Ages ranged from 65 to 86 years. The majority lived in NSW (69.86%). There were small numbers of participants from Queensland (16.44%), Victoria (6.85%) and Western Australia (2.74%). Other states and territories were not represented. About a third (36.23%) lived in a regional/rural area. More than half owned their own home (54.79%), 23.29% lived in private rental accommodation, and 17.81% lived in social housing. Most (94.52%) were male and 5.48% were female. The majority identified as either gay/homosexual, bisexual or queer (84.93%) and 13.70% identified as heterosexual. About two-thirds (65.71%) were born in Australia and the remainder were born overseas. Nearly all spoke English at home (98.52%). While 16.44% were employed, most were receiving the Age Care Pension (61.64%), and 21.92% reported being a self-funded retiree. Only 23.29% reported being religious, however, half (52.05%) described themselves as a spiritual person. Nearly three quarters (70.77%) had been diagnosed with a chronic health condition other than HIV. The most common conditions were mental health conditions, cancer, cardiovascular disease, metabolic disorders, osteoarthritis and hypertension. Issues participants thought would negatively impact on their ability to remain engaged in health care included:

- Loss of mobility
- Loss of licence and ability to travel to a doctor (particularly rural and regional PLHIV, but also PLHIV who live in an area with no access to public transport)
- Management of multiple medications with poor memory and lack of support
- Lack of finances and being poor
- Limited aged care services in rural areas.

## UTILISATION OF AGED CARE SERVICES RECEIVED BY PLHIV AGED 65 YEARS AND OVER, AND LEVELS OF SATISFACTION/DISSATISFACTION

The uptake of aged care by potentially eligible PLHIV (aged 65 years and older) was surprisingly low. Only 17 of the 73 PLHIV (23%) aged 65 years and older received or had received aged care services. Of these, 11 (15.1%) received help at home and 6 (8.2%) received short-term help after an illness or stay in hospital. None had accessed residential aged care. Figure 10 (below), shows the proportions of PLHIV aged 65 years and older accessing home care and short-term respite care after an illness or stay in hospital.

Figure 10.



Most who received aged care services, were satisfied. However, 3 were very unsatisfied. When questioned about why they were unsatisfied, reasons varied, but were principally 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. United Care is a dreadful home care service."*
- *"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."*

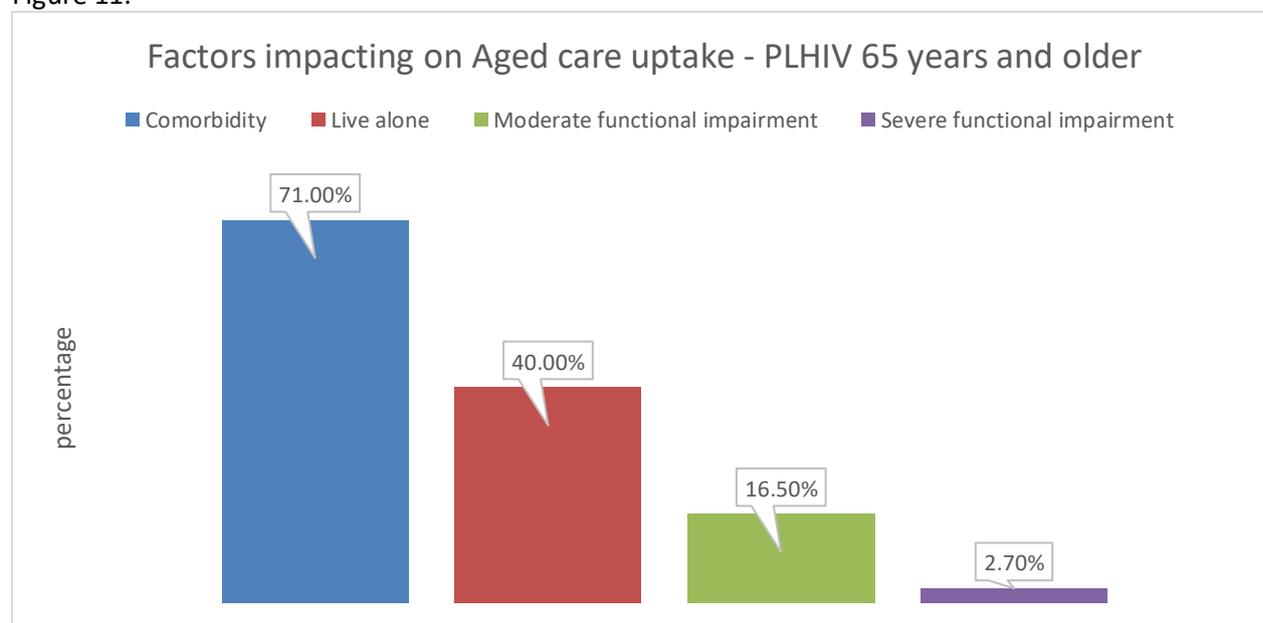
- *“I needed home care services after heart surgery, but despite trying, was unable to make any arrangements until I was in hospital recovering. It would have given me greater peace of mind if a preliminary arrangement was in place before the surgery.”*

## FACTORS IMPACTING ON THE POTENTIAL NEED FOR AGED CARE IN PLHIV AGED 65 YEARS AND OLDER

Analysis of the 73 PLHIV aged 65 years and older revealed that nearly three quarters (71%) had been diagnosed with a serious health condition other than HIV. Conditions included epilepsy, cardiovascular disease, liver disease, cancer, osteoporosis, osteoarthritis, HAND, kidney disease, heart attack, stroke, metabolic disorders, endocrine disorders, and mental health conditions. Many experienced multimorbidity. 40% were single and had no partner, friend or family member to help them at home and about one third (36.23%) lived in a regional or rural area. When questioned about their ability to take care of household responsibilities, 23.3% reported mild physical functional impairment, 16.5% reported moderate physical functional impairment, and 2.7% reported extreme functional impairments. Furthermore, 16.5% reported mild difficulty dressing themselves and 4.1% reported moderate difficulty. 9.6% had moderate difficulty washing themselves and 4.1% had extreme difficulty washing themselves.

