napwha national association of people with HIV australia

2022/23 Federal Pre-Budget Submission

24 January 2022

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National Association of People with HIV Australia

The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV (PLHIV). NAPWHA's membership of national networks and state-based organisations reflects the diverse make-up of the HIV-positive community and enables NAPWHA to confidently represent the positive voice in Australia. NAPWHA provides advocacy, policy, health promotion, effective representation, and outreach on a national level. Its work includes a range of health and education initiatives that promote the highest quality standard of care for HIV-positive people. NAPWHA also contributes to clinical and social research into the incidence, impact and management of HIV.

Background

NAPWHA's 2022-2023 pre-budget submission provides the government with investment advice on issues that are central to NAPWHA's work.

Agenda 2025 was launched in Parliament House in Canberra on the 16 July last year. This document is the election platform of the Australian Federation of AIDS Organisations (AFAO). NAPWHA is a peak member of AFAO and has endorsed Agenda 2025. The asks in the document are evidence-based and costed by health economists. They were developed to support the government to implement measures to end HIV transmission in the next parliamentary term. This goal is consistent with the targets in the eighth *National HIV Strategy 2018 – 2022*.

NAPWHA notes that in order to sustain virtual elimination of HIV transmission in Australia, PWHIV must be sustained, from diagnosis to old-age, in a situation in which they have ready access to high quality health services, affordable ARV treatments, can maintain an undetectable viral load, can maintain a good quality of life as they age, are free from HIV related stigma, and are integrated into a supportive network of their peers. Failure in any one of these areas will impair the health of the individual and will undermine Australia's efforts to be the first country in the world to eliminate HIV transmission.

NAPWHA was a key partner on the development of Agenda 2025 and we support its targets, many of which apply directly to the work that NAPWHA does and which are unachievable without people with HIV in Australia. Accordingly we have included in this document areas of advice for the government which we agree and support in common with our partner organisation, AFAO. We have also included additional advice that represent high priorities for people with HIV in Australia.

Advice

1. Ensure that people with HIV who do not have access to Medicare are aware of and can access (or transition to) the new State/Commonwealth arrangements for HIV testing, ARV access and HIV care as soon as possible after diagnosis (or without treatments breaks).

Impact: Ensuring that people with HIV who do not have access to Medicare in Australia are testing regularly for HIV, have high awareness of affordable HIV testing, treatment and care availability (regardless of Medicare status) and can access these new services without fear (of stigma or unwanted disclosures to insurers) will reduce HIV transmissions and preserve the health of HIV positive people. This represents a significant cost-saving investment to the healthcare system over the medium to long term.

Investment advice: $1,000,000 per annum

Problem:

- People with HIV who do not have access to Medicare in Australia (temporary visa holders) have problematic access arrangement to healthcare which can be prohibitively expensive.
- This poses additional and significant barriers to regular HIV/BBV/STI testing and, once diagnosed, to accessing treatment and care.
- This group continues to experience a higher rate of late diagnoses than the general population; with associated poorer health outcomes.

- New State and Commonwealth arrangements for access to ARV medications will come into effect as of July this year. However awareness of these arrangements among the communities that will most benefit from them is extremely low; as evidenced by the elevated rate of late diagnosis.
- For those already diagnosed, transition from existing compassionate ARV access schemes to the new arrangements carries the risk of lost-to-follow-up and treatment gaps.
- This population has a significantly higher prevalence of people for whom English is not their first language. This is another barrier to accessing healthcare services in Australia.
- Cultural attitudes toward HIV and sexual health further complicate access to HIV testing, care and treatment for this group.
- To date we have been unable to promote affordable testing, treatment and care to this group because no government system existed to provide this. This has now changed.

