NOUS group

Demonstrating the value of community control in Australia's HIV response

AFAO and Australia's State and Territory AIDS Councils

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FINAL REPORT



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Glossary

ACON	[Formerly the] AIDS Council of New South Wales
AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-Retroviral Therapy
CALD	Culturally And Linguistically Diverse
СВО	Community Based Organisation
GBM	Gay and Bisexual Men
HIV	Human Immunodeficiency Virus
HIV CBO	Community Based HIV/AIDS Organisation (in this report this primarily refers to AFAO and Australia's State and Territory AIDS Councils. This can also refer to other community organisations in the sector such as the National Association of People living With HIV/AIDS, the Scarlet Alliance and the Australian Injecting and Illicit Drug Users League)
IFRCRCS	International Federation of Red Cross and Red Crescent Societies
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
NACCHO	National Aboriginal Community Controlled Health Organisation
NAPWHA	National Association of People living With HIV/AIDS
NGO	Non-Government Organisation
PEP	Post-Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
QuAC	Queensland AIDS Council
STI	Sexually Transmittable Infection
SWOP	Sex Workers Outreach Project
VAC	Victorian AIDS Council
WAAC	Western Australian AIDS Council

Executive Summary

The Australian Federation of AIDS Organisations (AFAO) and Australia's State and Territory AIDS Councils have commissioned this report to articulate the evidence on the value of the community based response as part of the overall Australian response to HIV.

AFAO and the AIDS Councils wanted to substantiate their claim that their organisations make a critical contribution to the success of Australia's HIV response. They propose AFAO and the AIDS Councils were not only an important part of the historical response, but are also essential in managing the ongoing epidemic and other health needs within their communities.

AFAO and the AIDS Councils seek clearly to articulate the past, current and ongoing value they provide. This is in a context where much of the memory has been lost in mainstream health organisations, including public health providers and funders. Additionally, non-government organisations (NGOs) not embedded in HIV affected communities are keen to provide more services to those communities. AFAO and the AIDS Councils argue they have a particular capacity and ability to respond, which NGOs cannot replicate. AFAO and the AIDS Councils argue that their comparative advantage is in mobilising community-led responses to health issues, as community controlled organisations. This is the essence of the contribution of these organisations to the HIV epidemic in Australia to date.

AFAO and the AIDS Councils were keen to have an objective and documented account of the strength and continuing salience of their core value proposition in this changing environment.

AFAO and the AIDS Councils understand the need to be able to clearly articulate the value of their organisations, using a strong evidence base, to a range of stakeholders (particularly government).

AFAO and the AIDS Councils engaged Nous Group (Nous) to test the value of the community based response to HIV in Australia and the value of community control. Nous conducted the project in three stages from January to June 2016.

Nous used four key lines of enquiry (KLEs) to structure data collection and analysis activities. These were:

- 1. What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?
- 2. What are the features of the community based HIV response that explains any difference?
- 3. How has the epidemic and the health needs of communities changed?
- 4. How can governments be confident that the community based response will continue to be effective?

Nous focused on identifying existing evidence that described the features and value of community based responses to the HIV epidemic in Australia. We used complementary data collection methods to source a breadth of information and data and triangulate findings (where possible). Our data collection methods included:

- a review of AFAO and AIDS Council documentation
- a literature scan of peer reviewed and grey literature
- interviews with AIDS Councils and other key informants (other HIV CBOs, government and academics).

This report provides the outcome of this assessment. It includes:

- a description of the existing evidence that articulates the value of HIV CBOs
- analysis of the unique features of HIV CBOs that explain this competitive advantage in responding to HIV and the emerging health needs of their communities
- a description of how the HIV epidemic has changed over time and the emerging health and social needs of affected communities
- an assessment of how HIV CBOs will continue to evolve in the future to manage the evolving HIV epidemic and other health and social needs.

A strong existing evidence-base exists that demonstrates AFAO and AIDS Councils were and will continue to be critical to the success of Australia's ongoing HIV response.

In this report we refer to AFAO and Australia's State and Territory AIDS Councils as prime examples of community based organisations in the HIV sector in Australia and can be described as community controlled organisations. Other community organisations in the sector such as the National Association of People living with HIV Australia, the Scarlet Alliance and the Australian Injecting and Illicit Drug Users League also demonstrate similar features that have enabled these organisations to make an important contribution to the effective Australian response. These organisations are therefore also defined as HIV CBOs in this report. Our conclusion is that there is strong evidence to support AFAO and AIDS Councils' claim. HIV CBOs were critical in the success of Australia's response to the HIV epidemic. They will have an important role into the future in continuing to respond to the ongoing HIV epidemic and other health and social issues confronting affected communities. Table 1 provides a summary of the project findings.

KLE 1: What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?					
Finding	Description				
Community based HIV organisations are part of a strong partnership network between government, health practitioners, researchers and HIV affected communities.	 There is no standard definition for 'community control' in existing literature. However, key elements define community based responses, elements which have enabled these organisations to play a pivotal role in the overall response to HIV in Australia. Community based responses are: initiated, designed and implemented by the community responsive to the evolving needs of the community often enacted through partnership with mainstream organisations dependent on community for authority 				
There is strong evidence that compares the results achieved by community based HIV organisations to non-community organisations.	 Community based responses have been more effective than traditional public health approaches. Case studies can be used to demonstrate their comparative effectiveness, such as: Australia's success in responding to HIV versus other countries that did not use a community led response (and were less successful). The increased infection rates in Queensland and Victoria when the HIV partnership between government and supporting communities broke down. 				
There is evidence that community based HIV/AIDS organisations were key contributors to the overall response.	 Australia responded to HIV through a partnership model, which is widely credited as the reason for Australia's success in responding to the epidemic. Community based HIV/AIDS organisations play a distinct role in the overall partnership response. 				
KLE2: What are the features of the community based HIV response that explains this difference?					

Table 1: Summary of findings

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Finding	Description	
HIV CBOs have unique features that enable them to provide trusted, relevant and efficient services and programs.	 HIV CBOs are embedded within their affected communities, which supports a deep understanding of the contemporary issues and effective solutions. A number of examples demonstrated how HIV CBOs were aware of behavioural and other changes in the HIV epidemic and able effectively to address these changes arising ahead of other health organisations. HIV CBOs have attained unusually high levels of professional knowledge in specific domains, which informs successful service delivery. HIV CBOs typically have high credibility with mainstream service providers, government agencies, researchers and other stakeholders based on their professionalism and authority within the affected communities. 	
The combined value of HIV CBOs unique features place them in an advantageous position to respond to the HIV epidemic and other emerging health threats.	 HIV CBOs have permissions that many other public service organisations do not have. HIV CBOs work in partnership and collaboration with a broad range of organisations. HIV CBOs are recognised as leaders within their respective fields of expertise. 	
Programs and services delivered by HIV CBOs are cost effective.	• Overall, existing evidence shows AIDS Councils services and programs are cost effective when compared to other approaches. This is due to: their access to community intelligence and cultural knowledge; the cost-benefits of volunteers; greater reach; self-generated funds; and efficient data and information collection.	
KLE3: How has the epidemic a	nd the health needs of communities changed?	
Finding	Description	
Australia's HIV epidemic has been characterised by a strong community response and can be historically grouped into three phases.	 There have been three phases in Australia's epidemic. Each is marked by significant changes in prevention and treatment options. In each phase, HIV CBOs have led efforts to respond to the changing needs and requirements of communities affected by HIV. 	
New communities of people affected by HIV are emerging.	 New diagnoses have been rising among some Aboriginal and Torres Strait Islander communities New diagnoses have been rising among people who travel to and come from countries of high HIV prevalence 	
New health threats are emerging in HIV affected communities.	 HIV interacts with numerous other health issues and affected communities increasingly focus on a range of these other health concerns. These include: STIs, hepatitis and sexual health; mental health and alcohol and drug use; comorbidities; and aged care. 	
Non-health issues also have a large impact on the lives of	 These include: legal and policy issues; the re-emergence of politician led homophobia; and stigma and discrimination. 	
communities affected by HIV.		
	pe confident that the community based response will continue to be effective?	
•		

The inherent features of HIV CBOs will enable them to be adaptable.

• These inherent features are community embeddedness, professionalism of staff, extensive networks, democratic structures and the capacity to mobilise.

1 Background and Context

This section provides an outline of the:

- background and context for the project
- purpose of this report

Background

Australia's response to HIV is widely recognised as one of the most successful HIV and AIDS responses in the world.

The Australian response to HIV is lauded internationally. It is characterised by tolerance, innovation, agility and partnership (Feacham 1995; Kippax; Stephenson, Parker & Aggleton 2015; Yang et al 2014). Australia's HIV epidemic has been largely contained to gay men. The number of gay men with HIV (as a proportion of the total number of people infected) has remained relatively stable (Yang et al 2014). Gay communities in Australia were instrumental in the success of the response to HIV; they mobilised early and as a collective to contain the epidemic.

In addition, Australia has been an innovator. It was an early adopter of needle and syringe supply programs, with one state government supporting a medically supervised injecting room in the late 1990s. Australia also provided pragmatic regulation of the sex industry. Since the early days of the epidemic, we have assured HIV positive people they will have access to affordable treatments as they became available (Feacham 1995).

All of these gains required political effort from the communities impacted by HIV. The position of community based HIV organisations in the Australian response immeasurably assisted this effort.

However, the context for HIV CBOs is changing on all fronts:

- **The epidemic is evolving**. The Australian epidemic has had distinct phases and is still evolving. The initial phase was from the early emergence of HIV to the introduction of effective antiretroviral therapies (ART). The response then shifted to focus on treatment and managing chronic disease. Currently, we are in the 'treatment as prevention' phase. While this is expected to dramatically reduce the cycle of transmission for gay men, it is also likely to draw heightened attention to the more difficult to reach populations where HIV transmission will continue to occur including gay men, but also Aboriginal and Torres Strait Islander people, people travelling to and from Australia, and others.
- **Community based HIV organisations are becoming more mature and diversified**. HIV CBOs evolved from within the affected communities that were under direct existential threat. Over the past 30 years they have developed into more sophisticated health promotion organisations. Many have now expanded to tackle health and social issues other than HIV (in addition to working to maintain the low incidence environment).
- The breadth of NGOs working with affected communities is changing. Whilst many nongovernment organisations operate in the health and social services sectors, few are organically connected to community. Many are ignorant, at best, about the needs of LGBTI, drug user and

sex worker communities. However, a number of NGOs have recognised they have LGBTI clients and are trying to develop better capability and practices to serve these communities.