Figure 11 (below), shows the proportions of PLHIV aged 65 years and older with comorbidity, who live alone, and who experience moderate and severe physical functional impairments. A comparison between the proportion of PLHIV who receive aged care (23%) and the proportion who would potentially benefit from aged care, suggest an underutilisation of services by PLHIV who live alone, experience multimorbidity, and who report physical limitations and difficulty performing activities of daily living.

Figure 11.



## WHETHER PLHIV AGED 65 YEARS AND OLDER INTEND TO APPLY FOR AGED CARE

When participants who did not currently receive aged care services were asked if they planned to apply at some time in the future, more than half (57%) intended to apply and about a third (31%)

were unsure. Of the 39 who intended to apply, most (76%) intended to apply for home support, and about a quarter (27%) thought they would need short-term help after a stay in hospital or illness. Interestingly, only about a quarter (24%) thought they would apply for residential aged care services. This may have been due to fears of discrimination and mistreatment by facility staff or other residents, and an intention to stay in their own home until they die. We were particularly interested why 12% reported they would not apply for any aged care services. Analysis revealed a deep distrust of aged care services and fear they would experience stigma from service staff. The following quotes illustrate the range of fears:

- *"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"*
- *"Don't 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"*

### Significance

Considering the compounding issues of comorbidity, functional impairment and living alone, it would appear there is a significant current underutilisation of aged care services by PLHIV aged 65 years and older. Many will experience a significant disease burden and difficulty performing activities of daily living. As they age and their health conditions worsen, physical functional limitation will likely escalate, and they will struggle to perform activities of daily living, and to maintain independent living. To increase uptake of aged care services, community organisations like Positive Life should be supported to provide services that: (1) improve navigation of aged care services; (2) support PLHIV to apply for aged care services; and (3) help PLHIV to find service providers who can adequately meet their unique care needs.

### CHARACTERISTICS OF PLHIV AGED 50-64 YEARS

203 PLHIV aged 50-64 years participated in the consultation. The vast majority were male (93.0%) and born in Australia (72.16%). Most (87.6%) identified as gay male/homosexual, bisexual or queer. 9.5% identified as trans or gender diverse, and 1.5% identified as Aboriginal. Most lived in NSW (74.0%). Three quarters (75.4%) lived in a metropolitan area and the remainder (24.6%) lived in a regional or rural area. 15.2% reported planning to relocate from a city to a regional or rural area. Most were living in their own home (45.1%) or private rental accommodation (37.1%) and 14.85% lived in social housing.

About a half (50.1%) were employed and 5.0% reported receiving Unemployment Benefit. 29.2% received the DSP, Aged or Carers Pension. 13.86% received income from a range of sources, including superannuation, investments, income protection and being self-employed. Few reported being religious (11.34%), however half (52.82%) described themselves as a 'spiritual person'. More than half (52.20%) had been diagnosed with a chronic health condition other than HIV. The most commonly diagnosed 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:

- Reduced 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
- Limited aged care services in regional/rural areas.

### UTILISATION OF AGED CARE SERVICES BY PLHIV 50-64 YEARS, LEVELS OF SATISFACTION AND NEED FOR SUPPORT SERVICES

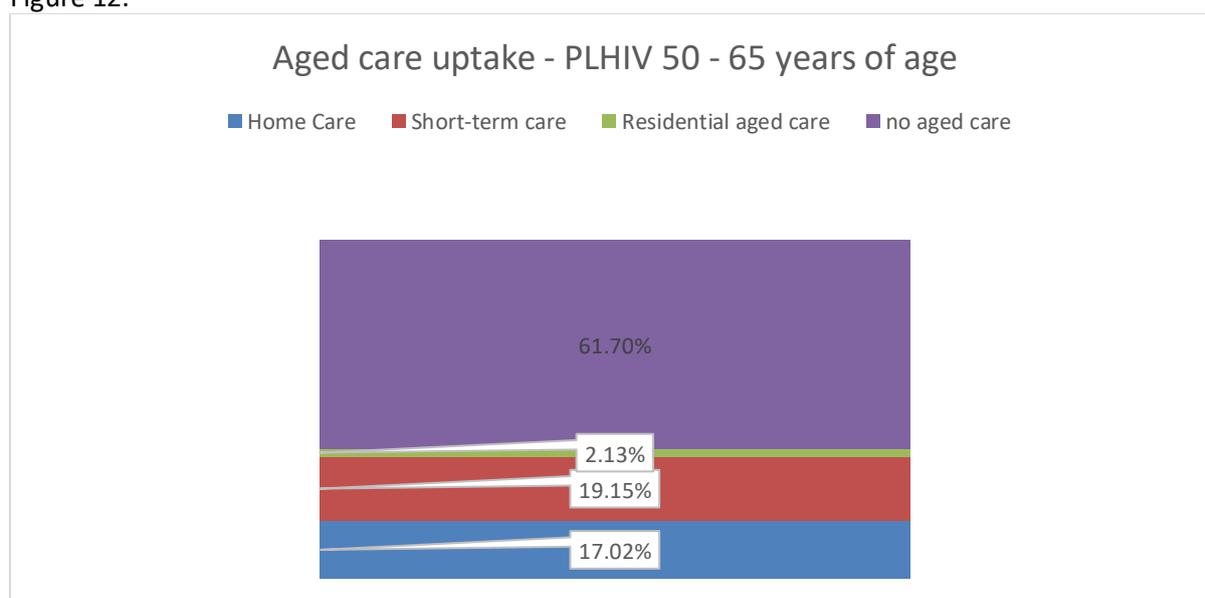
203 PLHIV aged 50-64 years (48% of the PLHIV sample) participated in the consultation. A significant number reported receiving aged care services (38.3%), despite being ineligible for aged care (under 65 years). Of those who received services, 17.0% received help at home and 19.2% received short-term help after an illness or stay in hospital. 2.1% received care in a residential facility. We were unable to establish who provided the services; however, we think most were likely provided by community organisations, funded by state health departments.