Activity to solve the problem:

- Invest in a scheme that resources the organisations that represent the various populations of people who are not eligible for Medicare in Australia to promote the existence of free and confidential HIV testing and care services and affordable HIV treatment access to ensure awareness and uptake of these services by this population is high.
- Invest in a scheme to engage HIV specialist healthcare professionals to ensure awareness of these new services is high and that transition to these services of people already diagnosed with HIV occurs without a break in care or treatment.

2. Support the increasing number PLHIV who are ageing in Australia

Impact: This investment will ensure that those who are living longer with HIV maintain a better quality of life and are supported to 'age in place', thus minimising reliance on clinical and aged care services. Ageing with HIV is also a new development in the clinical management of HIV disease and this investment will ensure less of an impact on the general health system and reduce demands on the aged care system.

Investment advice: $2 million per annum

Problem:

- Around half of all people living with HIV (PLHIV) in Australia are now over 50. This number is projected to rise.
- Older PLHIV, in particular, are likely to require enhanced care and support. This has important implications for Australia's health and aged care services across regional, rural and urban areas.
- Older PLHIV are likely to have significantly reduced financial resources as they age. Many left the workforce early (or had extended employment breaks) due to illness before HIV treatments were available in the 1980s and 1990s and have been unable to recover full participation in employment. Many in this cohort have very few financial resources to draw upon as many accessed superannuation savings early in anticipation of shortened life expectancy and have been unable to recover savings for retirement.
- Amongst this population there are increasing comorbidities, side effects of long-term treatment, the burden of a lifetime of health interventions and uncertainties about future care. This is evidenced in literature from Australia and overseas.
- Biological ageing processes often occur earlier for PLHIV, and multi-morbidity and polypharmacy are also common. The cost burden of multiple treatment prescriptions negatively impacts older PWHIV's ability to purchase the additional support services they may need.

- As PLHIV live longer they are at risk of increased disability and poorer physical and mental health-related outcomes compared with the general population.
- There are uncertainties surrounding future care, including concerns related to health providers' knowledge of HIV and ageing, and management of complex comorbidities present challenges in older PLHIV.
- Uncertainties about clinical management of HIV remain and are more confronting for an ageing population in terms of increasing occurrence of HIV related neurocognitive disorders (HAND). Many live with the effects of long-term persistent depression and anxiety.
- For those diagnosed in the early years of the epidemic post-traumatic stress due to the high rates of death in their friendship networks, stigma from the community and ensuing social isolation are of great concern.

Activities to solve the problem:

- Enhance investment in schemes that address the problems of social isolation so that older PLHIV can remain connected to care and to their peers.
- Invest in peer navigation services that support the capacity of those ageing with HIV to negotiate the aged care, disability care and other support services.
- Resource training for the aged-care workforce to tackle the significant problems of HIV and LGBTIQ+ stigma in aged-care settings.
- Resource an investigation into the applicability of HIV geriatric care units (like those that have been successfully implemented in the UK and Canada) to the Australian context.

3. The removal of the co-payment for the purchase of HIV combination antiretroviral therapy (cART) across Australia for PWHIV.

Impact: Removing the co-payment on cART will remove the cost barriers many individuals experience in commencing and sustaining life-long adherence to daily medication. This prevents the risk of unnecessary HIV infection through onward transmission and maintains the health of the person with HIV, thus reducing onward costs to the healthcare system.

Investment advice: $4,645,442 per annum

Problem:

- The cost of the co-payment is a co-factor in sub-optimal adherence to cART alongside poverty, poor mental health, substance use and stigma, which is likelier to be experienced by people with HIV, people of colour, people who are homeless, PWID, sex workers and people from some ethnic and cultural backgrounds.
- People with HIV who have been living long term with the virus are much more likely to experience financial stress and problems affording prescription medications. This group is far more likely to be taking multiple medications (to combat an increased number of comorbidities) and combinations of ARV medications (to combat resistance) that cannot be purchased in single pill formulations. Further, this group experienced long-term employment breaks due to illness in the days before HIV treatments were available and they accessed their superannuation in anticipation of shortened life expectancy. Older people with HIV are therefore significantly poorer than HIV negative people of the same age. This is a significant adherence risk.
- Culturally and linguistically diverse (CALD) populations were less likely to commence cART within six months of HIV diagnosis than people born in Australia. Migrants to Australia from Southeast Asia, Eastern Asia and Europe had larger gaps in commencement of cART than non-migrants.
- Aboriginal and Torres Strait Islander PWHIV commenced cART and sustained an undetectable viral load later than non-indigenous Australians.