 Changing health priorities and the loss of 'corporate memory' are impacting the relationship with government. Historically, community organisations enjoyed bipartisan support. Governments attempted to leverage their knowledge and expertise to fight other communicable diseases (e.g. in attempting to convince AIDS Councils to become AIDS and Hepatitis Councils in 1996). The loss of corporate memory on the effectiveness of community organisations and the tendency for all government funding to be competitively tendered is impacting the funding arrangements and sustainability of AIDS Councils.

The effects of these changes amplify each other. Community based HIV organisations are concerned about losing funding and the ability to track and contain the epidemic and other health needs within their communities as the sector and the epidemic evolves.

Purpose of this report

This report outlines the value of the community based response to HIV as the sector and the needs of affected communities evolve.

Within this context, AFAO and the AIDS Councils engaged Nous Group (Nous) to test the value of the community based response to HIV in Australia. This report provides the outcome of this assessment. It includes:

- a description of the existing evidence that articulates the value of community control and other features of community based HIV organisations
- analysis of the unique features of HIV CBOs that provide them with a competitive advantage in responding to HIV and the emerging health needs of their communities
- a description of how the HIV epidemic has changed over time and the emerging health and social needs of affected communities
- an assessment of why HIV CBOs will continue to remain critical in the future to manage the evolving HIV epidemic and other health and social needs.

2 Methodology

This section provides a high-level overview of the methodology Nous used to conduct the project.

In this project Nous focused on identifying existing evidence that described the features and value of community based responses to the HIV epidemic in Australia. We used complementary data collection methods to source a breadth of information and data and triangulate findings (where possible).

Nous conducted the project in three stages over six months from January to June 2016, as shown in Figure 1 and detailed below.

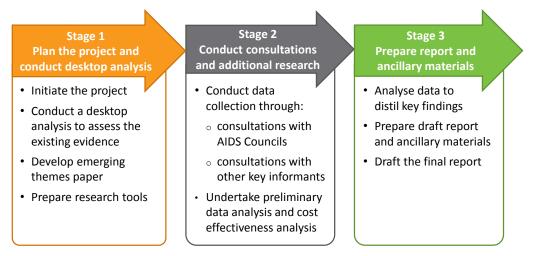


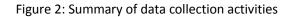
Figure 1: Stages of the Demonstrating the value of community control project

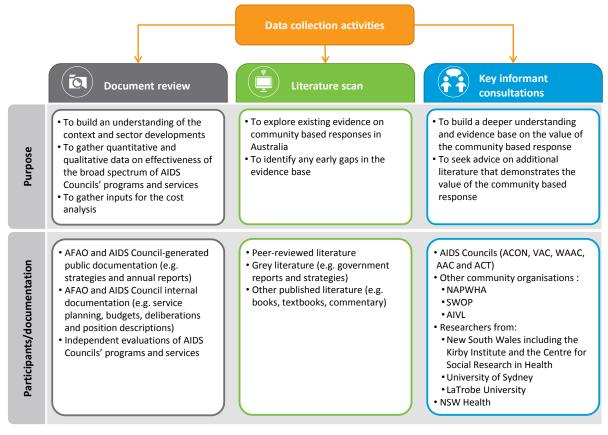
Stage 1: Establish the project and conduct desktop review

Nous commenced the project by developing key documents to guide project activities. These included a project plan and data collection plan (see Appendix A). The data collection plan outlines the key lines of enquiry that informed data collection activities, guided synthesis of findings and provided structure to the final report. Nous worked with AFAO and the AIDS Councils to refine the key lines of enquiry throughout the project. The four key lines of enquiry were:

- 1. What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?
- 2. What are the features of the community based response that explains this difference?
- 3. How has the epidemic and the health needs of communities changed?
- 4. How can governments be confident that the community based response will continue to be effective?

Nous used a suite of data collection activities to gather a broad evidence base and where possible triangulate findings. The three data collection activities are summarised in Figure 2.





At the end of Stage 1, Nous undertook a document review and a literature scan. These data sources provided Nous a deeper understanding of the current context, the type and volume of existing evidence and the features that make HIV community based organisations valuable.

The Project Reference Group provided relevant documentation for the document review. This included: annual reports, independent and non-independent evaluations of programs and services, strategies, service planning documentation, position descriptions, partnership agreements and other AIDS Councils and AFAO generated material. For the literature scan, Nous conducted online searches to identify peerreviewed and grey literature. To ensure we leveraged the maximum amount of existing evidence, Nous sourced additional literature by contacting eminent researchers in the field from The Kirby Institute and the Centre for Social Research in Health at the University of NSW, La Trobe University and the University of Sydney.

Nous used the findings to inform the design of the stakeholder interviews (in Stage 2).

Stage 2: Conduct stakeholder consultations

In Stage 2 Nous collected qualitative data through interviews with key informants. Nous and the Project Reference Group identified AIDS Councils, other HIV CBOs, governments and researchers to include in consultations. Nous used the consultations to explore gaps in the evidence and particular areas of interest. A full list of stakeholders consulted is provided in Appendix B.

During Stage 2 Nous collated the information and data for the cost analysis. The purpose of the cost analysis was to assess the cost effectiveness of AIDS Council's services. We did this through: a cost effectiveness analysis of an AIDS Council testing program; a review of existing evaluations of AIDS

Council services and programs that assessed cost effectiveness; and a review of peer-reviewed literature on the cost effectiveness of community based service delivery more broadly.

Stage 3: Distil key findings and develop recommendations

During the final stage, Nous synthesised the information obtained from the document review, literature scan and stakeholder consultations to distil key findings (detailed in section 3). The findings are structured by the key lines of enquiry.

Nous also developed a selection of case studies on AIDS Councils' programs and services (this is included in Appendix C).

3 Findings

In this section we detail our findings against the four key lines of enquiry (described in section 2).

3.1 What is the evidence that the 'community controlled' HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?

There is a large existing body of evidence that articulates the success of the community-led response to the HIV epidemic in Australia. This section focuses on describing the breadth of evidence. Specifically, in this section we outline:

- a definition of community control, HIV CBOs and elements of the community based response to the Australian HIV epidemic
- evidence that compares the results achieved by the community based approach with other approaches
- evidence that demonstrates community based HIV organisations are an essential part of an effective overall response to HIV in Australia.

3.1.1 Community based HIV organisations are part of a strong partnership network between government, health practitioners, researchers and HIV affected communities

There is no standard definition for 'community control' in existing literature.

One intended focus of this project was to describe the value of 'community controlled' organisations. However, existing literature in the HIV and public health space typically uses 'community based organisations' or 'community based responses' to describe organisations such as AIDS Councils (Mindel & Kippax, 2013; Kippax & Stephenson, 2016). The terminology around 'community control' has emerged more recently in the sector.

This has been an attempt by AIDS Councils to distinguish themselves from NGOs, community health centres and even public sector health organisations 'based' and embedded in the community due to their distinct and specific elements and integral role in the HIV response in Australia (as reported through key informant consultations). It is important to recognise these elements to understand the value of community based approaches such as those initiated by AFAO and AIDS Councils in Australia. **AFAO and Australia's AIDS Councils can be described as community controlled organisations as they are embedded in their community and have accountability back to their community through formal governance structures.**

There are key elements that define community based responses, which have enabled these organisations to play a pivotal role in the overall response to HIV in Australia.

Governments, academics, public health organisations and community organisations agree the Australian response to HIV was a success (Feacham 1995; Kippax; Stephenson, Parker & Aggleton 2015; Yang et al

2014). These stakeholders also typically agree the community led approach was a critical success factor of the overall response.

In the changing landscape for community organisations (see section 1 of this report), it is important to be able to articulate what distinguishes community based HIV organisations from other organisations in the sector and beyond. Throughout this project, we worked with sector leaders including academics, government and AIDS Councils to agree on a definition for HIV CBOs. Figure 3 below illustrates the critical components of community based responses (as distilled from stakeholder consultations and through the literature review). To be characterised as a true community based and led response, these features would all need to be apparent (as they were in Australia's response to HIV).

Figure 3: Elements that characterise community based responses¹



Below we outline these elements in more detail.



Community responses are initiated, designed and implemented by the community.

Community responses emerged early in the HIV epidemic in Australia. Affected communities – namely gay men, sex workers and drug users – came together early to educate their peers and advocate for their community's concerns (Brown et al 2014). Affected, marginalised and disadvantaged communities created state and national HIV CBOs to ensure operational efficiency and an organised approach to advocacy activities and service delivery. Services and programs in Australia's HIV response were typically designed and (predominantly) implemented by the affected communities themselves (through their state and national HIV CBOs such as AIDS Councils). Evidence demonstrates the superior effectiveness of these community-led services and programs (compared to non-government or government led public health approaches) (IFRCRCS, 2009; Gorne & Wright, 2006; AIVL, 2006).



Community based HIV organisations are highly responsive to the needs of their communities.

Embedded HIV CBOs are able to rapidly identify, interpret and respond to community needs and adapt to specific social contexts and emerging health threats. This component is further detailed under Section 3.2.



Community responses are enacted through partnership with mainstream providers.

Partnership with mainstream organisations (known as 'the partnership' in the literature) is a key feature of HIV CBOs in the HIV response in Australia. This partnership is defined and commonly cited as community engaged, politically active and provided with resources (Brown et al 2014).

¹ Cahill, Valadez & Ibarrola, 2013; stakeholder consultations

In recognition of the early success of these new state and national community organisations in Australia's HIV response, key sector players quickly began to foster partnerships with community organisations. Australia was one of the first countries to have active partnerships between key leaders across the HIV sector, which has since been proven by many academics as a critical success factor in Australia's HIV response (Mindel & Kippax, 2013).



Community based HIV organisations depend on their community for authority.