While 46.6% were either satisfied or very satisfied, the majority (33.3%) were neither satisfied nor dissatisfied with the services provided. 13.3% were unsatisfied with the services provided, and 6.7% were very dissatisfied. The principal reasons for the dissatisfaction were:

- Service costs
- Unhelpful service provider
- PLHIV felt judged by service provider
- Service provider was unable to provide the requested service
- Poor service coordination by provider

Figure 12 (below), shows the proportions of PLHIV aged 50 to 64 years who receive aged care (home care, short-term respite care, after an illness or stay in hospital or residential aged care).

Figure 12.



9.2% of PLHIV aged 50-64 years reported wanting aged care services but were ineligible. Most reported needing help with home care responsibilities, such as cleaning, gardening, shopping and transport. More than half (56.2%) reported not having a partner, friend or family member who could help them with activities of daily living.

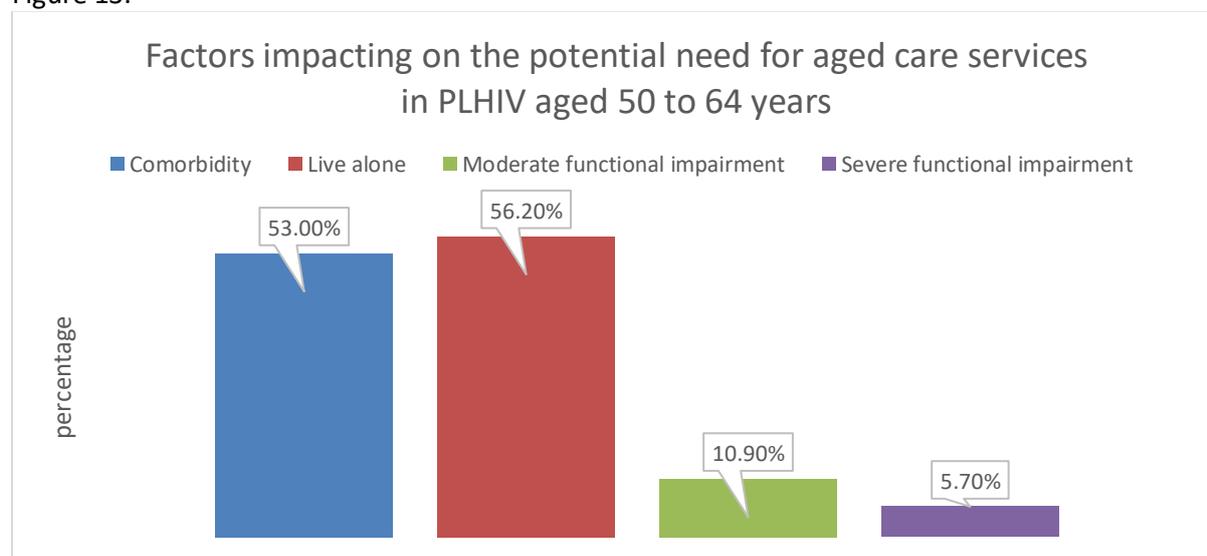
### FACTORS IMPACTING ON THE NEED FOR AGED CARE SERVICE IN PLHIV AGED 50-64 YEARS

We noted in an earlier section of the submission that PLHIV in the 50-64 age group experience the poorest health of any age group, including those aged 65 years and over. We were therefore interested to assess whether poor health impacted on the ability of PLHIV in this age group to perform activities of daily living. More than half (53.3%) had been diagnosed with a chronic health condition other than HIV. Health conditions included serious and debilitating chronic health conditions such as hepatitis B and C, diabetes, cancer, chronic obstructive pulmonary disease, osteoporosis, osteopenia and osteoarthritis, cardiovascular disease, HAND, HAD, psychiatric disorders, Graves' disease, stroke, heart attack, and mental health conditions.

In relation to participant's ability to take care of themselves and household responsibilities: overall, 19.4% experienced mild physical functional impairment, 10.9% moderate functional impairment, and 5.7% severe functional impairment. In relation to personal hygiene, 8.5% experienced mild difficulty washing their body, 6% moderate difficulty, and 2% extreme difficulty. Getting dressed also presented problems for some, with 11% experiencing mild difficulty, 5.5% moderate difficulty, and 1.2% extreme difficulty.

Figure 13 (below) shows the proportions of PLHIV aged 50 to 64 years of age, with comorbidity, who have no partner, friend or family member to help them, and who experience moderate and severe physical functional limitations. If these factors are compared with PLHIV aged 65 years and older, it can be seen that while PLHIV in the 50 to 64 years age group experience a lower prevalence of comorbidity (71% vs. 53%), the proportion of PLHIV aged 50 to 64 years who do not have a partner, friend or family member to help them is substantially higher than PLHIV aged 65 years and older (56% vs. 40%). The prevalence of severe physical functional limitations/impairment is also higher (5.7% vs. 2.7%).

Figure 13.



### Significance

Considering the health burden experienced by PLHIV in the 50-64 age group, the proportions who have no partner and live alone, and the proportions with moderate and severe physical functional limitations, we think there is a strong case for relaxing eligibility restrictions for PLHIV in this age group. The provision of aged care (particularly home care) to PLHIV aged 50-64 years who have limited support, 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 their health, admissions to hospital and/or relocation to a residential aged care facility.

### THE INTENTION TO APPLY FOR AGED CARE IN THE FUTURE - PLHIV AGED 50-64 YEARS

Nearly half (49.4%) of PLHIV aged 50-64 years planned to apply for aged care at some time in the future, and 38% were unsure. Three quarters (75.2%) thought they would need help at home and about one third (37.3%) thought they would need help after a stay in hospital or during/after an illness. A quarter (24.3%) thought they would need future care in an aged care facility. 12.4% reported they would not apply. The reasons varied. Some were unsure about the quality of service they would receive, others thought they would not qualify because of assets, while some wanted to die before they needed to go into care. As one participant said: *"I'm not sure I want to live that long."*

9.2% reported needing aged care support now but were ineligible due to the age restrictions. Most needed home support services and transport to get to a doctor or specialist.

