



# LEARNING FROM ONE PANDEMIC TO LIVE WITH ANOTHER

Two great pandemics of the past fifty years – HIV and COVID-19 – have shaken societies around the globe. The immediate crisis of COVID-19 has many of the hallmarks of the early HIV pandemic – fear, rapid action, wall-to-wall media coverage and political attention. In time, we learned to live with HIV. As we enter its fourth decade, what insights from HIV can help us live with COVID-19?

## AUSTRALIA IS AGAIN LEARNING HOW TO LIVE THROUGH A LONG-TERM PANDEMIC.

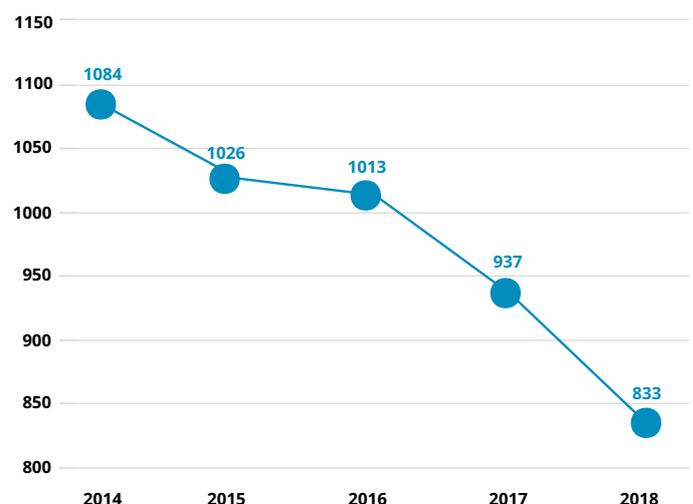
Many people were buoyed by the initial success of our response to COVID-19. It appeared strong leadership from the National Cabinet and an equally strong response from the community had put us well on track to end COVID-19. However, we have now learned that as long as there is transmission, there is potential for the pandemic to re-emerge. Despite our best hopes, a vaccine for all will be some way off.

Over the past thirty-five years, we've learnt a great deal about sustaining an effective public health response to a pandemic. AFAO's and ACOSS' combined advocacy draws on insights into the real-world experience of people experiencing crisis and hardship. This has included the sustained action of communities that carry the burden of HIV to prevent its transmission and keep Australian infections low.

With COVID-19 cases now falling again, we are at a crossroad – we are past the initial crisis and yet well short of a vaccine or cure. COVID-19 is not HIV. They are very different. Yet, both require the voluntary cooperation of the community to do things over the long-term that will keep us and each other safe. We must learn to live with COVID-19.

We offer these reflections as a contribution to national efforts and call for governments to work more closely with civil society, particularly those who bear the greatest impacts of COVID-19.

## Number of HIV Notifications from 2014



## AFAO AND ACOSS

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# INSIGHTS

## 1. COMMUNITY NORMS ARE POWERFUL

It is easier to change what we do when we observe others doing likewise. Norms remind us what is expected even when it doesn't come naturally. In responding to HIV, we have continually worked with communities to create and reinforce norms around safe behaviours.

## 2. POSITIVE REINFORCEMENT BEATS SHAME

COVID-19 requires each of us to maintain new behaviours – physical distancing, hand sanitising, testing when symptomatic – even after the initial sense of urgency has passed. This is hard and no one will get it right all the time. Valuing positive behaviours and rejecting blame are needed for the long-term.

## 3. PEOPLE LOOK TO TRUSTED LEADERS

There are people we trust and listen to in every neighbourhood and community. We need many voices working together on COVID-19 – faith leaders, civic leaders, community elders, workplace champions, public commentators, public health and clinical leaders and politicians.

## 4. LEAD BY CONSENT

Community leadership is a powerful and under-utilised tool for COVID-19. Effective leaders understand their communities, work to their strengths and know their constraints. This makes community leaders a vital source of intelligence to governments and a trusted, accountable channel to communities.