The authority and governance of community organisations outlined in the evidence relate to organic connections, not necessarily formal governance (as evidenced through stakeholder consultations). Governance and accountability back to the community is important but not the defining feature of the organisations in the HIV response in Australia. This is in contrast to the Aboriginal context where governance is a key defining feature. The National Aboriginal Community Controlled Health Organisation (NACCHO) articulates the authority of the community in the governance and management of the organisation. It defines Aboriginal community controlled services as "...operated by the local Aboriginal community to deliver... health care to the community which controls it, through a locally elected board of management" (NACCHO, 2016).

AFAO and AIDS Councils demonstrate all of these features and are increasingly defined as 'community controlled organisations' to distinguish themselves in the sector.

The above section describes the key elements that characterise community based responses. Whilst these elements typically underpin the operations of community based organisations, AIDS Councils have consistently demonstrated these key elements since their inception. AIDS Councils argue that these long-standing organisational elements combined with their proven success in responding to the HIV epidemic distinguish them from other community organisations (e.g. government appointed HIV organisations). In recent years AIDS Councils have attempted to move towards defining themselves as 'community controlled organisations' in recognition of the differences in how they operate and design and delivery services and the accountability back to their community through formal governance structures. Throughout this report, 'community based HIV organisations' are used to describe AFAO and Australia's AIDS Councils, to remain consistent with existing literature that informed the report.

3.1.2 There is strong evidence that compares the results achieved by community based HIV organisations to non-community organisations

Community based responses have been more effective than traditional public health approaches.

Overall there is compelling evidence that demonstrates community based responses to the HIV epidemic have been more effective than non-community based approaches. This includes traditional (stand-alone) public health approaches and the involvement of other organisations including NGOs (Mindel & Kippax, 2013). There are many global examples that demonstrate this argument. We identified two commonly cited case studies that clearly demonstrate the effectiveness of Australia's community based response (see Figure 4 overleaf).

Figure 4: Case studies that demonstrate the effectiveness of community responses



Australia versus rest of the world

Governments built strong links with affected communities, clinicians and biomedical, epidemiological and social researchers (Mindel & Kippax, 2013). The 'partnership' invested in peer-led education and community building programs, to which the success of the response is widely credited. Other countries did not exploit partnerships and were not as successful in their response.

Partnerships that break down

NSW maintained steady infection rates in the early 2000s when incidence increased in Victoria and Queensland. It is widely cited that this is due to the HIV partnership with government supporting communities. "partnership is not static and Australia witnessed divestment and political neglect in some states" which resulted in increased incidence of HIV (Brown *et al* 2014; Mindel & Kippax 2013).

In addition to these two case studies, a series of evaluations further demonstrate the superior effectiveness of peer led and community based approaches in the HIV sector. A selection of these evaluations is outlined below:

- Effectiveness of peer education in HIV prevention. Evaluations have shown benefits including cost effectiveness, access to hard to reach populations, building credibility and trust which results in behaviour change, and empowering communities. Early in the epidemic, gay communities were active in initiating, developing and promoting safe sex strategies including condom use. These strategies formed the basis of the early education and prevention programs developed through a strong collaboration between AIDS Councils and the community (Feacham, 1995).
- Ability of community led approaches to influence behaviour. Evaluation of the first national HIV/AIDS strategy found the education and prevention program had resulted in behaviour change in the gay community (Mindel & Kippax 2013).
- Ability to increase the knowledge and understanding within affected communities. An evaluation of ACON's "Talk, Test, Test, Trust" campaign, which was developed and run by gay men, found it added to gay men's understanding of how to safely negotiate unprotected sex within negative sero-concordant relationships (Mindel & Kippax 2013).
- Effectiveness of community responses compared between states. The National Centre for HIV Social Research and AFAO conducted a project to examine the differences between epidemiological and behavioural data, policies, strategies and community responses between states (to account for state based differences in HIV response). The study found an active commitment to and adequate resourcing of HIV prevention by all stakeholders in the partnership is critical to an effective response (Brenard, Kippax & Baxter, 2008).

3.1.3 There is evidence that community based HIV/AIDS organisations were key contributors to the overall response

Australia responded to HIV through a partnership model, which is widely credited as the reason for Australia's success in responding to the epidemic.

Australia responded to the HIV epidemic through a partnership prevention model (the partnership) (Ellard 2012). Government, public health organisations, community organisations, epidemiological and social researchers worked in partnership to understand and contain the epidemic (Feacham 1995; Kippax et al 2015) (see Figure 5).

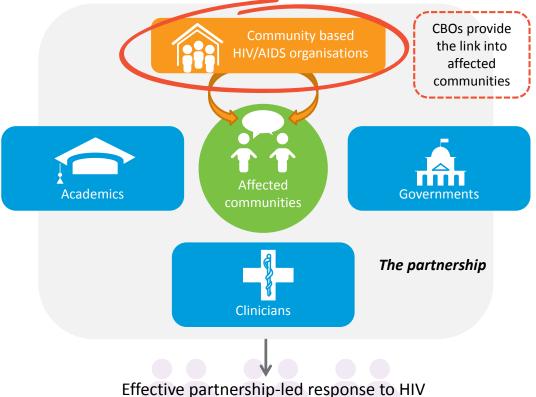


Figure 5: Players involved in Australia's HIV partnership response

Evidence clearly demonstrates Australia's initial HIV response was more effective than many other countries because of the broad-based partnership response (ACON 2015; Gupta, Parkhurst, Ogden & Aggleton 2008; Mindel & Kippax 2013). Australia's strong partnership meant key players in the response were all engaged with the community, informed about epidemiological trends and behaviours, politically active and provided with the right resources (Brown et al 2014). Evidence that demonstrates the effectiveness of a partnership response includes:

0 Many other countries did not adopt a partnership-led response and saw significantly worse outcomes in containing the epidemic. For example, France, Italy, Spain and Canada had significantly higher HIV prevalence in the general population than Australia. Studies found this is largely because of the lack of community involvement in the response (Ellard 2012; Mindel & Kippax 2013).

• Evidence on incidence rates since the early epidemic reiterates the importance of a strong partnership approach to HIV. When HIV prevalence began to increase again in the 2000s, Australian jurisdictions that invested less in their HIV partnerships experienced much worse outcomes (Mindel & Kippax 2013).

Community based HIV/AIDS organisations play a distinct role in the overall partnership response.

All organisations involved in the partnership had a critical role in effectively responding to the epidemic. HIV CBOs played a particularly important and distinct role in the overall response. They provided the link into affected communities (primarily AFAO and AIDS Councils to gay communities). It is through this link and the organisations' embeddedness within affected communities, that the partnership-led response was able to remain informed about epidemiological trends, community attitudes and behaviours, and acceptability of interventions (Ellard 2012; Mindel & Kippax 2015). HIV CBOs also built the capacity of gay communities to manage and respond to the epidemic in their own right (Brown et al 2015; Kippax et al 2015).

3.2 What are the features of the community based HIV response that explain this difference?

This section details the features of HIV CBOs that make them unique and successful at providing costeffective, targeted and meaningful services. Specifically we describe:

- the unique features of HIV CBOs and how these features enable them effectively to respond to the HIV epidemic
- how the combined value of these unique features provides HIV CBOs an advantage in responding to the HIV epidemic
- the cost-effectiveness of community based programs and services.

3.2.1 HIV CBOs have unique features that enable them to provide trusted, relevant and efficient services and programs

HIV CBOs have unique features that support their nimble, targeted and highly effective response to the HIV epidemic and other health or social issues within their communities. The three unique and most valuable features of HIV CBOs are illustrated in figure 6 below (as identified through the literature review, document review and key stakeholder consultations).



Figure 6: Unique features of HIV CBOs

Each of these is described in detail below.

HIV CBOs are embedded within their communities, which supports a deep understanding of the contemporary issues and effective solutions

Understanding how people are socially organised and networked is important for understanding the patterns of transmission of HIV. It is also important for understanding the ways in which people can be reached or mobilised for prevention (Brown & Reeders 2016; Adam 2011; Bernard, Kippax & Baxter 2008).

AIDS Councils and other HIV CBOs, like the Sex Workers Outreach Program (SWOP) the Nous team interviewed in Sydney, have a deep understanding of and embeddedness within their communities. This was evidenced through the literature review and also during consultations with SWOP and other informants.

Engagement is more than listening to clients and conducting consultations. It refers to the unique relationship a peer-led organisation has within its community, such as the ownership a community feels towards the organisation, the drawing of staff and volunteers from the community... The unique opportunity peer-led programs have is to participate in, rather than intervene on, their community - Brown and Reeders 2016

This community embeddedness is highly valuable in supporting AIDS Councils and other HIV CBOs to:

- provide more targeted and acceptable campaigns and services
- respond more quickly to changes in the HIV epidemic and other emerging health and social issues
- foster a greater sense of trust in their organisations (within their communities).

Each of these is described in turn below.

AFAO and AIDS Councils provide targeted, acceptable and meaningful health promotion and prevention services.

Evidence from the literature review and review of AIDS Council generated documents demonstrated that AFAO and AIDS Councils provide services and programs that are more likely to be targeted, acceptable and meaningful to their affected communities.

HIV CBOs involve the community in the development, implementation and study of public health

strategies. This ensures campaigns and services are relevant, effective and acceptable to their targeted communities. This way of working is referred to as a 'social public health' approach, which focuses on the affected communities as drivers of health

 On the contribution of community organisations:
 '[It's] in the way they understand and think about... the nuance of service delivery and policy advice. It's based in the knowledge and experience of the community. The community relate to people who deliver these services; there is greater understanding and rapport.'
 Key informant consultation?

outcomes (Sullivan, Carballo-Diéguez, Coates et al 2012).

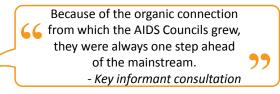
This social public health approach was demonstrated when the HIV epidemic first reached Australia. Gay communities responded to the epidemic in a variety of ways, including developing strategies aimed at reducing harm. AIDS Councils were created by the community leaders of discussion within the gay

community in the first couple of years of HIV's arrival in Australia. They were, therefore, aware of and understood these strategies from the beginning, due to their creation by and embeddedness within the communities. They were able to develop HIV prevention and health promotion activities that appropriately responded to community needs and practices. This meant their services and activities were more likely to be meaningful and acceptable to gay men to whom they were targeted (Bernard et al 2008; Kippax & Stephenson 2012, IFRCRCS 2009).