### WHAT WOULD IMPROVE AGED CARE SERVICES FOR PLHIV AGED 50-64 YEARS

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 are not patronising and treat clients with respect
- Employing workers who are keen to help, are adequately trained, and not judgemental
- Employing workers who can communicate with clients

### RESPONSES FROM PARTNERS, CARERS OR FAMILY MEMBERS OF PLHIV

#### CHARACTERISTICS OF PARTNERS, CARERS

35 partners, carers and family members of a person living with HIV participated in the consultation. Most lived in NSW (77.1%), although some lived in Queensland (14.3%). Two thirds (65.6%) lived in a city and a third lived in a regional or rural area. 59.4% of the partner, carers were aged 50 to 64 years of age, and 15.6% were aged 65 years and older. Three quarters (75.8%) described themselves as not religious and slightly more than half (51.5%) described themselves as a 'spiritual person'.

## UTILISATION OF AGED CARE BY PARTNERS, CARERS

We were surprised that only 1 partner carer (2.9% of this cohort) reported receiving aged care. The service they received was home-based care and they were satisfied with the quality of the services received.

## FACTORS IMPACTING ON THE POTENTIAL NEED FOR AGED CARE SERVICE

About a quarter (28.0%) of the PLHIV they cared for had chronic health conditions in addition to HIV. 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.

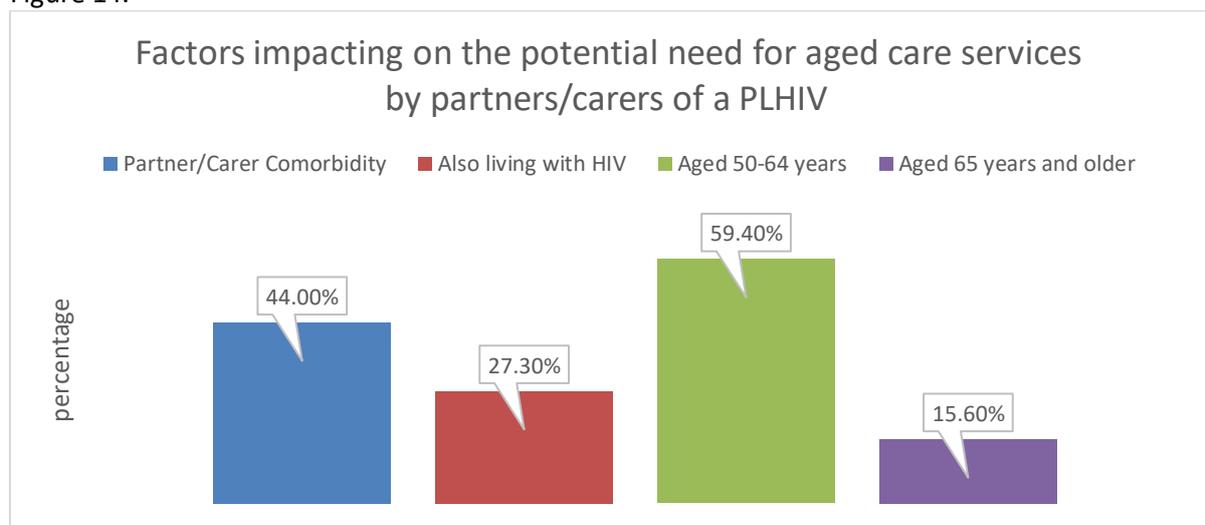
In addition, overall, 18.6% experienced mild functional limitation, 8.4% experienced moderate functional limitation, and 7.5% experienced extreme functional limitation, and difficulty taking care of household responsibilities. 21% also experienced mild difficulty getting dressed and 4% experienced moderate difficulty getting dressed. 8% also had moderate difficulty washing their body.

More than half (53.6%) of the PLHIV cared for by a partner, friend or family member, planned to apply for aged care services in the future, and about a quarter (25.0%) were unsure whether they would apply or not. 21.5% reported they would not apply, and the primary reason was perceived ineligibility. About half (54%) thought they would need help at home and 40% thought they would need short-term help after an illness or stay in hospital. 29% thought they would eventually need residential aged care. 12% reported they currently need aged care but are ineligible due to age or other restrictions.

We asked the partners, carers or family members if they had health issues of their own that may impact on their current and future ability to provide care and support to the PLHIV. A significant proportion (44.0%) answered yes, and reported serious health conditions including aggressive arthritis, diabetes, cardiovascular disease, mental health conditions, stroke, neurological conditions, and cancers. Many were also living with HIV themselves (23.3%).

Figure 14 (below), shows the proportions of partners, carers who experience HIV, health and other issues that may impact on their ability to provide care, and who are aged 50 to 64 years and 65 years and older. Nearly three quarters were older than 50 years of age. When these circumstances are considered, along with the burden of health conditions of the PLHIV they are caring for, it is surprising that only 2.9% of these couples reported receiving aged care services.

Figure 14.



### FEARS FOR THEIR ABILITY TO CONTINUE CARING FOR THE PLHIV

More than half (53.12%) were fearful of not being able to care for their partner or family member at some time 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"

#### Significance

There appears to be a significant underutilisation of aged care services by PLHIV who are being informally cared for by a partner, friend or family member. Many of these partners/carers are also in poor health and aged. As they get older and their health deteriorates, the ability to provide care and support will likely decrease. Aged care services will then be required for both individuals. Overall, health and independence could be substantially improved if PLHIV and their caring partners were encouraged and supported to apply for and receive aged care services, particularly home-based care.