*“At the end of 1984 Blewett toured America, visiting cities where the impact of AIDS was already devastating. He had been moving to a policy of full partnership with affected communities and this trip galvanised his views. He described it as the ‘single most significant influence on my own views about AIDS’.”*

Fighting for Our Lives: The history of a community response to AIDS. Nick Cook, 2019

## 5. A PARTNERSHIP WITH COMMUNITIES IS NEEDED

Community leaders have helped shape every aspect of the HIV response, from education messaging to government policy. Community involvement has helped engage communities, build trust and ensure messages and approaches are relevant. Empowered communities can mobilise behaviour change, prevent panic and confront stigma.

## 6. PRIORITISE THOSE MOST AFFECTED

Some people will be harder hit by a pandemic than others. The HIV response is effective because it is targeted to the needs of those most affected. COVID-19 vulnerability takes different forms – some are at greater risk of infection, others of severe disease or death, and others due to being on low incomes, from diverse backgrounds, subjected to COVID-19 restrictions or facing other vulnerabilities.

## 7. ONE SIZE WON'T FIT ALL

Governments have increased their investment in physical and mental health during COVID-19. However investment in mainstream services won't always reach people on the margins. Alongside mainstream investment, we need community-led services and supports targeted to specific communities being left behind.

## 8. COLLABORATION DRIVES INNOVATION AND IMPACT

Australia fast-tracked a partnership-based approach to HIV, bringing together government, affected communities, researchers and clinicians. Each member of the partnership brings specialist knowledge and ideas to the table, driving evidence-informed decision making and innovative solutions.

### CASE STUDY: DRIVING ACCESS TO ESSENTIAL MEDICINE

By 2016, it was clear Australia was falling behind in access to a new HIV prevention drug. AFAO brokered discussions between government and the pharmaceutical industry to have the drug assessed by government experts and to drive a lower price. This is a role neither industry nor government could perform alone because they are expected to remain at arm's length.

## **9. NON-PARTISAN POLITICAL LEADERSHIP IS CRITICAL**

Politicians today are stewards of an unbroken line of non-partisan political leadership on HIV. Keeping politics out of HIV has allowed Coalition and Labor governments to implement the sometimes sensitive strategies needed to combat HIV. The National Cabinet provides COVID-19's platform for consensus, non-partisanship and collective problem-solving.

## **10. BLAMING SHIFTS THE FOCUS FROM COLLECTIVE RESPONSIBILITY**

The historic blaming of people living with HIV, gay men, sex workers and people who use drugs continues to hold Australia back from its HIV goals. In COVID-19, we have seen people from migrant communities and the young blamed for outbreaks. This is counter-productive.

## **11. LISTEN TO THE DATA**

Australia's HIV response is driven by epidemiological and research data and insights from community leaders. Data must also drive our response to COVID-19. We need simple, real-time ways to share data across agencies and borders.

## **12. COMMUNITY CONNECTION IS PROTECTIVE**

In HIV, those who are more community connected adopt safer behaviours, are more resilient and more likely to access information and health services. Australian communities are rallying in response to COVID-19. Supporting community connection and resilience is a vital investment for the COVID-19 response.

## **13. CREATE AN ENABLING ENVIRONMENT**

Individuals and communities want to take care of each other. From the earliest days of HIV, community leaders worked with government to create policies and laws that supported HIV prevention and removed barriers to testing and care. Policies, laws and easy access to COVID-19 testing will either enable or impede our success.

## **14. DISRUPTION DRIVES INNOVATION**

HIV profoundly changed the relationship between 'patients' and doctors, bringing greater collaboration with benefits for both. Likewise, the rapid response to COVID-19 has led to valuable changes – working from home, Telehealth and greater support (albeit temporary) for those who are unemployed. We must embed these innovations.

## **15. HEALTH AND THE ECONOMY GO HAND IN HAND**

It is not useful to dichotomise COVID-19's economic effects from its health and social impacts. Each affect the other and rounded, whole-of-government solutions are needed.

