

The vital role of PLHIV in HIV prevention

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**National Association of People with HIV Australia (NAPWHA),
on behalf of the PLHIV membership, and in collaboration with Living Positive Victoria,
Positive Life New South Wales, Positive Life South Australia and Queensland Positive People**

On who we are . . .

People living with HIV gather together in many forms such as alliances, collaborations and networks. We acknowledge that our uniqueness is our lived experiences, the voice and action of people living with HIV and that this must remain vital and central to an effective response to HIV locally and globally. Our organisations include all the ways we respond to HIV.

On what we do . . .

People living with HIV organisations are committed to the notion of the greater involvement and meaningful engagement of people living with HIV (GIPA) in the health, social and structural responses to HIV, including government, clinical, research and civil society responses.

People living with HIV organisations aim to represent and advocate on behalf of the diversity of people living with HIV. They are founded in a commitment to the involvement and empowerment of the group most affected by HIV – people living with the virus. The organisations draw on the experience of the consumer health movement, community based health promotion, and community development and they embody and promote the peer legitimacy of peer led approaches to health.

People living with HIV organisations are informed by the lives of people living with HIV and actively seek the engagement of the diversity of people living with HIV to ensure that their organisational voice is credible, relevant and timely.

On how we work . . .

People living with HIV organisations aim to ensure that the voices of people living with HIV are heard as a partner in all research, policy and program responses to HIV and further promote the leadership of people living with HIV as full, equal and essential partners to guide this work. These organisations strive to build the capacity of people living with HIV to participate in all aspects of society as informed, enabled and empowered participants in their own right and for their community's development and social change.

People living with HIV organisations represent and acknowledge the diverse and evolving experiences of living with HIV. This 'lived experience' identity and its authority are essential to the ongoing production of quality and effective prevention, treatment and care responses to HIV. It is the quality of these responses that continues to allow people with HIV to live in dignity, maintain and improve their health, and make choices that have beneficial impacts for themselves, their partners, families and communities.

People living with HIV organisations seek to be responsive to the evolving challenges and strengths of people living with HIV and advocate on behalf of people living with HIV at an individual, a community and a systemic level.

Background

The vital role of people living with HIV in all aspects of the HIV response, including HIV prevention, is firmly embedded in a variety of international agreements and 'best practice' documents. It is most explicitly articulated in the 2007 UNAIDS Policy Brief on the *Greater Involvement of People Living with HIV* (GIPA). NAPWHA member organisations are committed to implementing this policy within their own structures and advocating for the involvement of people living with HIV in all aspects of HIV policy and practice. These include treatment roll-out and preparedness and campaigns and public speaking – that is, treatment as prevention and HIV prevention education.

This is consistent with the health promotion responsibilities of NAPWHA member organisations. Involvement of HIV positive people in HIV prevention, can contribute significantly to achieving the outcomes advocated by the *Ottawa Charter* (WHO 1986) and the *Jakarta Declaration* (WHO 1997). In particular, it can play a crucial role in creating supportive environments for people living with HIV, strengthening community action and reorienting health services to better respond to the needs of HIV positive people.

UNESCO's 2010 *Short Guide to the Essential Characteristics of Effective HIV Prevention* further expands these themes and outlines best practice in HIV prevention. It sees the involvement of HIV-positive people in HIV prevention at both policy and practice levels, as fundamental to a human rights based approach. Similarly, GNP+ and UNAIDS (2012) have articulated the valuable role of HIV positive people in HIV prevention and the interdependence between effective HIV prevention and (legislative, cultural and service) responses to the needs of people living with HIV.

Australia played a leading role in the design and adoption of the 2011 *United Nations Political Declaration on HIV/AIDS (the UN Declaration)*. This Declaration committed to achieving dramatic reductions in the worldwide transmission of HIV, to significantly increasing the number of HIV positive people on treatment, and to eliminating all variety of forms of inequity, stigma and discrimination against people living with HIV, by 2015. The Australian Ambassador to the UN has recently expressed alarm at Australia's failure to date to meet our commitments under the UN Declaration. The effectiveness of our success in achieving these goals would be greatly improved by the involvement of HIV-positive people throughout the Australian response.

HIV treatment as prevention

Early treatment of HIV has significant individual benefits. Scientific evidence overwhelmingly supports the health benefits of earlier HIV treatment for people living with HIV, including inhibiting HIV replication and thereby stopping HIV disease progression, opportunistic infections and AIDS, as well as reducing the increased risk of cardio-vascular, renal, hepatic and neurological disease and malignancies. Yet research suggests that many HIV positive people not are on antiretroviral treatment (ARV).