- It is estimated people who inject drugs (PWID) who are living with HIV commence cART later than Australian born gay and bisexual men who are diagnosed with HIV.

Activity to solve the problem:

- Invest in a scheme that removes the need for hospital and community pharmacies to charge the consumer for a co-payment when purchasing cART. The scheme would be funded by a Commonwealth-led scheme where the Commonwealth absorbs the dispensing costs associated with purchasing cART.

4. Provide free or affordable home testing kits for HIV to anyone in Australia who is at risk of HIV transmission

Impact: This will remove barriers to HIV testing and so increase HIV testing in Australia, reduce the pool of undiagnosed HIV infection and ease the burden on testing clinics by removing competition for clinic appointments by the 'worried well'.

Investment advice: $2 million per annum

Problem:

- In order to end HIV transmissions in Australia HIV testing rates must increase significantly.
- Booking a face-to-face appointment at a clinic with a health professional for an HIV test is a barrier many who are at risk of HIV transmission cannot surmount.
- Unfamiliarity with HIV home testing may be contributing to low uptake.
- Many people who are very accustomed with HIV testing do not want the time inconvenience of clinic appointments.
- There are a limited number of clinic appointments and most will be taken by someone who will subsequentially tests negative for HIV.
- The resources of BBV/STI testing clinics could arguably be better utilised if most appointments were taken by people who required a confirmatory HIV test after getting a reactive result on an HIV home test.

Activities to solve the problem:

- Fund a system whereby anyone who is in need can order an HIV test from an online portal either for free or at a cost which represents the lowest possible barrier to regular home HIV testing.

5. Identify and implement a sustainable solution to inequitable access to PrEP in Australia based on citizenship

Impact: investment in this initiative will resolve the major structural barrier preventing equitable access to PrEP in Australia. Once implemented, this initiative will provide people at risk of HIV who have certain visa arrangements with the same access as people with access to Medicare. This will save the government considerable long-term costs associated with the delivery of life-long healthcare costs for people diagnosed with HIV.

Investment advice: $10 million per annum

Problem:

- Individuals without Medicare do not have access to PBS subsidised medication that prevents HIV infection.

- A population without access the tools of HIV prevention pose a significant risk of onward HIV transmission to the broader community and this undermines the billions of dollars Australia invests in public health annually.
- Australia cannot meet its target of virtually eliminating HIV transmission until this gap in PrEP access is resolved.
- Most people on long-term temporary visas either return to their country of origin or ***transition to Medicare eligibility*** within three years. Maintaining the health of temporary visa holders therefore represents a cost saving the healthcare system over the medium to long term.

Activity to solve the problem:

- Provide subsidised HIV PrEP to all who can benefit from it, regardless of visa status. It is important to note PrEP medication is no longer on a patent. Therefore, the cost of subsidising PrEP is very affordable, especially considering cost savings of averted infections in the long term..

6. Develop models for peer-led contact tracing and wrap-around clinical and peer support at diagnosis

Impact: This investment will reduce:
a) the prevalence of undiagnosed HIV and the pool of untreated HIV;
b) the time between diagnosis and treatment commencement; and
c) improve individual health outcomes and reduce the risk of onward HIV transmission.