More recent evidence demonstrates similar patterns by which peer-led and peer-based approaches have delivered effective HIV health promotion services to youth populations and Aboriginal and Torres Strait Islander communities. (Mooney-Somers, Erick, Scott, Akee, Kaldor & Maher 2009; Krulic 2015).

AFAO and AIDS Councils are able to respond more rapidly than governments and mainstream health services to the changing needs of their communities.

Embedded HIV CBOs are able to respond rapidly to community needs and adapt to specific social contexts and emerging health threats. They are able to monitor how programs are delivered, establish rapid feedback loops, and mobilise communities to identify problems and solutions (Collins, Greenall, Mallouris and Smith 2016).



AIDS Councils were often the first organisations to adapt to changes in the HIV epidemic (as consistently reported in key informant consultations). There are numerous examples of the rapid responses of AIDS Councils in the early days of the epidemic and also at key junctures

where the epidemic changed. For example, AIDS Councils responded before mainstream providers to changes in gay men's sexual practices. Figure 7 provides three examples of AIDS Councils proven track record of rapid response to community needs and issues.

Figure 7: Examples of AIDS Councils track record in rapid responsiveness

Situation		AIDS Councils' value
AIDS Councils were the first to advocate for the early condom use that was adopted by many gay men. It was the gay community that advocated and educated that condoms would protect them from HIV in the early days of the epidemic.	P	Nascent AIDS community-based organisations were the first to recognise these practices were emerging among their communities and responded with appropriate support (e.g. with information as it became available) (Bernard et al 2008).
AIDS Councils worked with communities to address the rise of non-condom based sex practices. Some gay men adopted riskier strategies such as withdrawal and making judgements about risk based on a partner's appearance.	Ļ	AIDS Councils knew of these strategies before PHOs. AIDS Councils worked with communities to assess the evidence and disseminate information in a respectful, non-judgmental way. This was in recognition that previous messaging was not salient to their targeted communities any more (Brown et al 2014, Race 2014, Kippax et al 2015,Sullivan et al 2012).
AIDS Councils helped men in sero- concordant negative relationships to develop strategies for safe sex. ACON's Talk-Test, Test-Trust program is an example of a campaign developed and run by gay men for gay men.		AIDS Councils recognised the need within the community for targeted strategies for men in relationships (Kippax & Stephenson 2016). An evaluation found the program added to gay men's understanding of how to safely negotiate unprotected sex within relationships (Sullivan et al 2012).

Communities have a high degree of trust in AIDS Councils, which means they actively seek out AIDS Councils for services and advice.

Informants consistently reported that gay men actively seek advice and services from AIDS Councils due to the high degree of trust they place in these organisations. The extensive involvement of members of

Peer leadership brings... an authenticity and credibility based within a long term relationship within the target communities. - Brown and Reeders 2016 the gay communities in the leadership and operations of AIDS Councils allows services to build this level of trust within the community (Collins et al 2016). AIDS Councils (including those to whom the Nous team spoke) are acutely conscious that this trust has to be earned and retained through respectful, evidence based and non-judgmental advice.

HIV CBOs have attained unusually high levels of professional knowledge in specific domains, which informs successful service delivery

AIDS Councils' workforces have attained a highly advanced knowledge base and diverse range of professional expertise. Combined, these support the delivery of targeted, evidence-based services and programs. AIDS Councils maintain a deep understanding of the epidemiology, virology, risk behaviours and components of an effective response. Many AIDS Council staff have accumulated high levels of expertise in all these domains of knowledge and also in the techniques of community health, health promotion, prevention education and peer based service delivery. This was stressed in key informant consultations.

This is an additional factor that differentiates AFAO and AIDS Councils from many other non-government organisations. It allows for a more sophisticated conversation between government, academics and health providers about how to best deliver services.

AIDS Councils' workforces possess a unique and powerful combination of relevant skills and knowledge.

The combined knowledge and skills of the AIDS Councils' workforce enable targeted and tailored programs and services. Figure 8 illustrates the valuable skills and knowledge possessed by AIDS Councils' workforces (as evidenced through stakeholder consultations and the literature review).

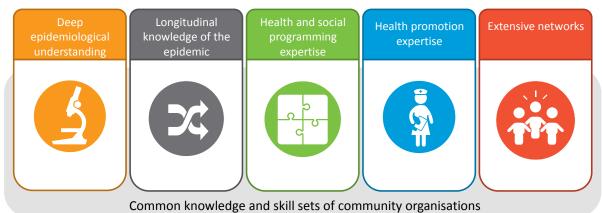


Figure 8: Knowledge and skill sets of community organisations

Each of these common attributes of community organisations knowledge and skill base is described below:

- **Deep epidemiological understanding**. Community organisations' services often provide additional epidemiological data not able to be replicated by mainstream services. This is often due to the greater reach of their services (e.g. into marginalised sub-populations). For example, M Clinic (run by WAAC) provides a level of detailed epidemiological data not collected elsewhere. Positivity rates for M Clinic clients have declined from approximately 13 positive results per 1,000 tests in 2010-11 to 5.6 in 2015. Through M Clinics data collection, WAAC can also demonstrate a decline in other sexually transmittable infections (STIs) (as reported through key informant consultations).
- Longitudinal knowledge of the epidemic. AIDS Councils and other community HIV organisations have been responding to the HIV epidemic for over 30 years. Their workforce and communities have worked in partnership throughout this time. This has fostered a deep longitudinal knowledge of the epidemic, the risk factors, evolving community needs and the most successful responses that are appropriate to the needs of communities.
- Health and social programming expertise. Community organisations' workforces understand the issues and difficulties in providing services within this sector. This translates to nuanced service delivery and policy advice, grounded in an understanding and experience of the community, including its needs and expectations around service delivery (as reported through stakeholder consultations). Examples of community organisations service delivery expertise are provided in Table 2 on page 21.
- Health promotion expertise. Collectively, the AIDS Councils have significant expertise in health research and health promotion. This extends beyond the HIV sector to other health needs such as STIs, drug use and others. This differentiates HIV CBOs from NGOs and provides an opportunity for a more sophisticated conversation (as reported through stakeholder consultations). For example, the AFAO Health Promotion Program provided national leadership to the community education and health promotion response. An independent evaluation found

it was highly relevant to demonstrated needs, engaged target audiences, provided useful information and influenced behaviours (Berg and van Reyk 2015).

 Networks between HIV CBOs. Community organisations have large peer networks and significant social capital. This results in organisational expertise and capacity building (e.g. between AIDS Councils and sex worker and drug user organisations) (Kippax & Stephenson 2012; key informant consultations). For example, the Victorian AIDS Council (VAC) has a wide membership base and provides their infrastructure and grants to smaller community organisations to help broaden the impact of the community response in their region.

The relevant professional expertise possessed by AIDS Councils' workforces was demonstrated by the professional breadth of the stakeholders interviewed for this project. It is also evidenced in the review of position descriptions for key roles within AIDS Councils. Figure 9 provides an example of some of the position descriptions within AIDS Councils and highlights the required unique expertise and knowledge.

Figure 9: Examples of position descriptions that demonstrate the workforce's expertise²



Director

The Director positions require a breadth of experience and extensive community networks. Common skill requirements across Director positions include: understanding of gay culture; knowledge of gay men's HIV and STI prevention approaches and partnerships; and an understanding of the evidence-base underpinning gay men's prevention.

Community health promotion officer (CHO)

This role is unique to AIDS Councils. CHOs implement outreach activities and promote the health of targeted communities. They are embedded within communities. Skill requirements include: understanding of gay culture; knowledge of gay men's HIV and STI prevention approaches and partnerships; and an understanding of the evidence-base underpinning gay men's prevention.

Regional manager

Regional Managers are responsible for planning and managing all aspects of programs and services in regional/rural areas. They are required to have broad knowledge of all health issues affecting the gay and other targeted communities. They are required to have a deep understanding of affected communities and their own regional communities.

HIV CBOs are expert at the delivery of successful services and education and media campaigns.

HIV CBOs deliver successful peer-based and peer-led services, programs and campaigns (as reported by stakeholders and evidenced in the literature review and document review). Many AIDS Council services and campaigns have been independently evaluated and demonstrated a high level of success in achieving their intended outcomes.

Overall, evaluations typically revealed AIDS Councils delivered successful, targeted, cost effective services and programs that achieved good reach into affected communities. In addition, evaluations noted a key success of community responses is the ability to run campaigns that are honest and give gay men the information to make empowered, informed decisions about their sexual practices. Table 2 below provides a description of the high-level objective of many AIDS Councils and other HIV CBOs services, programs and campaigns, supported by specific examples.

² Based on position descriptions provided by ACON for various Director roles, Community Health Promotion Officer roles and Regional Manager roles.

Objective	Description	Examples
Targeted services and campaigns	AIDS Councils have a proven track record of developing targeted materials which are more effective at achieving desired outcomes (e.g. delivery of health promotion messages and/or behaviour change) (Ellard 2012).	 A survey of gay and bisexual men recently diagnosed with HIV found that participation in community peer support programs was the only predicator of a measured reduction in sexual risk behaviours (Prestage et al 2016). Community based testing sites, such as M-Clinic and a[TEST], reach a higher proportion of gay and homosexually active men who have never been tested for HIV before compared with traditional testing sites (Holt 2005). AFAO's Health promotion program was highly relevant to demonstrated needs, engaged targeted audiences and influenced behavioural intentions (Berg & van Reyk 2015).
Greater reach	Community based HIV organisations achieve greater reach into affected, marginalised and/or excluded communities (such as criminalised or stigmatised groups).	 Evaluations of peer education and community development programs for gay men, sex workers, drug users and at-risk youth show they have been effective at reaching people are unlikely to be reached by non-community controlled programs. (Feacham 1995) Ending HIV, a community led education and prevention program, achieved up to 82% recall among gay men and 36% increase in people's knowledge about the health benefits of early treatment (ACON 2015). The campaign reached a far greater proportion than typically expected ('an unprecedented high number for a targeted HIV education campaign') (NSW Health 2014) Peer education and community development have been critical to the success of Australia's needle and syringe programs. They achieved reach into the injecting drug user population that wouldn't have been possible otherwise. In 1991 these programs prevented 3,000 infections, saving \$250 million in treatment costs (Feacham 1995).
Delivered through broad networks	HIV CBOs have strong links with each other, which supports an extensive peer network and assists with achieving greater reach and surveillance.	 AIDS Councils employ a wide and varied network of partnerships that deliver successful and comprehensive services (e.g. rapid testing services delivered through a partnership between government, the Sydney Sexual Health Centre and the Kirby Institute; the HIV Program delivered with Royal District Nursing Service) Examples of AIDS Councils links with other HIV CBOs include: VAC's relationships with religious groups (Catholic AIDS Ministry), social clubs (Vic Bears) and other health organisations (Royal District Nursing Service). ACON's relationships with government agencies and organisations (Hunter New England Local Health District, South Eastern Sydney Local Health District), health organisations (St Vincent's, Sydney Sexual Health Centre) and other HIV CBOs (SWOP, NAPWHA).
Longevity	Peer education programs and testing services support longevity as peers can reinforce learning through ongoing contact and using peer educators as good role models (Goren & Wright 2006).	 M Clinic in WA is a full sexual health testing site for gay and other homosexually active men. It has been operating on a full time basis for six years. It provides sexual health screening for approximately 43% of all homosexually active men in Perth (as reported by stakeholder consultations).