## RESPONSES FROM HIV SERVICES

### HIV services:

25 HIV specialist services participated in this consultation. The types of services included:

- Mental health, counselling and psychology services
- HIV health promotion, education and peer support services

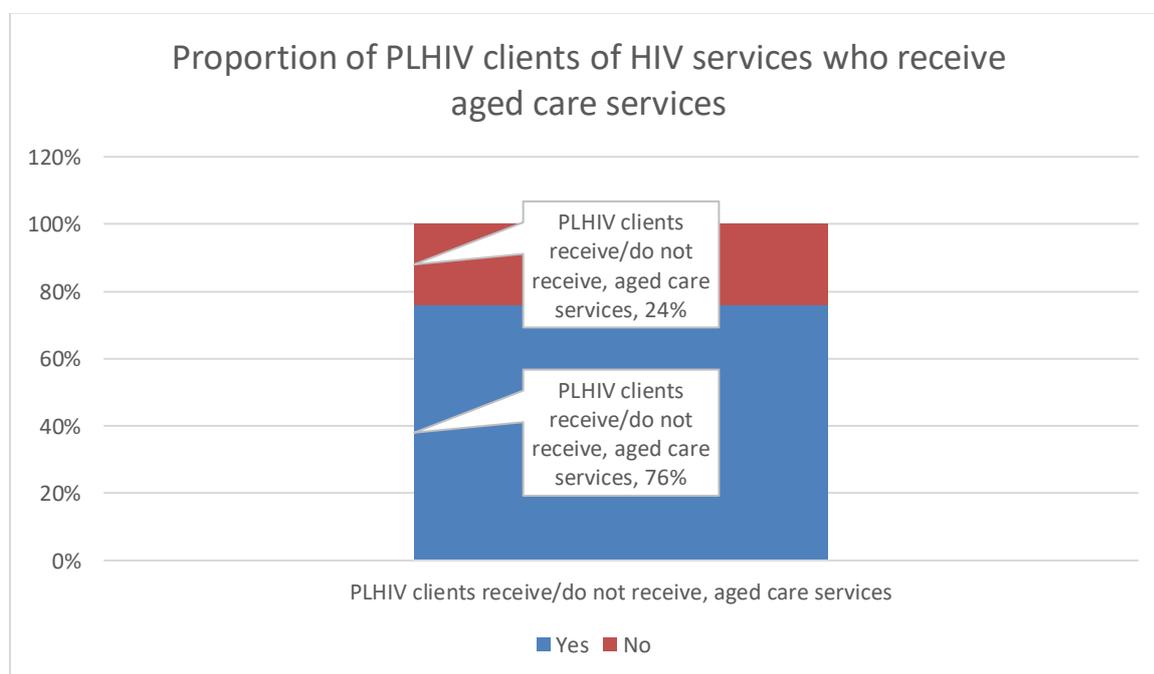
- HIV self-management services for PLHIV aged 50 years and over
- HIV clinical care services
- Allied health services
- Pharmacy services
- Community pastoral services to PLHIV and carers
- Social work services
- Community care and support
- Nursing
- Social support and respite care
- Hospital HIV specialist clinic
- HIV testing and monitoring
- Case management services

Over a quarter of services (28.0%) were in a regional/rural area, and nearly all (92.0%) were in NSW.

### UPTAKE OF AGED CARE BY CLIENT'S OF HIV SERVICES

More than three quarters (76%) of the 25 HIV services consulted reported having clients with HIV who were receiving aged care services. The services received by PLHIV were mostly home support (100.0%), followed by short-term support/respite care after an illness or stay in hospital (71.4%), and then residential aged care (42.9%). Figure 15 (below) shows the proportions of PLHIV receiving care from a HIV service who receive/do not receive aged care services.

Figure 15.



Overall, most HIV services were either satisfied (57%) or neither satisfied nor unsatisfied (43%) with the quality of aged care services received by their clients. When asked if aged care services met the needs of PLHIV, slightly less than half (42.86%) said yes. However, more than half (57%) said they did not meet the needs of PLHIV. Some examples of reasons why aged care services did not meet the 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. Co-payment for people transitioning from DSP to aged pension (for medicines) – who don't have savings to fund services. Waitlist for high level aged care packages is 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”*

## WHAT WOULD IMPROVE THE QUALITY OF AGED CARE SERVICES

We asked HIV services what would improve the quality of aged care. Many respondents thought there was a need for more services being available, so wait times were reduced. There was also calls for aged care services to have a better understanding of HIV, including an understanding that HIV cannot be transmitted by PLHIV who are being successfully treated with ART.

HIV specialist services were asked how difficult it had been to organise aged care for their HIV-positive clients. No HIV services reported it being easy, and more than half (57%) said it was difficult. 14% said it was very difficult. There were a range of reasons contributing to reported difficulty.

Reasons included:

- delays in getting ACAT assessments
- issues surrounding the clinical management and treatment of PLHIV with comorbidities and resultant drug reactions/interactions
- problems with behaviour management of PLHIV in aged care facilities
- wait times for packages to be approved
- staff being unaware of transmission risks
- inappropriate disclosure of HIV status, and
- difficulties navigating the My Aged Care service portal.

When asked if they had the necessary knowledge, skills, experience and time to help older people with HIV to engage with aged care services, most (71.4%) thought they did. About a quarter (28.6%) thought they did not have the knowledge, skills and time to assist. In these circumstances, HIV services referred onto other services who were able to assist.

### Significance

Three quarters of HIV services (76%) had clients who receive aged care. It would seem as though PLHIV who are connected to specialist HIV services have a significantly higher rate of engagement with, and access to, aged care than those who are not connected to these services. This is most likely due to HIV service staff recognising the need for aged care and supporting PLHIV through the application process.

## SUBSTANDARD CARE INCLUDING MISTREATMENT, NEGLECT AND ABUSE

During the consultation we asked what would improve the quality of aged care services. We considered the suggestions made to be proxies for substandard care. There were a range of issues identified where improvements were suggested. These primarily included:

### Transport services

There were complaints about community transport in regional areas cancelling service on the morning of medical appointments, despite being booked six months in advance. PLHIV rely on access to medical care. If they need community transport to get them to medical or hospital appointments, and the transport services are cancelled, acute and chronic health outcomes worsen.

### Quality of services provided and the attitude of providers

There were a range of complaints about the attitude and the quality of service staff. These complaints included:

- Being unhelpful, lacking empathy, being patronising and disrespectful
- Being unfriendly, impolite and not listening to the requests of clients
- Staff lacking training
- Staff not being able to communicate – not speaking English
- Services being too costly
- Services being too rigid
- Services not turning up as arranged
- The need for better coordination of services
- Many respondents thought there was an urgent need for more services being made available to reduce long waiting lists for services.