## **ABOUT US**

AFAO is the national federation for the HIV community response in Australia. AFAO works to end HIV transmission and reduce its impact on communities in Australia, Asia and the Pacific. AFAO's members are the AIDS Councils in each state and territory; the National Association of People with HIV Australia (NAPWHA); the Australian Injecting & Illicit Drug Users League (AIVL); the Anwernekenhe National HIV Alliance (ANA); and Scarlet Alliance, Australian Sex Workers Association. AFAO's affiliate member organisations – spanning community, research and clinical workforce – share AFAO's values and support the work we do.

The Australian Council of Social Service (ACOSS) is the peak body for the community services sector in Australia and national advocate for action to reduce poverty and inequality. Our vision is for a fair, inclusive and sustainable Australia where all individuals and communities can participate in and benefit from social and economic life.

## **RECOMMENDATIONS**

To strengthen the response and recovery to the health, economic and social crises of COVID-19, the Federal Government needs to work more closely with community leaders and organisations representing people facing higher risks. We recommend that the following actions be taken without delay to rapidly enhance existing engagement structures:

## FEDERAL GOVERNMENT LEVEL

### Collaborate and Partner with Community Leadership

1. Establish a Community Partnership Group to work closely with the Chief Medical Officer and PMO. The CPG would bring together community leaders representing people experiencing poverty, older people, Aboriginal and Torres Strait Islander peoples, CALD people and communities, people with disability, LGBTIQ people, and other groups who are at high risk of the health, economic and social impacts of COVID-19. This committee would be tasked with providing a rapid feedback and advisory process to inform Federal action ongoing that responds to the various health-related crisis impacts of COVID-10, including communication strategies, federal policies and local community supports.
2. Embed “Specific Population Strategies” that are community partnerships providing detailed advice to the Chief Medical Officer and the Federal Government on the needs of specific population groups in relation to COVID-19. Different communities will require different responses to this crisis. We strongly support the advocacy of FECCA, an ACOSS member, to establish a partnership focussing on the needs of CALD communities, and their first task should be developing a Management and Operational Plan for CALD people in relation to COVID-19. The Chief Medical Officer and Prime Minister should immediately invite submissions and recommendations from community organisations about how the Federal Government can assist to further strengthen partnership and collaboration amongst specific populations, including at the local and community level.
3. Create at least two dedicated Commissioners for the COVID Commission who have the expertise and represent the needs and interests of people experiencing poverty and facing higher risks. It is not appropriate to separate out advice regarding economic recovery from the health and social risks of communities. It is vital that the voice of people who are most at risk of all the impacts of COVID-19 are on the inside of the COVID Commission. The Federal Government should consult with community sector and First Nations peak bodies to identify candidates.

### Make targeted investments in community-led health promotion

In order to ensure that health promotion and education messages about COVID-19 prevention, testing and isolation are reaching hard to reach and at-risk populations, we recommend the following:

4. Develop formal health promotion and education strategies for specific hard to reach and at-risk populations that are informed by the data and evidence and developed in partnership with the relevant communities and the organisations that represent them.
5. Develop a partnership approach between government and community organisations delivering health promotion and education, where decision making on health promotion and education activities is led by community organisations and relevant epidemiology data is shared.
6. Provide targeted funding for community organisations representing key population groups to deliver peer-led health promotion and education to their own communities.

## ENGAGEMENT AT STATE, TERRITORY, REGIONAL AND LOCAL LEVELS

7. A community partnership approach should also be taken at state, territory, regional and local levels. Appropriate structures will vary depending on the specific context and the extent to which these approaches are already in place. State, territory, regional and local approaches should seek to:
  - a. Put people at the centre, ensuring that diverse individual needs of people at risk are prioritised and met
  - b. Involve and empower local communities from the outset, recognising their expertise and experience in effective planning, service delivery and communications that are suitable for their own community members
  - c. Use the skills and expertise of the COSS network and other relevant peaks and representative organisations in shaping health, economic and social policy and responses
  - d. Take a health rather than policing approach, with responses led by public health officials and community health services.