Table 2: Examples of HIV CBOs expertise in service delivery

The expertise and knowledge of HIV CBOs' workforces supports them as leaders in their communities and the sector more broadly.

Stakeholders consistently reported the strong leadership and direction AIDS Councils provided within their affected communities and the sector more broadly.

Key informants reported that AIDS Councils provide leadership to their affected communities. Community members look to AIDS Councils to keep informed and for guidance on emerging issues and biomedical tools. Stakeholders reported this as a key strength and differentiator from other organisations. AIDS Councils are able to provide informed guidance and advice to their community members due to the inherent knowledge and professional expertise of AIDS Council's workforces.

The active leadership of communities to influence policies and programs has and will continue to be critical to the success of HIV prevention (UNAIDS 2007). To date, AIDS Councils have provided strong leadership, guidance and direction within the sector (reported in key informant consultations). AIDS Councils' strong connection with, and embeddedness in the affected communities delivers multiple benefits in terms of service planning and delivery. For example, AIDS Councils are often 'one step ahead' of mainstream providers in noticing changes in the epidemic and/or successful responses. This enables them to share learnings with other organisations in the sector, as well as rapidly respond themselves.

HIV CBOs typically have strong relationships and high credibility with governments and other organisations working in the sector, based on their professionalism and authority within the affected communities

AIDS Councils and other HIV CBOs have maintained effective relationships and demonstrated credibility with mainstream service providers, government agencies, researchers and other stakeholders. This is based on their strong relationship with the community and their central role in the health system

response to HIV (as evidenced in key informant consultations and the literature review). They are widely recognised among government and academic stakeholders as the key community experts on HIV.

Another key strength of HIV CBOs is their professionalism. AIDS Councils are widely recognised as well-functioning organisations

It is important for researchers to understand the sexual practices of gay men and what it's like to be part of the community. For example, distinguishing between sexual partners and what motivates people in this community. - Key informant consultation

with sophisticated and robust management, financial and governance structures. This is evidenced by their central role in the health systems response to HIV (key informant interviews).

AIDS Councils have maintained effective working relationships with state and federal governments over the past 30 years. This is in part due to their ability to effectively respond to the epidemic and their recognised credibility, but also their ability to advocate and operate in a bi-partisan and non-political manner (as reported by key informants). The strength of this relationship is demonstrated by the longevity of the relationship. The relationship has operated effectively for almost 30 years and been maintained within the context of HIV being a potentially politically sensitive issue.

There are multiple examples of AIDS Councils demonstrated credibility, identified through stakeholder consultations and the document review. Four case studies that demonstrate AIDS Councils credibility are described below:

• **The syphilis epidemic in Sydney.** In the mid-2000s, syphilis rates rose to reach epidemic proportions among homosexual men in inner Sydney (AMA 2005). The Sexually Transmissible Infections in Gay Men Action Group (STIGMA), a public health partnership, led

the response. Through the partnership, Public Health Units were able to utilise their established relationships with ACON and Positive Life NSW (due to their representation of the gay and MSM community). PHUs provided surveillance data to STIGMA. Increases in syphilis notifications trigged media alerts and community health promotion initiatives (led by ACON and Positive Life NSW) (Botham, Ressler, Maywood, Hope & Bourne 2013).

- Credibility with academics. Researchers universally reported a high degree of respect for AIDS Councils and other HIV CBOs (as reported through stakeholder consultations). Researchers consistently cited the strong and mutually beneficial relationship between academic and research organisations and community organisations. This credibility is demonstrated through many examples, including the high degree of collaboration between researchers and community organisations in gathering data for large social research studies and understanding complex issues within the community context. Another important example of the strong relationship between researchers and AIDS Councils is VAC's inclusion on the board of multiple research advisory councils. This not only contributes to their collaboration opportunities but also building credibility and authority within the community.
- Credibility with the NSW Police. One community organisation interviewed for this project provided an example of their credibility with government agencies. Three community members approached the NSW Police for assistance. The NSW Police referred the community members to SWOP to seek advice on their rights, before formally approaching the NSW Police. This demonstrates the government's strong relationship with SWOP and its trust and credibility within a range of agencies.
- ACON and VAC Pre-exposure Prophylaxis (PrEP) lobbying. Australia is leading the world in large scale PrEP trials for HIV negative at risk-populations (Swannell 2016). A number of PrEP programs are being run by researchers in collaboration with community organisations to access at-risk communities. NSW and Victorian gay communities' high awareness of PrEP is unique and has enabled the success of the studies. "The study recruits were highly knowledgeable and therefore motivated to adhere to the daily regimen of medication to make PrEP medically and cost-effective" (Swannell 2016).

3.2.2 The combined value of HIV CBOs' unique features place them in an advantageous position to respond to the HIV epidemic and other emerging health threats

The unique features of HIV CBOs (described in 4.1.1) provide AIDS Councils a scope of action that is advantageous over other organisations operating in the same environment. Advantages community based HIV organisations enjoy include:

- permissions that public agencies (e.g. NSW Health) do not have
- the ability to work in strong partnership with a range of other organisations
- the capacity to lead within their field.

We describe each of these in detail below.



HIV CBOs have permissions that many other public service organisations do not have.

Peer-led and peer-based services can more easily adapt to suit specific social contexts and meet niche community needs. This is particularly critical to fill gaps in formal public health systems (Collins et al 2016). For example, HIV CBOs can design service delivery ublic sector organisations could not deliver

models that public sector organisations could not deliver.

ACON's Sexperts program is a peer-based health promotion activity. It involves volunteers going into gay venues and building trust with community members to more effectively disseminate targeted health promotion information. It positions ACON in the heart of the gay community to provide information in line with Ending HIV. This is an activity that reaches an important sub-population, but one that government services could not easily deliver. The Sexperts program was successful in increasing the uptake of self-testing kits at targeted venues (Gray 2011).



HIV CBOs are able to work in partnership and collaboration with a broad range of organisations.

HIV CBOs are recognised for their capability to work in strong partnership with a range of organisations and people, including PHOs, academics and public sector organisations (Aggleton & Parker 2015; Yang et al 2014; Kippax & Stephenson 2012, Sullivan et al 2: Renard et al 2008)

2012; Ellard 2012; Bernard et al 2008).

The Australian response was and continues to be a partnership between government, communities, public health and research institutions (Sullivan, Carballo-Diéguez, Coates et al 2012). Partnerships are widely recognised as critically important in the success of Australia's HIV response (Feacham 1995; Kippax et al 2015). The partnership approach allows ongoing monitoring and interpretation of HIV notifications, behavioural data and thus the highly effective educational and clinical response (Ellard 2012). Evidence from other countries also demonstrates that effective prevention is marked by genuine partnerships between government, researchers and the community, for example in Switzerland, Thailand, Uganda, Brazil (Kippax & Stephenson 2012).

The involvement of community develops the community capacity to respond and requires public health responses to address people as connected members of networks who interact (e.g. talk, negotiate, have sex and use drugs) (Kippax & Stephenson 2012). For example, ACON developed and delivered the a[TEST] service in partnership with NSW Ministry of Health, Sydney Sexual Health Centre and the Kirby Institute. An evaluation found it was successful at attracting sexually active gay and bisexual men and identifying previously undiagnosed cases of HIV and STIs (ACON 2014).



AIDS Councils and other HIV CBOs are recognised as leaders within their respective fields of expertise.

HIV CBOs have the capacity to lead, both within their communities and collectively as a group of organisations within their respective fields (as reported through stakeholder consultations). The features of HIV CBOs described in section 3.2.1 – their

embeddedness within communities, knowledge and expertise, and credibility with mainstream providers – combine to place HIV CBOs in a strong position to provide leadership.

Community organisations' embeddedness in the affected communities and knowledge and expertise in service delivery mean community members look to AIDS Councils and other HIV CBOs for advice and leadership. This is evidenced historically in how AIDS Councils and the communities interacted to learn about negotiated safe sex. More recently, it is evidenced through AIDS Councils leadership in lobbying for PReP trials.

Communities look to AIDS Councils for guidance and to be kept informed. - Key informant consultation Community organisations' credibility with mainstream providers, combined with their collective reach into often hard to reach segments of communities, supports their ongoing sector leadership. AIDS Councils' unique features means

they, and other HIV CBOs, are able to provide leadership to governments, PHOs and researchers who are looking to understand and respond to the epidemic. This leadership is in the form of specific expertise and knowledge of the community, the epidemic and service delivery, as well as access into the affected communities. Community organisations are in this position due to their deep understanding of the communities and, vice versa, community members' deep trust in the organisations.

"

3.2.3 Programs and services delivered by HIV CBOs are cost effective

Qualitative and quantitative evidence exists on the cost effectiveness of AIDS Councils services and programs. Overall, the evidence demonstrates AIDS Councils services and programs are cost effective when compared to other approaches. This is due to their access to community intelligence and cultural knowledge, the cost-benefits of volunteers, greater reach for the same level of expenditure due to the sites of intervention and the peer based workforce, the application of self-generated funds to augment government funded service delivery, the efficiency of data and information generated through community connectedness.