Investment advice: $300,000 per annum

Problem:

- Significant populations do not benefit from prevention and treatment science and peer support programs.
- These populations include gay men with infrequent HIV testing practices, people from CALD backgrounds, Aboriginal and Torres Strait Islander people, women living with HIV, and PWHIV who are not engaged in care.
- Late diagnosis and late commencement of treatment are a source of preventable morbidity and mortality for PWHIV.
- PWHIV who do not have access to HIV treatment or cannot achieve viral suppression may have complex social and comorbid health issues and/or may have difficulty accessing appropriate peer support and health services.
- Contact tracing requires highly nuanced, culturally appropriate and sensitive programming among populations, and if undertaken effectively, can help reduce undiagnosed HIV in the community, particularly among infrequent HIV testers.

Activities to solve the problem:

- Establish new and innovative peer-led models to provide contact tracing and wrap-around support for people who are not accessing treatment and/or may be at risk of being lost to care.
- Develop standards for peer-led models incorporating peer-led contact tracing approaches, use of peer support and peer navigator models, integrated clinical care and addressing systemic barriers that prevent access to care.
- In collaboration with community organisations, and with the input of clinical services and government public health officers, develop training programs for peer workforce to lead contact tracing services and to provide wrap-around support to individuals newly diagnosed with HIV.

7. Sustain gains and drive further reductions through community-led campaigns and peer education

Impact: Prevent the transmission of HIV and reduce the prevalence of undiagnosed HIV and the pool of untreated HIV.

Investment advice: $20 million per annum

Problem:

- PWHIV are crucial to HIV prevention efforts yet are routinely left out of many HIV prevention campaigns. PWHIV can prevent transmission of the virus by diagnosing and treating early, maintaining an undetectable viral load and they have lived experience in why prevention campaigns don't work. Involving them in prevention work will make those programs more effective and better value for money.
- Most HIV prevention work is focussed on GBM and continued investment in this type prevention is required; especially in areas where research shows less success or differences emerging, including amongst men who are not living in the gay inner-urban centres, men who are overseas-born (particularly those who arrived in Australia in the last four years), and younger (under 25) and older men (55 and over).
- 'Hidden populations' will account for a greater proportion of the health impact of HIV. HIV prevention work must seek to address more than just GBM and must include PWHIV.
- Reaching these populations will require highly nuanced programming, informed by the needs of each sub-population. Capacity does not exist across the sector to target the range of hidden populations, and a localised response to each hidden population would potentially duplicate effort across states and territories.
- The majority of community-led HIV organisations are small in size with a small education team and are staffed by individuals who are specialists in working with one population or delivering one aspect of community-led work.
- As these organisations endeavour to meet the needs of local populations, there is a risk of duplication and inconsistency in messaging, rather than collaboration.

Activities to solve the problem:

- Enhance investment in current national HIV education campaigns, enabling the implementation of comprehensive advertising strategies to disseminate key messages and enhance audience engagement, that involve PWHIV in program development, delivery and evaluation.
- Support community-led HIV organisations to develop and implement local campaigns targeted at population groups for their local context. This will ensure support for organisations with less capacity to develop messages that engage and reach to have impact, and to conduct local peer education activities to facilitate engagement with campaign messages.
- Implement comprehensive national campaigns, using mainstream and specialist media, targeting 'hidden populations' not being reached by current education initiatives to help reduce undiagnosed HIV within the community and challenge outdated notions of HIV and misinformation about transmission.
- Evaluation program to evaluate the activities at the intervention and program levels:
    - intervention level – reach, impact and outcomes of specific initiatives to make recommendations about strengthening messages and marketing, and to identify transferability to other localities and/or populations.
    - program level – evaluate the health, economic and cost-effectiveness impact of the overall program of interventions within the Australian HIV response.

8. Implement targeted education programs to reduce stigma in settings where it is especially acute

Impact: This investment will contribute to preventing poorer health outcomes among PWHIV, thereby reducing pressure on primary care and public health, and reducing late diagnoses and the health care costs associated with late HIV diagnosis.

