PositiveLifeNSW
the voice of people with HIV since 1988

Aged Care Workforce Strategy Taskforce
ACWSTaskforce@health.gov.au

Re: Aged Care Workforce Strategy Taskforce

Dear Committee Secretariat,

Thank you for the opportunity to provide input into the *Aged Care Workforce Strategy* consultation. Our submission to the consultation accompanies this letter.

Positive Life NSW is the state-wide peer based organisation that speaks for and on behalf of people living with and affected by HIV in NSW. We provide advocacy and leadership in advancing the human rights and quality of life of people living with HIV.

Our vision is that all people living with HIV in Australia are able to live valued and meaningful lives, free from the impacts of stigma and discrimination, and contributing to the end of HIV transmission.

We would like to commend Minster Ken Wyatt AM, MP, for this initiative to develop a strategy aimed at growing and sustaining the workforce providing aged care services and support to older Australians to meet their care needs.

If this submission requires additional information or clarification, I can be contacted on 0422 509 200, or alternatively by email at craigc@positivelife.org.au

Yours respectfully,

Craig Cooper
Chief Executive Officer

15 March 2018

Positive Life NSW Submission to the Aged Care Workforce Strategy Taskforce

Introduction - Positive Life NSW (Positive Life) thanks the Hon Ken Wyatt AM, MP for the opportunity to provide input to the Aged Care Workforce Strategy Taskforce on issues relating to older people living with HIV (PLHIV) in NSW. Positive Life is the public face and voice of all PLHIV in NSW. We are a state-wide peer-based non-government agency that makes a significant contribution to and impact upon a spectrum of health and social issues, on behalf of PLHIV. Positive Life collaborates with HIV specialist and mainstream organisations to improve the health and quality of life of PLHIV. We do this through evidence based health promotion, policy and advocacy advice, and peer support.

Demographic and background considerations - At the end of 2015, there were an estimated 25,313 PLHIV in Australia. The number of new HIV infections in Australia has remained stable for the past four years, with 1,082 cases in 2014, 1,030 in 2013, and 1,064 in 2012. This means that there will be approximately 28,000 PLHIV by the end of 2018, and approximately 30,000 by 2020.[1] While AIDS diagnoses peaked at 953 cases in 1994, after 1994, diagnoses declined rapidly due to the introduction of combination antiretroviral therapy (cART). The efficacy of cART prevents progression of HIV infection to AIDS and it also reduces infectivity. These days, few people are diagnosed with AIDS, and those who are, generally recover after antiretroviral therapy is commenced. And so, PLHIV are now living longer and growing older.

While gay men and other men who have sex with men continue to be the largest proportion of people impacted by HIV infection (currently at around 75% of the nation's population, or 19,097), the demographic mix of PLHIV is changing over time and becoming more diversified. For example, the proportions of Australians who have acquired HIV from heterosexual sex is gradually increasing, currently 21% or 5,306. However, this proportion varies from state-to-state and in each of the territories. It also varies according to where PLHIV live in each state and territory. Generally, higher proportions of heterosexual PLHIV live in outer capital city suburban and rural/regional areas, whilst gay men tend to live in inner metropolitan areas. There are also 541 Australians who have acquired HIV by injecting drug use and 142 by 'Other' exposures routes (i.e. mother to child transmission, blood/tissue recipient, health care setting, haemophilia etc.).[2]

The Australian population with HIV is also chronologically ageing. In 2000, 11.2% of PLHIV were 55 years and over. In 2010, 25.7% of PLHIV were 55 years and over and in 2020, 44.3% of PLHIV will be 55 years and over. The proportions of PLHIV aged 55-64, 65-74 and 75 years and older are all increasing.[3] For example, in 2000, 2.5% of the Australian population with HIV was 65 years and over, but by 2020, it estimated to be 17.3%, or approximately 5,200 people. Older PLHIV are therefore becoming an increasing proportion of the total Australian PLHIV population.

