Department of Health and Aged Care - New Aged Care Act Consultation
Sirius Building, Furzer St,
Woden Town Centre
ACT 2606
Sent via: AgedCareLegislativeReform@health.gov.au

8 March 2024

Dear Department of Health and Aged Care,

Re: Submission to the Department of Health and Aged Care for access to Government Funded Aged Care Services from the age of 50 for People with HIV

Executive Summary

NAPWHA respectfully submits that older PHIV should be able to access Commonwealth-funded aged care services from the age of 50.

Currently, PHIV that are between the ages of 50 and 64 are currently ineligible for Commonwealth-funded aged care services. In this submission, we draw attention to the fact that PHIV regularly experience significant, multiple health issues with high-morbidity associated with ageing *much* sooner than the general population (by some 15 to 20 years). Additionally, due to stigma and community alienation, older PHIV often experience poorer socio-economic outcomes than the general population, which necessitates early access to aged care services. Expanding eligibility for Commonwealth-funded aged care services to include PHIV between the ages of 50 to 65 will pose a negligible upfront cost to the Government and will likely save the government in the mid to long term.

About National Association of People with HIV Australia (NAPWHA)

Founded in 1989, NAPWHA is Australia's peak non-government organisation representing community-based groups of people with HIV. Through leadership in policy, health promotion, representation, education, and prevention, NAPWHA strives to minimise the adverse personal and social effects of HIV. By championing the participation of people living with HIV at all levels of the national response we aim to build a positive future for all in our communities.

NAPWHA strengthens the national response to the HIV epidemic by ensuring the meaningful involvement of all people with HIV and plays an active role in realising a partnership approach in all aspects of our response.

On average, PHIV experience symptoms of aging earlier in life than the general population.

Combination antiretroviral treatment (cART) has substantially improved the life expectancy of PHIV; however, symptoms of aging, due to comorbidities, on average occurs 15 to 20 years earlier in PHIV than the general population (D'Souza G, 2021) (Collins LF, 2023) (Marcus JL, 2020). Many PHIV acquired HIV before the availability of cART, resulting in prolonged immunodeficiency, and chronic disease that many are still living with today (Chawla et al 2018). The advent of cART in 1997 increased survival rates, however the medications were also toxic, often causing significant lifelong impairments.

Although cART controls HIV replication, chronic inflammation persists, accelerating ageing and immune system depletion. HIV-associated immune activation is driven by multiple factors across multiple body systems. To date the mechanisms are still poorly understood, and treatments for chronic immune activation are limited. (Taisheng 2021).

Common comorbidities that cause premature aging amongst PHIV include (but are not limited to):

- Neurocognitive disorders;
- Cardiovascular disease;
- Chronic kidney disease;
- Metabolic syndrome;
- Type 2 diabetes mellitus;
- Lung disease; and
- Osteoporosis.

Multimorbidity results in increased incidence of geriatric syndromes in older PHIV. This includes:

- Polypharmacy
- Delirium
- Incontinence
- Falls and fragility fractures, and
- Cognitive dysfunction.

Older PHIV also experience a higher incidence of non-AIDS malignancies, such as liver, anal and colorectal cancer. Research indicates that HIV is independently associated with frailty in middle-aged PHIV compared with similar populations that do not live with HIV (Kooij et al 2016).

Mental health and associated wellbeing issues are endemic among older PLHIV and include (but are not limited to):

- Anxiety disorders;
- Major depression and other depressive disorders;
- Post-traumatic stress;
- Complex trauma;
- Chronic fatigue; and
- Acquired brain injuries.

Many of these relate to the impact of diagnosis, living longer with HIV, having lived through the early epidemic, HIV related trauma and stigma, increased time living with multiple chronic diseases, younger age at diagnosis, prolonged periods on early HIV treatment or extended periods without any HIV treatment. (Woods, R. 2019).

In older people with HIV, cerebrovascular disease, diabetes, chronic obstructive pulmonary disease, or liver disease co-occurring in the presence of existing multimorbidity is associated with substantially increased risk of becoming frail within 30 months (Lorenz DR, 2021).

Mental health issues experienced by PHIV result from the direct effect of HIV on the brain and nervous system. HIV enters the brain and nervous tissue from the time of diagnosis causing physical and functional deficits. Most cART is unable to cross the blood brain barrier, leaving HIV in the brain untreated and resulting a major reservoir of replicating HIV.