## ACTS OF DISCRIMINATION AGAINST PLHIV

Participants were asked if they had any knowledge or experience of acts of discrimination against PLHIV receiving aged care. 120 participants provided feedback on the issue. Many of the responses were from staff working in HIV specialist services who had received reports from their clients of discrimination. There were some common areas of discrimination, which are broadly described below:

- *“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 on one occasion 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 came. The second time he was removed from the facility and is now in a locked hospital ward, awaiting another placement”*
- *“I have seen elder abuse by a person’s primary carer”*
- *“I work in an aged care facility. The client was shamed and silenced”*
- *“Being ignored”*
- *“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 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 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"*

## ACTS OF ABUSE OR NEGLECT OF PLHIV

Participants were asked if they had any knowledge and experience of acts of abuse or neglect against PLHIV. The following describe some of those contexts:

- *"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"*
- *"Heard staff say he's probably got AIDS when it was non-related cancer"*
- *"I heard earlier this year, 2019, some caring staff at a Perth aged care facility refused to care for a newly arrived resident who was living with HIV. The issue was resolved by support staff from the hospital where the person was a patient. The staff concerned received counselling and were told they could not refuse to care for the person. They continued to refuse and were dismissed"*
- *"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 in 2016 to recover in an aged care facility in Eastern Sydney. 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"*

## PROVIDING CARE TO PLHIV WITH HAND AND HAD

During the consultation we asked participants if they had suggestions about how aged care could best be provided to PLHIV with HAND and HAD. 175 people provided feedback. While about a third (36%) were either unsure or unable to provide suggestions, the other two-thirds provided feedback.

The primary concerns were in relation to aged care service staff (both home-based and residential) not understanding HIV, HAND and HAD, and how PLHIV with HAND/HAD present. Suggestions to improve the quality of service included HIV specialist services (who have experience dealing with HAND and HAD) providing specific training to aged care and home care staff with clients with these conditions. Services such as Adahps (formally the AIDS Dementia and HIV Psychiatry Service) would be well qualified to provide such training. Others thought community organisations who care for PLHIV should provide the training. However, there was general acceptance that the issue is one that needs urgent attention and discussion with neurological specialists and community organisations.

There were calls for more person-centred care. PLHIV often experience HAND in quite different ways. Creating one-page profiles for clients may assist with communication and service coordination and delivery. 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, gender dysphoria, drug use, and HIV. There were concerns raised that PLHIV with HAND and 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 unreported.

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

PLHIV with HAND 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.

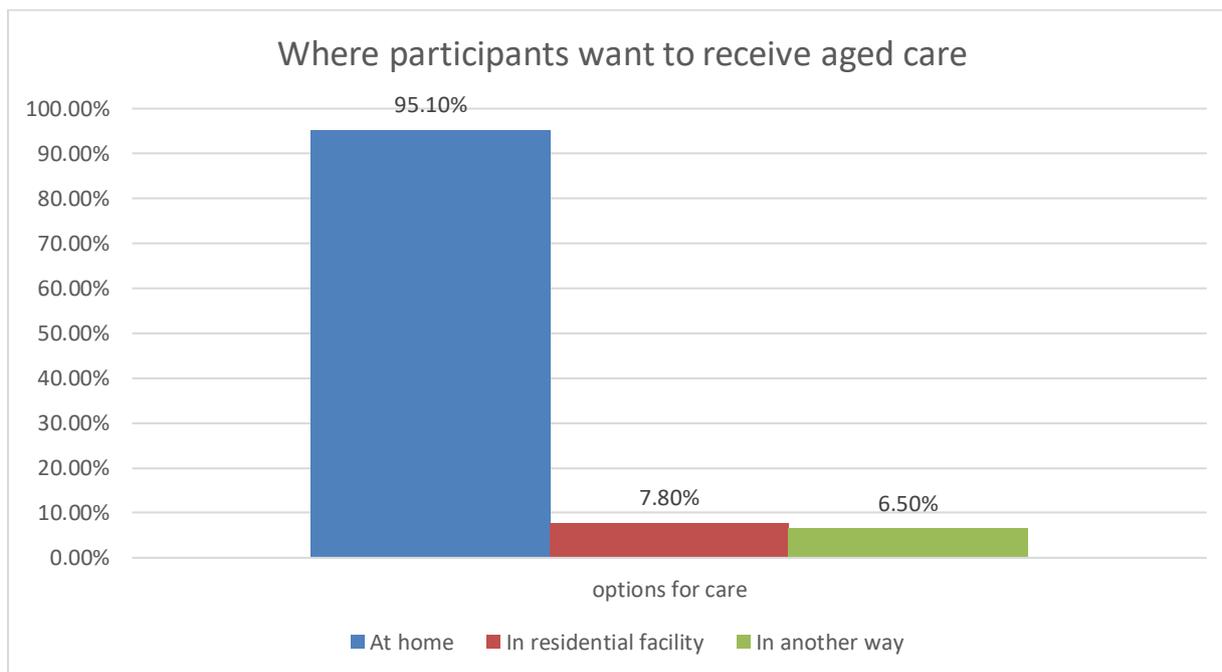
*"I have been diagnosed with HAND. My intellectual functioning is continuing to deteriorate. I have a very real sense that my world is 'shrinking'. I will need increasing levels of support to remain in my own home, particularly as my partner/carer is now 82 years old." - A survey respondent*

## PREFERENCES WHERE AGED CARE SERVICES ARE PROVIDED AND BY WHOM

### PREFERENCE WHERE SERVICES ARE PROVIDED

A majority (95%) of PLHIV expressed a clear choice to remain living in their own home until such time as they could no longer manage. A small proportion (7.8%) preferred to receive care in a residential facility, and a few nominated 'in another way' (including gay retirement home, purpose-built facility for PLHIV, shared private housing, or in the company of peers). Figure 16 shows the proportions of participants who reported preferences where aged care services should be provided to them.

Figure 16.