In addition, the population distribution of PLHIV throughout Australia varies substantially from state and territory, to state and territory. NSW has the largest population of PLHIV (41.1%) or 9,683 as at 30 June 2017, followed by Victoria (24.5%), Queensland (19%), South Australia (5.1%), Western Australia (7.1%), Tasmania (1%), Northern Territory (0.8%), and Australian Capital Territory (1.2%).[4]

Medical considerations for PLHIV - PLHIV require continuous treatment with cART to prevent HIV disease progression and death from AIDS. Clinical care of PLHIV is provided by HIV specialists (usually

[1] HIV data for Australia is drawn from the Kirby Institute's 2016 Annual Surveillance Report (for the year ending 31 December 2015) https://kirby.unsw.edu.au/report/annual-surveillance-report-hiv-viral-hepatitis-stis-2016
[2] Annual Surveillance Report 2016, Kirby Institute
[3] Wilson, D. 2011, Mapping HIV Outcomes: geographical and clinical forecasts of people living with HIV in Australia, Table 5. Number of people living with diagnosed HIV by statistical region and year
[4] Jansson J, Wilson D, (Kirby Institute) Watson J, (NAPWHA) 2011. *Mapping HIV Outcomes; geographical and clinical forecasts of people living with HIV in Australia*

GPs who have undergone HIV specialist training). These GP specialists, or S100 prescribers, have authority to monitor HIV and prescribe cART to PLHIV. While GPs who are not qualified can share care of a PLHIV with an HIV specialist, these arrangements have to be negotiated. Developing shared care arrangements takes time and may present challenges for residential aged care facilities, who have no prior experience of HIV management or associations with HIV clinical specialists.

In addition, the distribution and availability of HIV specialist doctors across Australia varies significantly from area to area and state to state. Whilst there is good access to HIV specialist GPs in most major cities (i.e. Sydney, Melbourne and Brisbane), access is significantly reduced in outer suburbs areas and rural and regional areas.[5] In the case of NSW (with the highest PLHIV population and with nearly a quarter of PLHIV living outside the Sydney metropolitan area), there is no resident HIV specialist west of Orange. PLHIV in western, far-western and southern NSW, are reliant on a visiting HIV specialist (one-to-two days per month). Lack of local HIV specialist in rural and regional areas will create substantial challenges for aged care residential facilities who want to care for PLHIV in regional areas.

Multimorbidity is also an issue for PLHIV who are at risk of a range of serious chronic health conditions associated with HIV infection and ageing. A 2015 Australian prospective study of 446 HIV positive and HIV negative (228 HIV positive and 218 HIV negative) gay and bisexual men (GBM) aged 55 years and over (*The Australian Positive & Peers Longevity Evaluation Study*), found that HIV positive GBM (when compared to HIV negative GBM) reported much higher rates of thrombosis (10.5% vs 4.2%), diabetes (15% vs 9%), heart disease (20% vs 12%), neuropathy (23% vs 1%), and shingles (32.5% vs 16.9%). When adjusted for smoking and age, a significantly elevated risk of melanoma, prostate cancer and osteoporosis were also identified. HIV positive GBM are also 50 times more likely than the general population to be diagnosed with anal cancer[6], and rates of depression, anxiety and other mental health conditions are much higher in PLHIV than in the general population.[7]

For both HIV positive and HIV negative cohorts in the above study, multimorbidity became more prevalent with increasing age and HIV positive GBM reported significantly higher mean numbers of comorbidities compared to HIV negative GBM. For example, 85% of HIV positive GBM reported one or more comorbidities, and just over half (56%) reported two or more comorbidities – in addition to HIV. Increased prevalence of traditional risk factors among PLHIV (such as smoking, elevated lipids, hyperglycaemia, altered body composition, alcohol and recreational drug use) significantly contribute to the increased risk of many of these non-communicable diseases.[8]

PLHIV are also at increased risk of HIV Associated Neurocognitive Disorder (HAND). Despite cART crossing the blood brain barrier, inflammation in the brain from HIV, albeit at low levels, persists due to some combinations of HIV medication working better than others. It is estimated that somewhere between 15-70% of PLHIV will have some degree of neurocognitive impairment from HIV infection. The persistent inflammation has also been attributed to the board range of early or premature aging and other neurological manifestation observed in PLHIV.[9] At this stage, it is unclear whether HAND will progress to dementia. Science is still in the process of determining progression; however, we do

