



**PositiveLifeNSW**

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## **National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy – Draft Consultation**

### **Introduction**

Positive Life NSW is a not-for-profit community organisation representing the interests of people with HIV in NSW, their partners and family. It was founded in 1988 and is funded by the NSW Ministry of Health. Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigmatisation and discrimination. It provides information and targeted referrals, outreach and community development, publications, education and health promotion programs, policy development and systemic advocacy related to health and community services.

Positive Life NSW commends the Australian Government and the Department of Health and Ageing on the development of the draft National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy. We became aware of the consultation, late in the progress and have hurriedly developed this submission. We apologise for its lateness.

Positive Life NSW will confine the scope of this submission to the nexus between HIV, ageing and gay and bisexual men.



## Issues

At 31 December 2011, an estimated 24,731 people were living with diagnosed HIV infection in Australia. Transmission of HIV continues to occur primarily through sexual contact between gay men and men who have sex with men (MSM). In 2007-2011, 66% of new HIV diagnoses occurred among gay men or MSM<sup>1</sup>.

At the same time, the Australian HIV positive population continues to age. In 1985 the proportion of people with HIV aged over 55 years was 2.7%. In 2010, it was 25.7% and by 2020 it is expected to be 44.3%<sup>2</sup>. New South Wales is the state with the highest population of people with HIV, with 9,924 people in 2010<sup>3</sup>. This has risen to approximately ten and a half thousand people in 2012.

Due to the efficacy of HIV antiretroviral therapy (ART), deaths from AIDS have dramatically reduced and HIV has been reclassified as a chronic manageable disease. The changed health reality has led to the emergence of a significant ageing population with HIV in Australia. The quality of life of those ageing with HIV is however often compromised by medical complications, comorbidities, poly-pharmacy, poorer mental health, social isolation, stigmatization and discrimination. Australian HIV social research reports that a significant number of people with HIV are living below the poverty line (31%)<sup>4</sup>.

Further, there is an emerging consensus that HIV and the effects of its treatment, affects the process of ageing and the development of diseases typically associated with advanced age. When populations of people with HIV are compared with those who are uninfected with HIV, those with HIV experience higher rates of multi-morbidity.<sup>5</sup> HIV-associated co-morbidities such as cardiovascular disease, infectious and non-infectious cancers, osteopenia/osteoporosis, liver disease, kidney disease and neurological impairments, impact on the health and independence of those ageing with HIV in Australia.

Ageing people with HIV also face considerable psychosocial challenges in relation to social engagement, adequacy of informal social supports, and utilization of community-based services.

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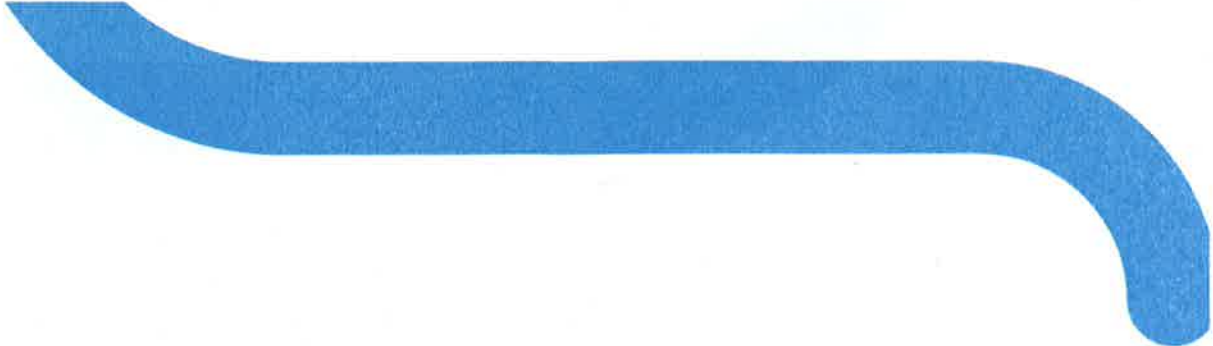
<sup>1</sup> 2012 *Annual Surveillance Report, HIVC/AIDS, viral hepatitis and sexually transmissible infections in Australia*, Kirby Institute p7-11.