Investment advice: $3 million per annum

Problem:

- HIV-related stigma and discrimination continue to be a central part of the lives of many PWHIV across Australia.
- HIV-related stigma and discrimination are experienced in a range of settings, including by the Police, the Courts, in the gay community, the general community, health care settings, government agencies, workplaces and mainstream and online media.
- The effects of stigma and discrimination are multifaceted. HIV-related stigma and discrimination is a source of significant harm in the lives of individuals, causing both a decline in well-being and quality of life (through social isolation, shame, anxiety and depression) and in physical well-being (social isolation is correlated with poorer adherence to HIV treatment).
- Stigma and discrimination present a barrier to people presenting for regular testing, disclosing HIV status, and sustaining contact with health care and treatment adherence.
- There has been limited investment to date in innovative activities to address stigma and discrimination.

Activities to solve the problem:

- Invest in interventions that build individual resilience among PWHIV so that individuals can withstand stigma and discrimination where it does occur.
- Develop strategies to address systemic factors that perpetuate stigma and discrimination, including policies, processes and laws that regulate key populations and have an adverse impact on those populations.
- Address HIV-related stigma and discrimination in clinical settings by designing interventions that address context-specific stigma and discrimination partnering with: professional health bodies, medical schools, colleges and other related vocational learning, and government health bodies.
- Conduct research to increase the evidence base for promising and effective stigma-reducing interventions.

9. Establish an HIV media program to positively engage journalists, digital content developers and influencers to tackle stigma

Impact: This investment will contribute to preventing poorer health outcomes among PWHIV, reducing pressure on primary healthcare and public health through reduced late diagnoses and the health care costs associated with late HIV diagnosis.

Investment advice: $1 million per annum

Problem:

- HIV-related stigma is driven by a range of factors, including outdated notions of HIV and misinformation about transmission and transmissibility.

- HIV-related stigma and discrimination is a source of significant harm in the lives of individuals, causing both a decline in well-being and quality of life (through social isolation, shame, anxiety and depression) and in physical well-being (social isolation is correlated with poorer adherence to HIV treatment).
- Stigma and discrimination are barriers to people presenting for regular testing, disclosing HIV status, and sustaining contact with health care and treatment adherence. These factors undermine the public health investment from governments in reducing HIV transmission.
- There are significant gaps in knowledge about stigma related interventions that have been shown to improve care or increase access to care for PWHIV.

Activities to solve the problem:

- Engage communication and media specialists to design a sophisticated, integrated communication plan that targets community settings, news and specialist media, social media and digital channels.
- Create a:
    - working document of key messages, supported by proof points, case studies and anecdotes; and
    - target list of national, specialist and community media journalists and outlets and monitor for opportunities to intervene in the news cycle with stories, commentary and other supportive content.
- Partner with community opinion leaders, social influencers and journalists to promote positive representations of PWHIV, challenge prejudice and challenge outdated notions about living with HIV and misinformation about transmission.
- Production of media assets (such as videos, advertisements, blog posts, website content, images, podcasts) for partners to use that involve PWHIV sharing their stories and experiences and challenging prejudices and incorrect assumptions.

10. Fund foundational and implementation research to better understand and monitor HIV stigma and build evidence for effective interventions

Impact: This investment will enable a stronger evidence base for HIV stigma related activities through ongoing HIV stigma program evaluation. This will reduce the barriers to healthcare access from stigma related decision-making, in turn, improving the health outcomes for PWHIV and, particularly, PWHIV who are diagnosed late.

Investment advice: $5 million per annum

Problem:

- Stigma reduces individual health, well-being and quality of life and leads to social and economic exclusion that is a fundamental cause of population health inequalities.
- Stigma is driven by a range of factors, including perceptions of blame and fear of contagion, and is entwined with stigma against homosexuality, as well as outdated notions of HIV and misinformation about transmission and transmissibility.
- Stigma reduces screening, diagnosis and treatment uptake and is a barrier to HIV testing, reducing willingness to disclose HIV status and engage in HIV treatment.
- Issues of layered stigma associated with multiple stigmatised identities require specific attention. These issues are particularly relevant for people living with (or at risk of) HIV who are Aboriginal or Torres Strait Islander or from CALD backgrounds. This is also a consideration for people who are multiply labelled because of their HIV status and other practices/identities which attract stigma (such as sexual orientation, injecting drug use, sex work or co-occurring health conditions).