A number of AIDS Council and AFAO services have been independently or internally evaluated. Figure 10 summarises a selection of independent evaluations of AIDS Councils services and programs, highlighting findings on cost effectiveness. It demonstrates there is credible evidence that exists on how and why AIDS Councils are able to deliver cost effective services.

In addition to the evaluation of the evidence on cost-effectiveness, Nous has conducted a cost effectiveness analysis for a community campaign; 'ComePrEPd'³. The results of this analysis show that ComePrEPd's marketing campaign is cost-effective based on available data. The campaign has also been able to create genuine engagement with those it reaches. However, the true impact of the program will best be assessed when data is available on the usage rates, and the subsequent effect on infection rates⁴. The goal of the campaign is to raise awareness, primarily through directing attention to its website. As such, the campaign's effectiveness is at this stage best measured through the website activity, despite marketing cost going through a number of other channels including online social media, print advertising and collateral. After development costs, the marketing campaign has spent \$1 per page view⁵. Even more encouragingly visitors are engaging with the material, with 56.4% of those views beyond the front page, and each viewer spending an average of almost two minutes on each page. Furthermore, other avenues of engagement beyond the website should be considered in the effectiveness measures. For example, the boosted Facebook video in December had over 11,600 views, at a cost of just 19c per view. It should be noted that this is also not a perfect measure of effectiveness, as it does not capture untracked results (for example conversations) which may be a better measure of the cost effectiveness on collateral. This cost-effectiveness analysis has reinforced our findings that community based and community-led programs and campaigns are cost effective when compared to

³ ComePrepd is the Queensland AIDS Councils (QuAC) new campaign for pre-exposure prophylaxis (PrEP) which was launched on 19 September 2015. ComePrepd is primarily an online awareness campaign which aims to encourage open discussion about PrEP in the community. <u>www.comeprepd.info</u>

⁴ The NSW Government suggests assessing effectiveness of advertising in terms of behavioural change outcomes in *Cost Benefit Analysis* of *Government Advertising: A User Guide.*

⁵ Based on internal data. There were 20,295 page views since September 2015, and \$20,200 in costs for marketing and collateral, with a further \$7,200 in website development considered to be a long term investment outside of the marketing campaign. If the website costs are included, the cost per page view increases to \$1.35.

other approaches. Nous would recommend additional analysis be conducted on the 'ComePrEPd' campaign as further data becomes available and evaluation measures are developed.

Figure 10: Sample of evidence on the cost effectiveness of AIDS Council programs and services

Education and Prevention Program (national)			
Program Description The Education and Prevention Program was one of the four programs of the National HIV/AIDS Strategy 1993-94 to 1995-96.	Cost effective evidence An economic evaluation found the program was effective at reducing transmission between 1984 and 1993, saving the government between \$78 and \$1,341 million in avoided treatment costs (Feacham 1995).		
AFAO Health Promotion Program (AHPP) 2012-2014 (AFAO)			
Program Description Through the AHPP, AIDS Councils work collaboratively and in partnership with their constituents to build effective, sustainable and appropriate responses to the HIV epidemic.	Cost effective evidence The national roll-out of state initiatives reduced duplication of work and ensured funding was used in the most cost-effective way (Berg & van Reyk 2015).		
Rapid HIV testing (ACON)			
Program Description ACON offered rapid testing for HIV was offered to gay, bisexual and other men who have sex with men. Twenty-two clinical and community-based health services offered rapid testing through this program.	Cost effective evidence An evaluation of the program found the total cost of offering rapid testing was lower in services where peer-workers and enrolled nurses conducted the testing (Keen et al 2016).		
'Ending HIV' (ACON)			
Program Description The 'Ending HIV' media and education campaign employed a mixture of advertising strategies including paid media channels and voluntary resources and assets.	Cost effective evidence An independent evaluation found the campaign was cost effective. The value of ACON's intangible assets (voluntary work and unpaid media) contributed to more than \$520,283 to the campaign (Pedic 2015).		

Informants consistently reported the cost effectiveness of service delivery as a key strength of AIDS Councils (through stakeholder interviews). Reasons given for cost effectiveness included that AIDS Councils were able to leverage community support for little or no cost (e.g. volunteers) and have access to community venues or cheaper access to other venues (e.g. pubs, clubs). AIDS Councils' deep involvement in the community means they are better placed and more effective at leveraging these benefits from the target communities (compared to governments or other organisations).

Emerging evidence from international jurisdictions provides further support to the claim that community-based HIV programs and services are cost effective. For example, an economic evaluation of community-based HIV prevention programs in Canada found the programs averted 16,672 HIV infections and resulted in \$6.5 billion in savings to the provincial health care system (Choi, Holtgrove, Bacon et al 2016). Another example is from Brazil, where the World Bank encouraged community involvement in an AIDS/STI control project in recognition that they often apply a cost effective approach (Rodriguez-García, Wilson, York et al 2013).

Community based approaches to deliver services and programs are cost effective in many sectors (not just the HIV sector). Evidence exists that demonstrates the cost effectiveness of community based approaches for peer education programs (more broadly than the HIV sector) and for working with injecting drug users and sex workers.

Peer based approaches can be cost effective in comparison to programs and services delivered predominantly by professional staff and requiring complex resourcing (Turner 1999; Turner & Shepherd 1999; Goren & Wright 2006). Reasons for the comparative cost effectiveness include:

- The use of volunteers. The cost effectiveness often stems from the use of volunteers as peer educators (Goren & Wright 2006, Australian Injecting and Illicit Drug Users League 2006). This is compared to the payments made to health professionals in non-peer based approaches. In addition, volunteers improve the reach of services as they can access at-risk populations and marginalised communities that other organisations including community health centres are not able to access (e.g. highly vulnerable drug users and illegal immigrant sex workers). This greatly improves the effectiveness of services and programs and is integral to reaching the most at-risk groups.
- The flexibility in service delivery. Peer based approaches are often less rigid and more informal than many highly structured interventions. This flexibility allows organisations to be nimble and change and adapt as needed (Western Australian Centre for Health Promotion and Research 2010).
- The venues in which services and programs are delivered. Peer-led interventions are often delivered in more informal settings than traditional health promotion or treatment services. Peer-led services are typically delivered in settings where the target community already live, work and interact (for example, clubs, bars and other venues). This facilitates greater reach to the target population for the same cost as less community embedded programming and delivery models. (Cowie 1999; Green 2001).

There is evidence that community based approaches are also more cost effective for working with injecting drug users and sex workers. For example, the 1993-96 evaluation of the National AIDS Strategy found that peer education and community development have been a critical to the success of Australia's needle and syringe programs. In 1991 these programs prevented 3,000 infections, saving \$250 million in treatment costs (Feacham 1995).

3.3 How has the epidemic and the health needs of the communities changed?

The community response and health needs of affected communities have changed considerably since the HIV epidemic first emerged in Australia. In this section, we describe:

- how Australia's epidemic has changed over the past three decades 0
- the emergence of new communities of people affected by HIV 0
- other health issues that are of concern for communities affected by HIV 0
- 0 social and political issues that impact on the lives of communities affected by HIV.

3.3.1 Australia's HIV epidemic has been characterised by a strong community response and can be historically grouped into three phases

Australia's current HIV epidemic reflects the strength of the HIV response over the past three decades. HIV prevalence is less than 0.2 per cent, which is very low compared to other developed countries. However, some challenges remain. The current status of Australia's epidemic is described below.



Australia's HIV epidemic has been concentrated among gay men and other men who have sex with men. They account for majority of people living with HIV in Australia and 86 per cent of newly acquired HIV infections (Kirby Institute 2015). Other populations at risk of infection include people who inject drugs, sex workers, Aboriginal and Torres Strait Islander communities and people who have travelled from countries with high HIV prevalence (Kirby Institute 2015).

Incidence has plateaued recently but this varies between states and territories. The number of new infections rose throughout the past decade but has been relatively stable for the past three years. Victoria experienced the greatest increase over this period (40 per cent between 2004 and 2013) while rates in New South Wales remained relatively stable. Incidence increased in Queensland and Western Australia over the past decade but has plateaued more recently. The Northern Territory and Australian

Capital Territory have experienced a rise in incidence in the past three years (Kirby Institute 2015).



Risk behaviours have remained unchanged for some populations and fluctuated for others. The percentage of gay men who reported engaging in condomless anal intercourse in the past six months increased from 33 per cent in 2005 to 39 per cent in 2014 – the highest rate recorded. However, gay men also reported using other risk minimisation strategies. These include PEP and PrEP, serosorting, strategic positioning, withdrawal and viral-load based intercourse (Kirby Institute 2015; de Wit et al 2015).

Needle and syringe programs have helped minimise risk behaviours among drug users. Prevalence of use of a needle and syringe after someone else used it has remained unchanged at approximately 15 per cent. Sex workers report very high rates of condom use, which is evidenced by the fact that prevalence is less than 0.1 per cent for this community (Kirby Institute 2014).



Access to HIV treatment is high but adherence remains a challenge. This impacts on health outcomes.

Of the estimated 23,800 people with HIV in Australia who have been diagnosed with HIV, around 73% were receiving antiretroviral (ARV) treatment in 2014 (Kirby Institute 2015). 92% of people on ARVs have an undetectable viral load (Holt M et al 2015).

People who start treatment early and adhere to treatment guidelines are expected to have a similar life expectancy to HIV-negative people. However co-morbidities remain a challenge for people who are diagnosed late and people who have not had adequate treatment. Around 7,000 people have died of AIDS-related causes in Australia since the epidemic began (NSW Health 2012).

Figure 11 below provides a snapshot of the current state of Australia's epidemic.

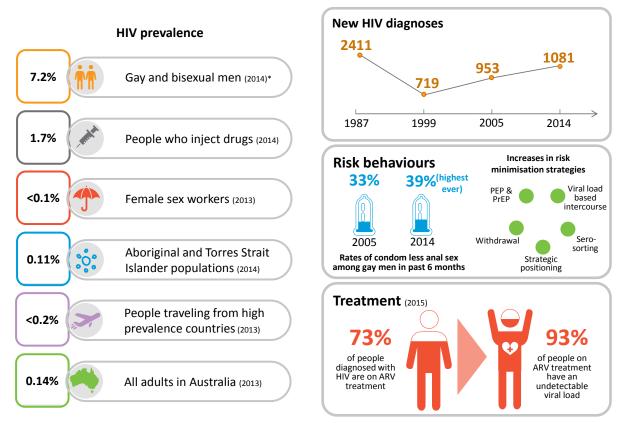


Figure 11: Snapshot of the current HIV epidemic in Australia

Note: *HIV prevalence in gay men using self-reported HIV-positive status (The Gay Community Periodic Survey)

Sources for other statistics: Kirby 2015; Kirby 2014; de Wit et al 2016.