<sup>2</sup> 2010, Wilson, D. *Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*, National Centre in HIV Epidemiology and Clinical Research, p5.

<sup>3</sup> *Ibid*, p5.

<sup>4</sup> Grierson J. et al, 2009, *HIV Futures Six, Making positive lives count* p 53.

<sup>5</sup> Guaraldi G et al. 2011, *Premature Age-Related Comorbidities among HIV-Infected Persons Compared with the General Population*, 1120-1126.



Those ageing with HIV tend to have limited and inadequate social networks, especially in regard to traditional family supports<sup>6</sup>. These truncated social networks result from a variety of reasons, including HIV stigma and social isolation due to rejection from social networks, poverty and self-protective withdrawal.

Isolation has been linked to high levels of loneliness and depression and may be attributed to an insufficient level of emotional support from both families and friends. Limited social networks have negative implications for an ageing population with HIV because carers are typically drawn from these networks. As a result, this population will need to rely on formal community-based services, yet this is further complicated by the competency of mainstream services providers to effectively interact with this population and provide the required care and social support in a non-stigmatising manner. The fact that many aged-care service providers are operated by faith-based organisations is likely to lead to an underutilization by gay men with HIV and perceived and real discrimination due to a lack of understanding of HIV by a workforce that has limited exposure or understanding of HIV and the associated issues and needs of this population.

## Conclusion

Positive Life NSW notes that there is minimal inclusion of HIV and its impacts on gay and bisexual men in the draft National LGBTI Strategy. We believe that HIV associated ageing issues are important matters for inclusion in the Strategy. By 2020, more than 50% of the approximately 30,000 people living with HIV will be over the age of 50 and two thirds of these will be gay men. 17.3% are predicted to be over the age of 65<sup>7</sup>. Significant proportions of these individuals will experience multiple age related comorbidities at younger ages than their HIV negative peers. Since this population will be unable to rely upon traditional family care giving structures, they will be more reliant upon formal community-based and aged care services to meet their increasing health and social support needs.

Positive Life NSW believes that the National LGBTI Strategy needs to acknowledge and incorporate the reality that gay and bisexual men ageing with HIV have significant health and social support needs and that these issues will need to be accommodated and planned for. We suggest that the following issues be added to the Strategy.

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<sup>6</sup> Grierson J. et al, 2009, *HIV Futures Six, Making positive lives count*, p 36-37

<sup>7</sup> 2010, Wilson, D. *Mapping HIV outcomes: geographical and clinical forecasts of numbers of people living with HIV in Australia*, National Centre in HIV Epidemiology and Clinical Research, Figure 12, proportion of people living with diagnosed HIV by age group and year.



## Recommendations

- HIV be acknowledged and included within the preamble (paragraph 4)
- *Guiding Principle 3 "Access and Equity"* – "HIV positive people may experience age-related comorbidities earlier than HIV-negative individuals. Consideration of individual cases for access to aged care services should be provided as part of an ACAT assessment".
- *Goal 2 - Inclusive, educated and supported workforce.* We propose inclusion of training on HIV health, transmission and social issues as part of LGBTI training.
- *Goal 3 – Older LGBTI people will be a target of ageing and aged care research.* We proposed that HIV be included within ageing research where appropriate to gain a deeper understanding of HIV and age-related comorbidities and their impact on service planning and provision.
- *Goal 4 - Access and Equity.* "The Department of Health and Ageing will work with ACAT assessors to ensure understanding of the age-related comorbidities and psychosocial issues faced by people living with HIV in Australia and ensure appropriate access to aged care services are provided for people who are younger than 65 and who meet necessary criteria.

For further information in relation to this submission, please contact Lance Feeny on (02) 9206 2174 or email [lancef@positivelife.org.au](mailto:lancef@positivelife.org.au)

Yours sincerely



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