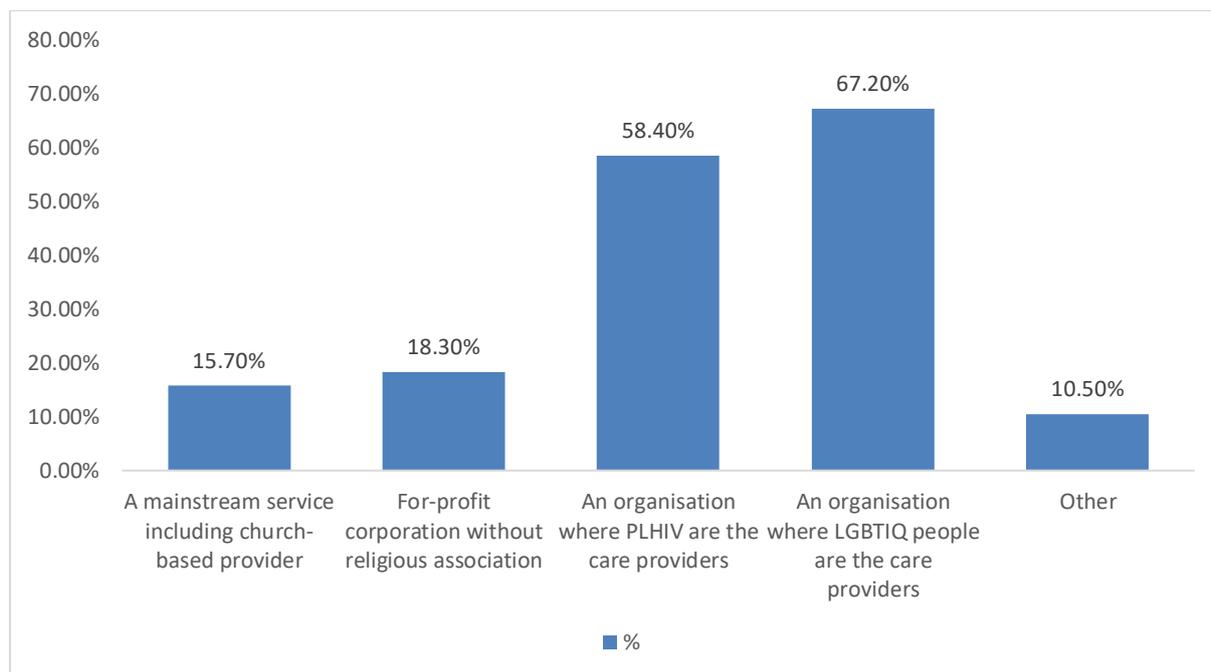


### PREFERENCE WHO PROVIDES SERVICES

Participants were asked who they would prefer to provide aged care services. A majority (67.2%) wanted LGBTIQ people to be the care providers, followed by PLHIV (58.4%). 18.3% nominated a for-profit organisation without religious associations, and 15.7% nominated a mainstream service provider including a church-based provider. The remaining 10.5% reported a range of other options including:

- *“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 17 (below) shows the proportional preferences of participants.  
 Figure 17.



Participants were asked why their preference was important and many expressed deep concerns about being cared for by faith-based organisations. Persecution and discrimination by religious institutions (churches) is remembered and deeply felt by LGBTIQ people, particularly gay men, who have experienced or witnessed vilification and discrimination by the church. The following comments illustrate the levels of concern, suspicion, and mistrust of faith-based organisations/services by PLHIV, and their ability to provide non-discriminatory care to PLHIV and LGBTIQ people:

- *“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”*
- *“The church has caused such damage and pain. I would not want a church-based provider to look 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."*

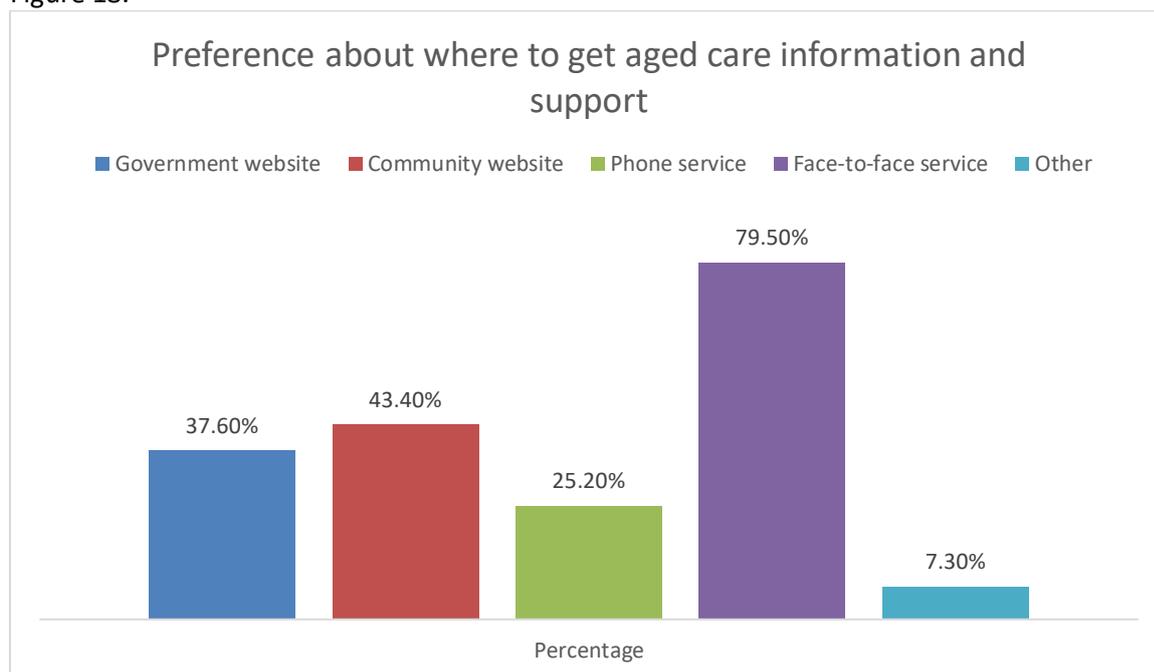
Gay men with HIV expressed fears they would not be treated with respect by care providers who were not community attached or had limited understanding of gay men and their lifestyle choices. Many respondents wanted to be cared for by other people with HIV, or at least by members of the LGBTIQ community. 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 & become more vulnerable, it intensifies the need for PEER SUPPORT programmes & service delivery. HIV and AIDS has been highly specific health phenomenon & 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 & 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 & I have concerns at the prospects of being in the care of such individuals"*

## PREFERENCES ABOUT WHERE INFORMATION AND SUPPORT ARE PROVIDED WHEN APPLYING FOR AGED CARE

Participants were asked how they would prefer to get information and support when they needed to apply for aged care. Figure 18 (below) shows the proportionate preferences of participants.