[5] http://www.ashm.org.au/prescriber-locator/
[6] Grulich A Kirby Institute, 2017 presentation, E Ianoy et al, International J Cancer, 2011
[7] *HIV Futures Seven, Making positive lives count*, Grierson J et al, ARCSHS, La Trobe University , 2009
[8] *Prevalence of self-reported comorbidities in HIV positive and HIV negative men who have sex with men over 55 years – The Australian Positive & Peers Longevity Evaluation Study* (APPLES) 2017. Petoumenos, K. et al.
[9] *Developing Resources to Assist People Living with HIV Associated Neurocognitive Disorder (HAND),* Crawford D. 2016, Positive Life NSW http://www.positivelife.org.au/images/PDF/2016/PLNSW-HAND-Report-2016.pdf

know that rates of HIV Associated Dementia (HAD) are currently estimated to be 2% of PLHIV[10] and that PLHIV with HAD require high levels of specialist, and in most cases, residential care.[11]

The combination of HIV, multi-morbidity and ageing can frequently lead to progressive frailty in PLHIV. After diagnosis and treatment of cancer, heart attack, stroke and fractures for example, PLHIV are prone to increasing symptoms of frailty and an inability to function autonomously. Symptoms include: low endurance and reduced energy reserves, poor strength, reduced exercise tolerance and loss of muscle mass, loss of balance, dysregulation of physiological systems including immunity, neurologic, inflammatory and endocrine systems, increased susceptibility to falls, fractures, loss of independence and death.[12] Frailty increases with age and time of HIV infection for PLHIV. PLHIV infected for 8-12 years at age 55 years, exhibit a nine-fold higher risk of frailty than aged match controls.[13] Frailty leads to reduced functional independence, and increased accommodation and care needs.

Non-medical influencing factors - There are now measurable changes in the backgrounds and mix of PLHIV, and newly infected with HIV in Australia. The most noticeable difference from the experience of the last century is the growth in the number of PLHIV from non-English speaking backgrounds, in the number of women generally, and in the number of men who do not identify as gay or bisexual. Of the 25,313 Australian PLHIV, 14,675 (58.0%) are Australian-born non-Indigenous, 469 (1.8%) are Aboriginal and Torres Strait Islander, 2004 (7.9%) were born in Sub-Sahara Africa, 2360 (9.3%) were born in South-East Asia, and 6938 (27.4%) were born in another country of origin.[14] By HIV exposure category, 19,097 (76.1%) are men who have sex with men (MSM), 5,306 (21.1%) are Heterosexuals, 541 (2.2%) are people who inject drugs, and 142 (0.5%) have acquired HIV by 'Other' means.[15]

Cultural or environmental factors have been acknowledged by the Ottawa Charter[16] as important issues impacting on the health of PLHIV and their ability to live independently in society. Even relatively simple medical conditions may become more complex as a result of the contextual realities in which people live. These factors are external to the person but can influence their health, functioning, and interaction with the health system, and other services such as aged care services - either positively or negatively. Factors include: a history of unsatisfactory housing; lack of social support; being without spousal, family supports or support from friends; being of low socioeconomic status; living in a rural area; lack of access to transport; lack of access to technology; and, the impacts of HIV associated stigma and discrimination etc.[17] Variations in these situational or environmental factors unequally expose PLHIV to influences that damage health, in different ways and make them more likely to need support at younger ages.

Factors such as: gender, race, age, cultural circumstance, lifestyle, upbringing, educational background, all impact on the way PLHIV experience HIV, other health conditions and the world around them. These elements impact on the way PLHIV interact with aged care services and with health care systems in general, but also with the way health and other information is understood, and by the way PLHIV engage, or don't engage, with services and their own care. A PLHIV's ability to participate in their own heath care and activities such as learning, applying knowledge, communication and self-care, can be significantly impacted by the severity of multiple co-occurring

[10] Brue B. Neurologist, St Vincent's Hospital Sydney, 2016
[11] Adahps (formally the AIDS Dementia and HIV Psychiatry Service) Darlinghurst Sydney
[12] Sandy Beveridge, Director of Geriatric Medicine and Ambulatory Medicine St Vincent's Hospital Sydney, Presentation to the South eastern Sydney LHD HIV Complex Care & Ageing Forum 2013
[13] Ibid, Source – Desquilbet, et al. J Gerontal Med Sci 2007; 62A:1279-86
[14] *Annual Surveillance Report 2016*, Kirby Institute p53
[15] Ibid
[16] http://www.who.int/healthpromotion/conferences/previous/ottawa/en/
[17] International Classification of Functioning, Disability and Health, 2001

medical conditions, situational factors and the reactions of aged care services staff to these varying and interrelated domains.[18]