These impairments make it difficult for the brain to carry out everyday functions (memory, cognition, planning, socialising), and difficult to cope with mental health disorders. These health issues manifest from the time of diagnosis and are often progressive. Research continues, but currently there is no effective treatment or cure.

Poor mental health outcomes and HIV related neurological and cognitive disease further impair the PLHIV to meet their health and care needs.

ASHM Health (fmr Australasian Society of HIV, Viral Hepatitis and Sexual Health Medicine) tabled a report at the National HIV, Ageing and Quality of Life Roundtable (2019) highlighted similar findings to the above noted research outcomes, and stressed the importance of:

- Improvements in geriatric models of care for people with HIV infection, support for Aged Care Services (including My Aged Care) to meet the needs of diverse groups of individuals,
- Elimination of both perceived and actual stigma and discrimination through peer educators and advocates, and
- Continued HIV education for the 'revolving door' of aged care workers, this includes cultural training, to ensure that aged care services are welcoming spaces for LGBTIA+ people (link)

The poorer health outcomes experienced by PHIV between the ages of 50 and 64 are analogous to those experienced by Aboriginal and Torres Strait Islander populations of a similar age cohort (Fortin M, 2004). Populations that experience early onset of symptoms and co-morbidities associated with ageing should be considered when determining age-related thresholds for accessing Government funded Aged Care services (Kokorelias et al 2023). Therefore, NAPWHA submits that it is reasonable for PHIV to be allowed to access Commonwealth-funded aged care services from the age of 50, as is the case for First Nations populations (Aged Care Engagement fact sheet number 9).

PHIV can require earlier access to aged care services than the general population for socio-economic reasons.

Many older PHIV have not been able to work and accumulate capital comparable to their equivalent HIV-negative cohort due to HIV-related illness and treatment toxicity. Many older PHIV lost their most productive years, and had to access superannuation early and sell their assets in order to make ends meet, in the expectation of significantly-reduced longevity. Familial rejection, the deaths of peers and partners, combined with HIV/LGBTQIA+ stigma that persists today, has resulted in diminished support networks for many PHIV. Thus, many older PHIV do not have the financial or social capital to manage multiple chronic health issues while sustaining independent living. Decades of social ostracisation and disadvantage perpetrated against PHIV means many in this cohort will likely need to rely on the public health system in coming years.

Expanding eligibility for Commonwealth-funded aged care services to include PHIV between the ages of 50 to 65 will pose a negligible upfront cost to the Government and will likely save money over time.

While certain PHIV in Australia certainly require access to aged care services prior to 65 years of age, this will not pose a substantial cost to the Commonwealth in the short-term. At the end of 2022, there are an estimated 28,870 PHIV in Australia (King et al 2023). This constitutes less than 0.15% of the population. Due to improvements in treatment and care and the resilience of PHIV generally, it is expected a proportion of PHIV will opt not to utilise Commonwealth-funded aged care services between the ages of 50 and 65, even if given the option.

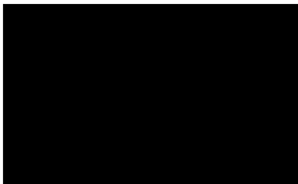
Additionally, Australia has a finite group of older PHIV (current approximately 14,000 people but which will peak at less than 29,460), with increased frailty and functional impairment. Rates of HIV transmission in Australia are amongst the lowest in the world and continue to decrease. Australia is on track to on track to virtually eliminate the transmission of HIV by 2030. Australia has already virtually eliminated HIV transmission among sex workers and people who inject drugs.

Not all older PLHIV will require access to Government funded Aged Care services. Of those who do most will prefer to stay in their own home for as long as they can. Even though some older PHIV may have some of their care needs met through the NDIS, this is an onerous and complicated undertaking that many younger PHIV with disability find difficult. Also, frailty and other geriatric syndromes result in increased risk of acute deterioration at a significantly younger age. Many older PHIV will be best supported in Government funded Aged Care services.

NAPWHA is deeply concerned that if older PHIV cannot access aged care services from the age of 50, this cohort will otherwise be required to access the general public health care system. This would represent a significant, costly and entirely avoidable burden to that system. Furthermore, as older PHIV seek care through the public system from non-specialist HIV services they are more likely to be exposed to unnecessary stigma and discrimination.

NAPWHA respectfully submits that the Department of Health and Aged Care, based on the evidence above, would be justified in allowing older PHIV access to Commonwealth-funded Aged Care services from the age of 50.

Please contact me if you require further information.



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living positive victoria

PositiveWomen
Support and advocacy for women living with HIV

ashm

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