Activities to solve the problem:

- Co-design a series of evidence-informed interventions in collaboration with PWHIV and affected communities to reduce stigma and challenge outdated notions about living with HIV in different settings.
- Conduct implementation research studies designed to demonstrate what interventions are effective at reducing stigma and discrimination in different settings, particularly in the provision of health care, as well as within the general community, and at multiple levels such as individual, interpersonal, organisational and structural.
- Scale up interventions that show promising outcomes, in collaboration with community, government and clinical partners, in reducing stigmatising and discriminatory attitudes and monitor impact and outcomes.
- Publish monitoring and evaluation reports on HIV-related stigma and discrimination and key findings of interventions that have been effective or show promise at combatting HIV stigma.

11. HIV Community Workforce Development Program – HIV Online Learning Australia (HOLA)

Impact: The program builds the capacity of the community HIV workforce to lead efforts to virtually eliminate HIV transmission and support the health and wellbeing of people affected by and living with HIV.

Investment advice: $4.55 million from 1 April 2023 across three years and three months. (The program is currently funded to the end of March 2023, so this investment includes the three months from April to June 2023 to bring it in line with financial year funding periods).

Problem: The program is unfunded from 1 April 2023

Activities to solve the problem:

The continuation of funding will sustain the program to allow for the delivery of learning activities to the community HIV workforce across the country and the impact of an effective workforce development program responding to a rapidly changing and progressing response to HIV.

The external monitoring and evaluation for the current program have already shown the success of the program, and also points to additional learning needs not part of the funding for the current program.

The program will include a range of activities, including the learning activities proven as effective in the external evaluation of the current project, the uptake of recommendations for updates and additional activities from the evaluation to reflect the learning needs of the community HIV workforce.

This includes building on the existing online activities of the program:

- Maintenance and hosting of existing integrated online learning platform for the delivery of training and peer learning events.
- Continued external monitoring and evaluation of the program.
- Update of existing self-directed e-learning modules (and new modules for emerging topics if required) providing evidence-based baseline knowledge at the depth required by educators to work effectively with communities to ensure these are contemporary and meet the needs of the workforce.
- Creation of skills development packages to equip educators with practical capabilities required to develop and deliver innovative, effective contemporary health promotion.
- Development of practice leadership packages that assist educators to interpret and apply knowledge and skills in ways relevant to their local communities.

- Knowledge progression and translation through the development of discussion papers on emerging new research, technology and practice, and the release of these through community workforce webinars and discussion generation, to ensure Australian community practice remains at the global forefront and to inform future strategies.
- Whole-of-workforce convenings to discuss major emerging issues with a focus on translating research to practice, showcasing innovation, enabling cross-disciplinary learning and coaching local health promotion staff to adapt community education and health promotion practice.
- Communities of practice with specific workforces (e.g. outreach workers) to share knowledge and further develop skills through peer learning.
- Convening a national HIV Education Manager's Forum of AFAO, NAPHWA, AIDS Councils and NAPWHA member organisations to provide project governance and advisory input, promote cross-jurisdictional sharing and coordination and strengthen local leadership for the life of the program.

This also includes additional activities identified as needs of the community HIV workforce in the external monitoring and evaluation of the current program that are not part of the current program:

- More in-depth, intensive formats to further support workforce development (for example, training courses that span over multiple days).
- Some program elements (e.g. skills development packages and communities of practice) to be delivered face-to-face to enhance learning opportunities and enable greater social connections and collaboration.