The evidence also indicates the additional public health benefit of ARV - that remaining on treatment and sustaining an undetectable viral load reduces the onward transmission of HIV. NAPWHA recognises that making a decision to begin treatment is a major life decision which requires thoughtful, informed cost/benefit analysis: the decision about whether, or when, to commence treatment must remain a personal choice. Given the strength of the available evidence, the better informed HIV positive people are about all the (social, economic and

health) implications of committing to a lifetime of sustained treatment, the more likely they are to choose to undertake treatment. Over time, an increase in the number of HIV positive people on treatment can be expected to pay a dividend in improved health outcomes for individuals. There will also be reduced rates of new HIV infections and associated public health expenditure.

Treatment adherence is critical to the success of a treatment as prevention strategy: low viral loads are only sustained over time whilst HIV positive people continue to take ARV. Provision of non-medicalised, non-judgmental, peer-driven treatments information to people living with HIV would play an invaluable role in increasing the number of people commencing ARV. There is little value in encouraging people to commence treatment, if they are not also supported to maintain treatment. Providing opportunities for ongoing peer education and support can be expected to play an equally vital role in helping HIV-positive people to remain up-to-date with medical advances, address barriers to adherence and, therefore, maintain their HIV treatment regime. It would also improve people's capacity to make sophisticated risk elimination and reduction decisions which are informed by the latest evidence.

Wider HIV prevention education

Involvement of HIV-positive people also optimises the effectiveness of HIV prevention education amongst communities at particular risk of HIV, service providers and the general public. This includes provision of advice on broader strategies that contribute to HIV prevention such as harm minimisation approaches, HIV treatment guidelines and improved HIV testing uptake.

Some of the best prevention programs – those that effect change on multiple levels by changing knowledge, attitudes and behaviours – place HIV-positive people in a central role in their design, implementation and evaluation. Sometimes the role of HIV positive people is explicit (e.g. positive speakers) and sometimes it is more subtle (e.g. incorporating the stories and voices of people living with HIV into a learning experience).

Positive Speakers Bureaus are a feature of all funded NAPWHA member organisations. Audience feedback overwhelmingly demonstrates the greater impact of HIV education delivered by a person living with HIV. HIV-positive public speakers and educators represent the diversity of the wider community – men and women; parents and grandparents; gay and straight; and people from many different cultural and professional backgrounds. Accordingly, they are well-placed to provide HIV prevention education in their own high risk communities – including people who inject drugs, sex workers and people from high (HIV) prevalence countries. In particular, HIV positive gay men are best qualified to deliver HIV prevention education to men who have sex with men, who still remain the most affected, and at risk, community in Australia. The lived experience of HIV-positive speakers and educators qualifies them to provide optimum professional education for HIV sector workers and service providers across the health and community services industry more widely.

Efficient and effective delivery of HIV prevention

Many Australian communities – both geographic communities and communities of interest – are not safe and inclusive places for people living with HIV. Stigma and discrimination are widely recognised as barriers to effective HIV prevention. Both have a direct impact on the mental health of HIV positive people, contributing to a reduced capacity by some to maintain

HIV treatment. Stigma, discrimination and criminalisation are an active disincentive to HIV-positive people disclosing their status in situations where HIV transmission is a risk. The fear of stigma, discrimination and criminalisation is a key barrier to HIV testing for many at the greatest risk of HIV. The viability of efforts to prevent HIV transmission depends, in large part, upon addressing the stigma, discrimination and disadvantage faced by people living with HIV.

Treating people with HIV as vital to the HIV prevention response has added benefits. It concurrently educates communities about the impact of HIV-related stigma and discrimination, whilst also engaging community members in addressing these. Equipped with a personalised understanding of the realities of living with HIV, communities are more likely to become safe and inclusive for their HIV positive members. It also functions as some protection against HIV education serving to generate fear in the community, through using coercion to motivate behaviour change, thus inadvertently victimising or demonising HIV-positive people.

Investment in PLHIV-driven prevention education is therefore efficient – it concurrently contributes to overcoming a number of interrelated factors which increase the risk of HIV transmission. It addresses both prevention education and other challenges, including promoting human rights and addressing discriminatory policies, laws and community attitudes.

Short-term investment for substantial long term savings

The UN Declaration has recognised that eliminating the transmission of HIV requires a dramatic scaling up of prevention programs - both treatment as prevention and education with at-risk populations. It has been predicted that a sufficiently comprehensive response can be expected to produce a plateau in infection rates within 4 years, with a progressive decline in infection rates (and associated treatment and care costs) in following years. Failure to make this investment will inevitably result in far greater future costs – both in immediate health care costs and in the economic and social impact on millions of individuals, their families and their communities, worldwide.

The lifetime cost of each new HIV infection in Australia is estimated to be approximately \$749,000. Over recent years, Australia has failed to sustain the earlier downward trend in HIV infection rates. Transmission rates have plateaued at approximately 1,000 infections annually – unnecessarily increasing projected future HIV-related health costs by approximately \$749 million each year. A substantial increase in funding for HIV prevention activities simply makes good economic sense.