This means that PLHIV are no longer a tidy homogeneous group. PLHIV will increasingly throw up a broad spectrum of health care and support challenges for aged care services and residential care facilities. And the spectrum of issues is only expected to compound in the next 20 years as older PLHIV lose the ability to self-care and transition into aged care. For example, the health and support needs of a 75 year old single gay man with HIV, HAND and heart disease, will be substantially different to a 75 year old heterosexual women from Uganda with a husband and children who is estranged from her community and has a history of trauma/violence in her country of origin, or the 60 year old Aboriginal man from the far-west of NSW who hasn't told his family he has HIV, hepatitis C and is bisexual. The challenge for aged care services will be to provide adequate care and support services to these different individuals while adeptly understanding and responding to cultural sensitivities and taboos.

HIV stigma and discrimination - HIV is a serious communicable disease which disproportionately affects groups who are already marginal in society (homosexual men, injecting drug users, Aboriginal and Torres Strait Islander people etc.) and is linked to taboo behaviours such as drug use, homosexuality and anal sex. Furthermore, because HIV is seen as a disease that affects socially marginalised groups, when a heterosexual woman or man is diagnosed with HIV, the stigma and shame is magnified and largely misunderstood. PLHIV are frequently devalued, seen as separate and potentially discriminated against on the basis of prejudice by members of the general community.

HIV related stigma is associated with less support and poorer mental and physical health outcomes. It is also a barrier to seeking help. The shame of living with HIV may force PLHIV to hide their HIV diagnosis and the illnesses associated with HIV, and to not ask for support. The non-disclosure and hiding of HIV (a chronic and manageable condition) has been reported to Positive Life by some members living in Aged Care facilities. PLHIV can self-isolate to safeguard against potential discrimination. This is particularly so for PLHIV who are heterosexual and from cultures of origin where homosexuality and drug use are illegal or taboo.

There is an added complexity for PLHIV in regional and rural NSW, where they report increased waiting and travel times when accessing services, isolation, and difficulty in disclosing their HIV status to care providers for fear of being found out in their community and then discriminated against. The taboos against HIV in some parts of the country and amongst some cultural groups is so pervasive that PLHIV have reported driving hundreds of kilometres to seek clinical care in another regional centre to avoid people in their own town/area becoming aware of their HIV status and/or homosexuality.

Strategic implications – Since the proportion of PLHIV in Australia over 65 years of age is estimated to be 17.3% by 2020, or approximately 5,190 individuals, a significant proportion (approximately 1,700 individuals) will come from NSW. Of those, approximately three quarters 78% (1,326) will reside in the Sydney metropolitan area, and about a quarter (22%, 374) will reside in regional/rural NSW.[19]

Many older gay men with HIV live alone, are estranged from family and will have no one to care of them in old age. Over the years, their support networks have declined or failed and many have lost friends and partners to HIV related diseases, or AIDS. For many, sickness (both physical and

[18] Schneidert, Hust, Miller & Ustun, 2003
[19] Jansson J, Wilson D, (Kirby Institute) Watson J, (NAPWHA) 2011. Mapping HIV Outcomes; geographical and clinical forecasts of people living with HIV in Australia

psychological) has prevented them from maintaining or reengaging in employment and triggered early retirement and a reliance on income support and public housing. These individuals have not had the opportunity to accumulate cash or assets to buy into private nursing home facilities. They will therefore be reliant on the public system to provide support in their old age. Many aged care services and aged care facilities are currently run by religious institutions. Despite anti-discrimination laws and national standards, many gay men with HIV have reported to Positive Life being fearful that they will be discriminated against on the grounds of their homosexuality.

