PositiveLifeNSW
the voice of people with HIV since 1988

Dementia, Ageing and Aged Care Mission Committee Secretary
Dementia, Ageing and Aged Care Mission
Australian Government Department of Health
DAAC.Mission@health.gov.au

Re: Submission into the Dementia, Ageing and Aged Care Mission Roadmap Consultation

Dear the Dementia, Ageing and Aged Care Mission Committee Secretary,

Positive Life NSW (Positive Life) welcomes the opportunity to provide a submission into the Dementia, Ageing and Aged Care Mission Roadmap Consultation.

Positive Life is the state-wide peer based non-profit organisation that speaks for and on behalf of people living with and affected by HIV (PLHIV) in NSW. We provide leadership and advocacy in advancing the human rights and quality of life of all PLHIV, and to change systems and practices that discriminate against PLHIV, our friends, family and carers in NSW.

Background:
The Dementia, Aged Care and Ageing Mission (Mission) is a medical research package focused on dementia, ageing and aged care funded through the Medical Research Future Fund of the Australian Government Department of Health. The Mission "will fund research to support older Australians to maintain their health and quality of life as they age, live independently for longer and access quality care when they need".[1]

The Mission is currently undertaking a consultation of their Roadmap, which is intended to guide the implementation of the Mission. Positive Life believes that this consultation is an important opportunity to gather community views and an evidence base from a diverse range of voices who are concerned about the state of the aged care system in Australia for an increasingly ageing population.

The Consultation requested submissions address a range of questions, of which Positive Life's responses are outlined below.

Is the Mission Statement appropriate for the vision and goals of the Mission?
Mission Statement: Through health and medical research, the Dementia, Ageing and Aged Care Mission aims to improve the quality of life for people as they age.

Positive Life suggests the Mission considers amending the Mission statement to read: Through health and medical research, and equitable service delivery, the Dementia, Ageing and Aged Care Mission aims to improve the quality of life of all people as they age.

Is the Vision statement appropriate for the investment being made towards the Mission?
Vision: Healthy ageing will enable older people to contribute socially, culturally and economically to the wider community and reduce the cost burden of disease by delaying the onset of symptoms, particularly those associated with more resource intensive health and aged care services.

[1] Australian Government Department of Health, 'Medical Research Future Fund: Mission for Dementia, Ageing and Aged Care', 2019, accessible at: https://consultations.health.gov.au/ageing-and-aged-care/dementia-ageing-and-aged-care-mission-public-consu/

- *Foster a culture of research excellence in dementia, ageing and aged care, including through research training.*
- *Consider new and emerging trends in dementia, ageing and aged care.*
- *Seek co-investment, through partnerships and appropriate governance, from the private sector, philanthropic organisations and government.*

Positive Life believes that the guiding principles also need to address confidentiality, privacy and dignity requirements of the government, researchers, age care service staff etc.

Guiding principle 3 should be amended to read: "Consider all older people, inclusive of all backgrounds and life experience, while acknowledging and working towards equitable outcomes for those older people more disadvantaged by intersecting and oppressive circumstances."

It is important to note that in guiding principle 4 relating to co-design, that lived experience is vital when working with individuals and communities of people, particularly in research and service delivery. This principle should be backed up by a governance framework that positions the "end user" central to the principles and prioritises their data sovereignty and ownership.

It is also important to note that in considering new and emerging trends in dementia and other neurocognitive disorders, ageing and aged care, there are also emerging populations that are ageing. For example, this is the first time in history that people are living with HIV long enough to age into the aged care system, require care and support services, and develop age-related neurocognitive disorders such as HIV-Associated Neurological Disorder (HAND) and HIV-Associated Dementia (HAD). This challenge to government, researchers and care providers should not be minimised or ignored.

Are there key barriers in the Australian research context that should be considered in framing these guiding principles to maximise the success of their achievement?
Yes, namely that there is no research governance framework established and recognised for research conducted on ageing PLHIV, as well as other groups of people who will also experience disadvantage in the aged care system.

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.

Future funding patterns - 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 is a significant barrier and the system needs to change in response. Both religious-based/backed 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.

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. HIV, viral hepatitis and sexually transmissable infections in Australia: annual surveillance report. Sydney: UNSW.) The same report noted that 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%). 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%).

Priority 1: *also needs to address HIV-related dementias, including HAND and HAD, and that research and 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.*

Cost-effectiveness should not be the only litmus test of successful care continuity, rather the priority should also acknowledge and strive for equitable access and cultural safety in care continuity, treatment and management of dementia and other ageing-related neurocognitive disorders.

Priority 2: *also needs to address stigma and discrimination and its impacts on physical and emotional health, particularly of those most vulnerable such as PLHIV, people who identify as LGBTQIA+, people who inject drugs, etc. 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 live with ongoing HIV-related stigma from the general community with considerable fear and concern 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 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 with less dignity and respect than others who are ageing who have experienced more mainstream conventional social environments.*

We have received a significant number of complaints through community consultation with ageing PLHIV about aged care service staff being poorly trained, rude and unhelpful, and in some cases, patronising and disrespectful. There have also been complaints about poor communication skills, the need for better service coordination and the need to reduce long waiting times for services. We have received reports of discriminatory behaviour by aged care service staff who have no or limited knowledge of HIV. Some feared they would contract this blood-borne virus. 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. 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 aged care services and staff maintain respectful and non-discriminatory care. 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. Additionally, 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.

Priority 4: *In order to extend the healthy, active years of life for all Australians who are ageing, particularly those who experience health or social circumstances which may accelerate their ageing, the system needs to improve access to and uptake of aged care services using indicators of physical functional limitation rather than merely age. This requires:*

- *redesigning, with an emphasis on co-design principles and practices, the aged care service system to enhance navigation, access and uptake;*
- *resourcing the HIV sector and HIV-specific sector community organisations to provide programs that assist and support all PLHIV regardless of sexual orientation to overcome personal and systemic barriers to a) access and utilise aged care services and, b) make a complaint about poor*

- *additional fly-in/fly-out s100 prescribers to manage HIV and non-HIV related health conditions for PLHIV.*

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.

Additionally, an overwhelming majority of ageing PLHIV surveyed by Positive Life (95%) wanted to remain living in their home until it became impossible for them to manage any longer. They wanted to receive services from other people living with HIV or carers trained and knowledgeable about HIV and LGBTIQ issues. 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.

Are there any specific areas of research that you would prefer to see funded under any of the priorities?
Research into HAND and HAD, as per above.

What should be the high priorities for the Mission?
Equity, access, cultural safety, stigma and discrimination, quality of life, quality (rather than merely quantity) of service delivery.

Summary:
Positive Life would like to commend the Dementia, Ageing and Aged Care Mission Committee in their dedicated and thorough research and consultation process with the aim of reforming the Dementia, Ageing and Aged Care Mission Roadmap Consultation to make it as strong as possible for all Australians including those of us living with HIV.

If this submission requires additional information or clarification, I can be contacted at ceo@positivelife.org.au or on 02 9206 2177.

Yours respectfully,

Jane Costello

Jane Costello
Chief Executive Officer

14 February 2020