There have been three broad phases in Australia's epidemic.

Each phase is marked by significant changes in prevention and treatment options. Changes in the social, policy and legal environment also saw large advancements in Australia's HIV response. In each phase, HIV CBOs have led efforts to respond to the changing needs and requirements of communities affected by HIV (Kippax & Stephenson 2016).

Figure 12 shows the change in diagnoses across the phases and key events in Australia's HIV epidemic.

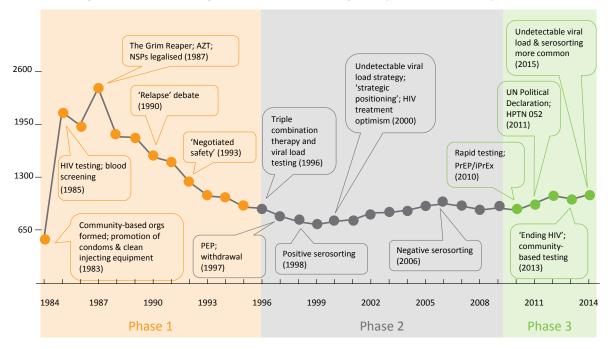


Figure 12: New HIV diagnoses in Australia during each phase of the HIV epidemic

Source: Adapted from Holt, M. (2016) 'The more things change, the more they stay the same? Anticipating the impact of biomedical HIV prevention,' Invited plenary presentation at the National Gay Men's HIV Health Promotion Conference, Sydney, 19th April; Data source: Kirby Institute 2015.

Phase 1: pre-antiretroviral treatment (1980s - 1996)

During the first stage of the epidemic there was no effective treatment for HIV. Survival rates were low and those diagnosed with AIDS faced a life expectancy of roughly 18 months (France 2009).

Incidence was highest among gay men. Between 1986 and 1995 male sexual contact accounted for at least 60 per cent of new diagnoses, followed by heterosexual contact (7 per cent) and drug use (6.5 per cent). 25 per cent of new diagnoses were undetermined so these figures could be higher (ABS, 1997).

New diagnoses peaked in 1987 at 2,411 (Kirby Institute 2015). Diagnoses then declined rapidly over the

next ten years as prevention efforts expanded and at-risk populations changed their risk behaviours (Plummer & Irwin 2006). Condom use rose dramatically as did the use of clean needles, negotiated safe sex and other prevention strategies (Merson et al 2008; Feacham 1995).

Stigma, discrimination and restrictive laws in relation to prostitution and drug use were initially a major barrier Legalising needle and syringe programs
 "In 1988, NSW became the first Australian jurisdiction to pass legislation to enable its Needle Syringe Program (NSP). This program was rapidly and comprehensively implemented across the state, quickly achieving the coverage levels needed to stem the transmission of HIV among people who inject drugs, and the rest of the population. This rapid response saved countless lives that would have otherwise been lost to HIV/AIDS. And this remains the case today."
 Associate Professor Ingrid van Beek AM Director, Kirketon Road Centre (NSW Ministry of Health, 2012)

to prevention efforts. However, strong advocacy from HIV CBOs and a positive response from most jurisdictions saw many of these laws overturned. Needle and syringe programs were established, heath promotion was expanded in brothels and stigma and discrimination among health workers decreased significantly (Feacham 1995).

Australia's HIV response during this period was one of the world's most successful. This was largely attributed to the prevention efforts of gay men and other affected communities, as well as the strong, well-funded HIV partnership between government and community based HIV organisations (Kippax and Stephenson 2016). Behavioural studies have shown the effectiveness of prevention efforts during this period. They demonstrate the link between declining prevalence and a reduction in risk behaviours among gay men (Zablostka et al 2012). For gay men alone, infection rates dropped by 33 per cent between 1993 and 1999 (Guy et al, 2008).

Phase 2: The emergence of effective antiretroviral treatment (1996 – 2009)

This stage was marked by the 1996 International AIDS Conference in Vancouver, where the first effective treatment for HIV was announced (IAS 2014).

We've gone from a 'death and dying' response to 'living with HIV.' - Key informant consultation

From the mid-1990s, combination antiretroviral treatments became widely available in Australia. This dramatically improved survival rates and quality of life for people living with HIV. Prevalence increased as mortality fell (Brown et al 2014).

Incidence continued to drop up to the late 1990s in Australia. In the early 2000s incidence stagnated in some jurisdictions and rose in others (Bernard, Kippax and Baxter 2011). Sexual contact between men accounted for 66 per cent of new HIV diagnoses between 2006 and 2010. Heterosexual contact accounted for 25 per cent and injecting drug use accounted for 3 per cent (Ellard 2012).

The rise in incidence in the 2000s was a common experience in developed countries. Condomless sex and other risk behaviours rose during this period. Some public health professionals described this as a 'complacency' effect. During this time, AIDS Councils and social researchers noted that, far from being complacent, gay men were actively discussing and enacting alternative risk reduction strategies, with mixed success (Kippax, and Stephenson 2016). As referenced earlier in this report, it was the AIDS Council's embeddedness within, and understanding of communities that enabled the Councils directly to address gay men about these strategies in an evidence based and non-judgmental way and maintain the success seen in Australia's response. AIDS Councils understood that gay men were exploring risk reduction strategies and they worked with communities to understand this and provide appropriate peer-led responses.

The HIV response during this period varied between jurisdictions. States and territories with well-functioning and well-funded HIV partnerships achieved better results, while others states saw incidence increase (Mindel and Kippax 2013). Figure 13 compares the percentage increase in new HIV diagnoses in different states and territories in Australia.

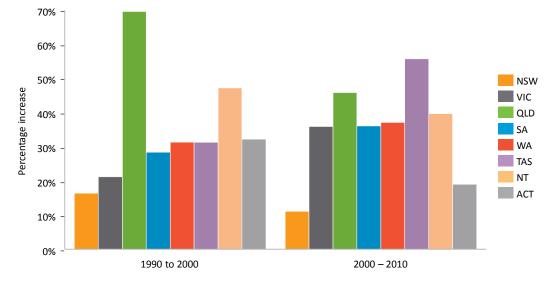


Figure 13: 10 year increase in the number of people living with diagnosed HIV by state and territory

Source: Jansson and Wilson 2010.

Phase 3: Treatment as prevention and towards ending HIV (2009 to current)

From 2009 there was growing evidence that people on HIV treatment were less likely to transmit HIV than people not on treatment. This was confirmed by a landmark study in 2011, which found that treatment dramatically reduced the likelihood of HIV being sexually transmitted by 96 per cent (Cohen et al 2011). From this, treatment as prevention emerged as an approach that would eventually lead to discussion of ending new transmission (UNAIDS 2014; Brown et al 2014).

The advent of treatment as prevention changed the nature of the response. Access to treatment has expanded significantly from the late 2000s and people diagnosed with HIV have been starting treatment much earlier. The percentage of HIV-positive gay men on HIV treatment increased from 60.3 per cent in 2005 to 83.5 per cent in 2014 (de Wit et al 2016). For the first time, ending HIV transmission has been seen as an attainable goal in Australia and other developed countries. This is the focus of the 2014-2017 National HIV Strategy.

This phase has also seen the advent of biomedical prevention tools, such as PEP and PrEP. Use of these medications has been low but is growing. Community based HIV organisations and researchers interviewed for this report said they expect PrEP to lead to a significant decline in incidence, particularly among gay men. However, they also recognised the continued importance of education and community action – to encourage frequent testing, early treatment and community dialogue about these new tools. The potential impact of PrEP in Australia is discussed further in section 3.3.3 below.

In this current phase of the HIV epidemic, prevalence remains concentrated among gay men. New diagnoses have remained relatively stable overall but increased among some new populations, including

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Aboriginal and Torres Strait Islanders and people from countries with high HIV prevalence (Kirby 2015). These populations are discussed further in section 3.3.2 below.

"The HIV Prevention Trials Network's HPTN 052 trial... demonstrated a 96% reduction of HIV transmission among serodiscordant heterosexual couples where the HIV-positive partner was being effectively treated, **resulting in a game changing relationship between treatment and prevention.**" -Brown et al, 2014

3.3.2 New communities of people affected by HIV are emerging

A key change in the epidemic has been growing incidence among new populations, such as Aboriginal and Torres Strait Islander and migrant communities. While prevalence remains low in these communities, there is concern that they are not being adequately reached by HIV services, increasing their risk of infection. Stakeholders have reported that current HIV prevention efforts are not adequate for these communities and need to be better targeted.

There have been some **HIV outbreaks in Aboriginal communities and outer Sydney in Indo-Chino gay men...** The usual HIV prevention stuff for young gay men will not resonate with these groups. We need to understand the dynamics that underpin this, such as substance abuse, and not just approach the issue from a cultural perspective or with a business as usual approach. [sic] - Key informant consultation



New diagnoses have been rising among some Aboriginal and Torres Strait Islander communities.

Prevalence among Aboriginal and Torres Strait Islander communities have remained on par with the general population. However from 2009, rates of HIV diagnoses began to diverge. In 2014, this rate was 5.9 per 100,000 for Aboriginal and Torres Strait Islander

populations compared with 3.7 per 100,000 for the Australian-born non -Indigenous population. These rates are based on small numbers and could reflect localised trends, not national trends. Nonetheless, several informants interviewed for this report expressed concerns about the low reach of HIV services among Indigenous communities, particularly in remote and regional areas (Kirby 2016).



New diagnoses have been rising among people who travel to and from countries of high HIV prevalence.

There have been a growing number of new diagnoses involving people who are from or have travelled to and from countries with high HIV prevalence is increasing. Some migrant communities are particularly affected and there is concern prevalence could

rise.

Of all new HIV diagnoses attributed to heterosexual intercourse in 2014, 39 per cent involved someone from a high prevalence county. These people were most commonly from Sub-Saharan Africa, South/Central America and the Caribbean or North America (Kirby 2015).