Figure 18.



## REASONS FOR THIS CHOICE

Many PLHIV thought they would be better informed and better understood by a face-to-face service (run by PLHIV). They thought a peer-run community service would be empathetic and understanding of their needs and provide reliable and trustworthy information and support. The face-to-face option was even more preferred by older PLHIV, many of whom were technophobic with limited ability to access or navigate government or community websites or did not have access to the internet. The following quotes illustrate participant's reasoning:

- "Government services focus on the public health response, whereas community and peer-based services speak to me as an individual living with HIV"
- "I believe to accurately assess a person's needs; it has to be face-to-face"
- "Because I will then know that the information is coming from people like me, who have similar experiences to me and so understand me better..."
- "A sense of community is very necessary for mental health, face-to-face is the clearest way to discuss issues"
- "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 are/can be hard to navigate but to have someone assist you, A PL advocate"
- "There is no 'one size fits all' when it comes to information dissemination"
- "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."

It should also be noted that many PLHIV (58% in this consultation) have no partner, friend or family member to help navigate the aged care service system. Older PLHIV will need an understanding support service that can assist them to successfully navigate and apply for services.

## IMPROVING PLHIV ENGAGEMENT WITH AGED CARE

Aged Care service navigation and access may seem a simple matter to many people, however navigating the aged care system can be complex and stressful for PLHIV in poor physical health, with mental health conditions, or cognitive impairment. This and other consultations have revealed significant concern by older PLHIV about where they will go to get information and about aged care services. 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. Many don't have access to the internet or choose not to engage with electronic information and mobile devices altogether. They want a person-centred service approach where information is tailored to the individual's needs and staff assist with assessments and service provider linkages and negotiations. Currently, there is no HIV specialist service that effectively meets the needs of a growing, diverse, and ageing PLHIV population with complex care needs who need to navigate the health, aged care, and disability service systems.

To address this service gap, Positive Life successfully applied for, and received seed funding from a pharmaceutical company to develop an aged care navigational service for older PLHIV in NSW. Once established, the Silver Warriors Pilot Programme will:

- Educate and support ageing PLHIV who want to navigate and access aged care, disability and health care services to overcome personal and systemic barriers, and improve linkage to and satisfaction with aged care, disability and healthcare services;
- Build a comprehensive knowledge base of Aged Care and NDIS services that meet the needs of PLHIV;
- Improve the physical and mental health and self-management skills of PLHIV;
- Enable partnership agreement and service linkages between aged care, disability and health care services as well as case management services;
- Measure the effectiveness of the program to meet the diverse and complex needs of older PLHIV in New South Wales; and
- Provide proof of concept and potential scale-up in other Australian jurisdictions.

Ageing PLHIV have also called on Positive Life to become an accredited aged care service provider. The reasons for this are:

- Positive Life understands the needs of PLHIV and the cultural contexts in which they live. It is well positioned to provide appropriate, respectful and sensitively delivered non-discriminatory and inclusive aged care services to ageing PLHIV
- A growing need for home services, such as cleaning and laundry services, social support services, transport, and help with shopping and food preparation activities, would benefit older PLHIV and permit them to remain living in the community longer, rather than in a residential aged care facility
- The enervating impacts of stigma and discrimination would be minimised if Positive Life were to provide My Aged Care services through peers to PLHIV
- Peer-delivered aged care services would be more likely to facilitate cultural connections, the sharing of mutual interests and values, and reduce feelings of social isolation and loneliness.

The reduction in feelings of loneliness would likely improve mental health and long-term health outcomes of older PLHIV.

While there are many advantages for PLHIV were Positive Life to provide aged care services, there are currently structural barriers that disincentivise not-for-profit organisations (like Positive Life NSW) from becoming an accredited service provider. These barriers include:

- Structural and legal entity issues (not-for profit community organisations)
- Accreditation and compliance issues
- Start-up costs
- Insurance costs
- Staff training costs

Not-for-profit community organisations like Positive Life NSW, would seriously consider providing aged care services to their communities, were these barriers to be minimised or removed. We think the Commonwealth Government should seriously consider reviewing the ways in which not-for-profit organisations can become accredited providers and deliver services to their communities. This outcome would have significant benefit for groups within the community who are currently marginalised and fall through service gaps.

## THE THOUGHTS AND FEARS OF AGEING PLHIV

A significant number of older PLHIV (65.35%) report being fearful of ageing. The proportion increases significantly in those aged 65 years and over (to 84.3%). The fears and issues that are most frequently reported are:

- The burden of being old with HIV, comorbidity, and poor health
- Living with dementia and HAND or HAD
- Isolation, loneliness and being without a support network of peers and family
- Discrimination or abuse from aged care services and other residents in aged care facilities
- Being immobile and trapped in an apartment or aged care facility room

Recent coverage in the media of physical and emotional abuse of residents in aged care facilities has contributed to concerns that the provision of non-discriminatory care of PLHIV is probably unlikely. PLHIV have told Positive Life NSW they have little hope of being treated with dignity and respect. 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.”*

The following quotes, sum up commonly held thoughts and fears by 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?"*
- *"Not looking forward to even contemplating aged care services"*
- *"I doubt it will be fun"*
- *"For most of us with HIV, there will be little different needs to anyone else. Sadly, stigma caused by fear and ignorance among care providers may still persist if sustained improvement of education for aged care providers is not maintained"*
- *"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"*

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