

The critical role of Civil Society Organisations in advocating for equitable and affordable access to PrEP in Australia

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KEY POINTS:

- PrEP was a highly sought-after medicine due to its potential to lower HIV transmission but was not subsidised and widely available.
- A civil society organisation, AFAO acted as an ‘honest broker’ between government, industry, clinicians and community to facilitate change.
- AFAO initiated the flow of information at moments of bureaucratic logjam, ultimately driving the listing of PrEP on the PBS.
- As a national peak organisation, AFAO worked with its membership of service delivery organisations across Australia to leverage and strengthen community demand for PrEP among priority populations.

BACKGROUND: We must learn from national public health experiences to address hyper-endemic HIV epidemics around the world. In Australia, for almost twenty years, HIV transmission was consistent at approximately 1,000 – 1,200 notifications per year in key populations. Despite the introduction of effective HIV treatment in 1996, documented rates of condom use among gay and bisexual men decreased. In 2016, Australia’s national peak community HIV organisation, the Australian Federation of AIDS Organisations (AFAO), led community advocacy for additional prevention strategies for key populations.

AFAO and its member organisations understood equitable and affordable access to Pre-Exposure Prophylaxis (PrEP – a daily pill that prevents HIV infection) was key to ending Australia’s HIV epidemic. The approval of PrEP by the Therapeutic Goods Administration (TGA) in May 2016 provided this opportunity. While TGA approval was the first step, affordable access needed to be subsidised and provided through the national Pharmaceutical Benefits Scheme (PBS).

Australia’s system for recommending subsidisation of medicines is passive, that is, the Department of Health will not approach industry to initiate an application for subsidisation. The Pharmaceutical Benefits Advisory Committee (PBAC), an agency of Australia’s federal Department of Health, subsidises medication deemed cost effective. The PBAC only recommends subsidisation if the price negotiated with industry is cost effective based on public health benefit. Industry will seek a price which recovers research and development costs across the life of the patent.



STRATEGY DEVELOPMENT: AFAO’s PrEP advocacy strategy was grounded in Australia’s intergovernmental National HIV Strategy which included the goal of ending HIV transmission. The strategy was heavily influenced by evidence from Australian feasibility studies and health economics modelling showing that if Australia was to end HIV transmissions, PrEP access had to be **rapid, scaled up** to population size and **targeted** to key populations. In Australia the key population was and is gay and bisexual men.

The opportunity to work towards rapid, equitable access to PrEP in Australia was triggered by the expiry of Gilead’s patent for Truvada as PrEP in mid 2017. AFAO strengthened its relationship with Gilead and developed trusted working relationships with generic manufacturers of

Truvada to create a competitive pricing environment. The strategy focused on developing a productive relationship among community, the pharmaceutical industry, and government.

STRATEGY IMPLEMENTATION: Previously two Gilead applications to the Pharmaceutical Benefits Advisory Committee for subsidisation of PrEP – made before the expiry of the patent - were rejected on price grounds. Therefore, AFAO began working with multiple pharmaceutical suppliers of PrEP to create a competitive pricing environment.

AFAO used its trusted relationship with Australia’s HIV sector, the PBAC, and industry to persuade generic manufacturers to develop applications. This included working with:

- Researchers to commission a report modelling the numbers of eligible PrEP users in Australia;
- Clinicians to inform changes to PrEP clinical guidelines to reflect the science on PrEP efficacy and epidemiology on priority populations in Australia; and
- Community leaders to publicise the evidence of the efficacy of PrEP among Australian gay and bisexual men to mobilise demand for PrEP among this target population.

AFAO, with its member organisations, coordinated conversations about the potential benefits from affordable and equitable access to PrEP, such as:

- Enhanced opportunities to engage individuals at higher risk of HIV to test more frequently;
- HIV/STI combination prevention, whereby individuals who are tested for HIV could also be more frequently tested for STIs enabling earlier detection of, and treatment for, STIs;
- Opportunities for increased community awareness of HIV primary prevention and treatment through pre-and post-test counselling.
- Significant medical cost savings associated with averted infections, and increased detection and treatment of STIs through simultaneous HIV and STI testing at routine quarterly PrEP clinical consultations.

In the capital cities community activists recognised the benefits of PrEP and were quick to start using PrEP through clinical trials and importation. These community members coordinated action to build the capacity of gay and bisexual men to understand PrEP effectiveness and to lawfully access PrEP well before it was universally accessible in Australia. Simultaneously, AFAO’s members, emboldened by community demand for PrEP, integrated PrEP awareness and education into health promotion activities. This included developing collateral for distribution at community events and hosting regular community fora to highlight the benefits of PrEP.

Alongside community mobilisation for PrEP, a significant structural barrier emerged. Despite multiple arms of government supporting PrEP, the operational systems of the health and treasury departments were unable to proactively facilitate subsidised access to PrEP in Australia. In effect, the various arms of government were operating within their ‘lanes’.

As a Civil Society Organisation, AFAO played an active intermediary role, enabling the passage of critical information between industry and the various arms of government to broker a public interest outcome. This illustrates the benefit of civil society organisations that can work across multiple and diverse stakeholders to achieve outcomes for the greater public good.

RESULTS: HIV Pre-Exposure Prophylaxis (PrEP) became available through Australia’s subsidised health system for Australian citizens with a valid script on 1 April 2018. This provided the most equitable access to PrEP in the world. Since then HIV transmission has dropped among gay and bisexual by 30% and is now at its lowest levels since the early 1990s.

NUMBER OF HIV NOTIFICATIONS FROM 2014