As well as HIV - which requires ongoing specialist monitoring and treatment - high percentages of PLHIV live with multiple serious chronic health conditions (CVD, mental health conditions, cancer, osteoporosis, metabolic disorders, neurocognitive disease, and frailty) which require ongoing monitoring and specialist treatment. Australian researchers have identified more than half of male PLHIV, 55 years and over, have two or more co-morbidities in addition to HIV infection. The range, number, and severity of these health conditions, will challenge the knowledge and experience of health care professionals in aged care residential facilities and aged care service in general. GPs who usually attend patients in aged care facilities are invariably not qualified to treat PLHIV. Special arrangements with HIV specialists will need to be put in place to meet the ongoing health care needs of PLHIV. Whilst this may be routine in city areas, finding HIV specialists to service PLHIV in regional aged care facilities will present significant challenges. As already stated, the availability of HIV specialist doctors in regional/rural areas is extremely limited.

Many PLHIV have been impacted by HIV stigma and discrimination. They are wary about disclosing their HIV status for fear of rejection or outright discrimination. PLHIV receiving care services from aged care workers need to feel safe and accepted members of the community. If they perceive that workers have prejudice against PLHIV or homosexuals, communication will be impaired and health outcomes will be negatively impacted. The aged care workforce, including within shared care arrangements, is complex and increasingly staffed by people from countries that are intolerant and judgemental of homosexuality, drug use and diseases such as HIV. The aged care workforce, which has particularly high levels of staff turnover, will need to be continually trained about HIV, co-morbidities and chronic health care so that cultural attitudes do not impact on the quality of care received by PLHIV. Sustained education initiatives will be required so that the aged care workforce is HIV literate, accepts LGBTIQ people and their modes of sexual expression and understands that discrimination towards PLHIV and homosexual people will not be tolerated. Where discrimination does occur, procedures need to be implemented to eradicate further episodes and educate offenders.

Although many PLHIV currently live in metropolitan areas of Australia, one quarter to one half live in regional and rural areas, and this percentage is predicted to rise as cost of living pressures force PLHIV to relocate from city to regional and rural areas. HIV related stigma and discrimination is often reported to be more overtly pronounced in regional and rural areas. Vigilance will be needed on the part of aged care service employers to ensure that workers do not discriminate against PLHIV who are receiving services in regional and rural areas, and that they adequately engage with, monitor and care for PLHIV as they age. Existing HIV non-government organisations have knowledge and experience of HIV and would be well placed to provide information/education to the aged care workforce on the specific needs of PLHIV and the cultural context from which they come.

Unintended Consequences – the result of the aged care workforce not meeting the needs of PLHIV will have a range of unfortunate and unintended consequences. These consequences will likely be:

- Equity of service delivery for PLHIV and service delivery options will be dissimilar and sub-standard throughout the different state and territory providers, as well as between metropolitan and rural service providers/areas. People will self-select as they'll come to know if a care

provider is able to support someone living with HIV. This will inevitably produce additional demand in some areas and reduced demand in others areas. Thus access 'bottle necks' and service inefficiencies will be created in the aged care service landscape.

- PLHIV have developed a highly attuned ability to detect people who hold stigmatising views about HIV, homosexuality, and drug use. To avoid acts of stigmatising behaviour and/or discrimination by aged care workforce members, PLHIV will hide they have HIV, are gay, bisexual, transgender and not disclose. This will result in sub-optimal and substandard care arrangements, a potential worsening of multiple health conditions and mental health conditions and lead to general unhappiness of the client.
- Carer's will attempt to pick up the slack, as the PLHIV attempt to maintain independent living arrangements, even when living in sub-standard accommodation or not being about to afford the cost of living. The burden and stress this will place on both the carer and PLHIV will be significant. Typically, the needs of carers are overlooked, or an after-thought and are not valued, validated or supported by the system.
- There will be a negative consequence on the morbidity and mortality of PLHIV if the aged care provider isn't able to provide an adequate standard of care. Positive Life has had members placed in aged care facilities, where staff are untrained. When staff failed to provide adequate care and a timely response to a particular PLHIV, the person needed to be admitted to ICU and died within 24 hours.

Conclusion - The needs of ageing PLHIV are numerous, complex and interrelated. The capacity of the aged care workforce and aged care facilities to meet the care needs, expectations and service requirements of PLHIV and their families and communities, will largely be contingent on the workforce and its employers systematically maintaining adequate knowledge levels and capabilities to effectively meet the needs of older PLHIV. To achieve the required levels of awareness, knowledge and capacity, the aged care workforce will need to receive systematic and routine training on the range of health and social issues faced by PLHIV in Australia, so quality standards of care can be achieved and maintained.