There are also reports of growing HIV diagnoses among 'fly in, fly out' workers. These are people from a range of industries such as resources, who travel to other countries on a regular basis for work. HIV CBOs and researchers are particularly concerned about rising HIV infections among mobile workers based in Western Australia (Brown et al 2014).

Is Australia's HIV epidemic moving to more marginalised communities?

In stakeholder consultations, some HIV CBOs said that Australia's HIV epidemic was at risk of becoming more concentrated in marginalised communities.

HIV transmission is expected to decline significantly among gay men with the expansion of early HIV treatment, PrEP and other prevention tools.

However, there is concern that prevention efforts are not adequately reaching Aboriginal and Torres Strait Islander populations and people who travel to and from high prevalence countries.

These communities are often harder to reach as they may be disengaged, have languages other than English, certain cultural differences, marginalised from mainstream society, or have a lower socio-economic standing.

Many HIV CBOs are expanding their initiatives to expand engagement with these communities. For example, several AIDS Councils also have initiatives to support HIV-positive and gay men from these communities. The National Association of People with HIV/AIDS (NAPWHA) supports a long-existing network for HIV-positive Aboriginal and Torres Strait Islander People. NAPWHA is also supporting research into HIV among people from culturally and linguistically diverse (CALD) backgrounds in Australia. The Sex Workers Outreach Program has initiatives to support sex workers from Asia and other cultural backgrounds.

HIV CBOs recognise it is important to expand engagement now, so they can respond if the epidemic does worsen in these communities.

3.3.3 Other health issues are emerging for communities affected by HIV

HIV does not exist in a vacuum and affected communities face a range of other health concerns. Some are long-existing while others have emerged more recently.

In consultations conducted for this report, several informants emphasised that a key strength of HIV CBOs is their capacity to respond effectively to the health needs of communities.

For example, community based HIV organisations have advocated strongly in support of pre-exposure prophylaxis (PrEP). However, they have insisted that efforts to make PrEP widely accessible must be accompanied with education about using PrEP effectively and managing associated health risks such as STIs (key informant consultations). PrEP is discussed further below.

HIV CBOs have demonstrated a strong ability to provide a range of health services to affected communities. Critical to this has been the ability to partner effectively with mainstream health providers and researchers.

HIV CBOs are distinct from other service providers in their ability to deliver a range of health services, and adapt these services as the health needs of affected communities change. Some of the key health issues of concern for affected communities are summarised in Figure 14 below. Each issue is described in detail in 61Appendix E.

Figure 14 Other health issues for communities affected by HIV

PrEP	 There is growing consensus that PrEP could drastically reduce HIV transmission. Studies in the United States have found that PrEP can lead to a rise in condomless sex, increasing the risk of STIs. HIV CBOs and researchers argue the benefits of PrEP greatly out way this risk. HIV CBOs stress that expanding access to PrEP must be combined with education and guidance on using PrEP and managing health risks (key informant interviews; de Wit et al 2016). Australia is home to some of the largest PrEP trails in the world. HIV CBOs have mobilised and recruited thousands of men to participate in these trials (Swannell 2016).
Sexual health, STIs and blood- borne diseases	 New cases of STIs and blood borne diseases like hepatitis C are rising among some affected communities (de Wit et al 2016; Kirby Institute 2015). A national survey found that many gay and bisexual have a limited understanding of preventing and treating these diseases (de Wit et al 2016). Affected communities have diverse sexual health needs. However, they often struggle to find adequate sexual health information and services (key informant interviews). There is a strong demand for sexual health services that are specifically designed for LGBTI people and other communities (key informant interviews; de Wit et al 2016).
Mental health and alcohol and substance use	 HIV CBOs have expressed growing concern about mental health issues among affected communities. These may be related to a person's HIV status or the specific circumstances of their community. Evidence shows that LGBTI people are at particularly high risk of mental illness and suicide (NSW Mental Health Commission 2014; DHHS 2015). There is growing demand among affected communities for mental health services, which HIV CBOs are responding to. ACON, for example, has LGBTI mental health and ageing services (ACON 2015). Alcohol and substance use are also of concern for affected populations. This can overlap with other risk behaviours, such as condomless sex. Patterns of alcohol and drug use can change rapidly among different communities (Brown et al 2015; Kippax & Stephenson 2016). Throughout Australia's epidemic, HIV CBOs have rapidly identified and responded to these changes with effective and wide-reaching health promotion initiatives (Brown et al 2015; Kippax & Stephenson 2016).
Co-morbidities and aged care	 HIV treatment has greatly improved life expectancy and quality of life for people living with HIV. However, studies show that co-morbidities continue to affect many HIV-positive people. The most common are hepatitis C, pulmonary disease, high blood pressure, high cholesterol and obesity (Weiss et al 2010). Co-morbidities are often neglected with improvements in treatment. HIV CBOS are advocating for more treatment and support services for co-morbidities (key informant interviews). There is also a growing need for aged care services as HIV-positive people live longer. HIV CBOS stress that there is a need to raise HIV-awareness among aged care workers to avoid the risk of stigma and discrimination (key informant interviews).

3.3.4 Non-health issues also have a large impact on the lives of communities affected by HIV

Affected communities face a number of existing and emerging non-health issues that impact on their health and well-being. This includes legal and policy issues, stigma and discrimination and the re-

emergence of politician-led homophobia and transphobia. In consultations for this report, informants reported that community organisations played a key role in addressing the social determinants of health through broader initiative to improve the welfare and well-being of affected communities. The major non-health issues of concern for communities affected by HIV are described below.

Legal and policy issues

Australia has a comparatively strong enabling environment, with some exceptions. There are no laws criminalising same-sex relationships, needle and syringe programs were legalised in most states in the 1980s and there is strong anti-discrimination legislation. However, there are a number of legal and policy challenges remain. The criminalisation of HIV transmission, sex work in some jurisdictions and drug use is hampering the community responses to HIV (Brown et al 2014).

In stakeholder consultations, HIV CBOs expressed concern about the criminalisation of HIV transmission in Australia, rather than the effective use of existing criminal and public safety laws.

The re-emergence of politician-led homophobia and transphobia

Brothels and street-based sex work are still criminalised in many jurisdictions

The decriminalisation of prostitution in Victoria, NSW and other states allowed for "extensive health promotion within the industry, the establishment of health and safety regulations for parlours (brothels), wide scale voluntary testing for HIV and STIs and very high levels of condom use. Success, as measured by the virtual absence of HIV in female sex workers has been extraordinary" (Mindel & Kippax 2013).

However some states are lagging. Brothels and street-based sex work (soliciting in public) are illegal in Western Australia, Tasmania, South Australia, Tasmania and the Northern Territory. This makes sex work far less safe, particularly for migrants. It also makes it much harder to reach sex workers with health promotion initiatives and health services (Scarlett Alliance 2016).

This has been seen in ongoing political debate about same-sex marriage. It is also seen in the hostile reaction to the Safe Schools Coalition Australia⁶ by some politicians and religious organisations. While the majority of Australians support same sex marriage, LGBTI community leaders are seriously concerned that these events will see an increase in homophobia and transphobia and health risks particularly for young LGBTI people.

Stigma and discrimination

Australia has laws and policies that prohibit discrimination based on HIV status. Stigma and discrimination has reduced considerably since the epidemic emerged in the 1980s as a result of awareness raising and education initiatives by HIV CBOs. Outside clinical health settings, people have reported that HIV-related stigma or self-imposed stigma has deterred them from accessing health services or being tested for HIV (Berg *et al* 2013). LGBTI communities, sex workers and drug users also continue to face stigma and discrimination in private and public life. HIV CBOs play an important role in combatting stigma and discrimination through advocacy, campaigns and public education initiatives.

⁶ Safe Schools Coalition Australia offers a suite of free resources and support to equip staff and students at primary and secondary schools in Australia with skills, practical ideas and greater confidence to lead positive change and be safe and inclusive for same sex attracted, intersex and gender diverse students, staff and families. Source: Safe Schools Coalition Australia (2016), http://www.safeschoolscoalition.org.au/what-we-do (accessed 12.5.16)

3.4 How can governments be confident that the community response will continue to be effective?

HIV CBOs have demonstrated a strong capacity to effectively adapt their programs and services in response to changes in Australia's HIV epidemic. This section describes:

- the evidence that community organisations have changed their strategy and service offering to meet changing needs
- the features that enable HIV CBOs to be adaptable and therefore continue to be effective
- the risks and challenges of a community based response
- how community based organisations will ensure treatment as prevention and PrEP are effective and contribute to 'Ending HIV.'

3.4.1 There is strong evidence that AIDS Councils have changed their strategies and will continue to adapt to meet changing needs

HIV CBOs have a strong track record of adaptability. As Australia's epidemic has changed, HIV CBOs have effectively adapted their responses and they are continuing to do so. Table 3 shows how communities have adapted to key changes in the epidemic.

Key changes	How community adapted
Changes in treatment	 Early HIV medications had severe side-affects. They extended life expectancy but often at a great cost to quality of life. HIV CBOs responded with education programs to assist people living with HIV make informed choices about treatment. They also fed back information to health professionals and researchers on the side effects of treatment. When effective HIV treatments became available in the mid-1990s, community organisations successfully adapted their education programs and campaigns. This led to increased awareness of the reduced side-affects and medical benefits of HIV treatments. As treatments improved, HIV CBOs conducted education and campaigns on the benefits of HIV treatments. This contributed to a marked rise in rates of testing and treatment adherence. When treatment as prevention emerged in 2009, HIV CBOs responded with education campaigns on the importance of early treatment. Evaluations show this led affected communities to get tested more frequently, start treatment earlier and adhere better to treatment guidelines (key informant consultations; community organisation program evaluations; Moodie et al 2012).
Changes in testing	 When HIV tests first emerged in the 1980s, HIV CBOs developed and advocated protocols for pre and post-test counselling. As testing and treatment advanced, HIV CBOs adapted their programs and promoted testing. A key example is the Talk, Test, Test, Trust prevention campaign launched by the AIDS Council of NSW in 1996. Evaluations show this campaign was highly effective at increasing testing rates and expanding the use of negotiated safe sex strategies (Mindel & Kippax 2013). HIV CBOs recognised that the inconvenience, cost and medical nature of mainstream health settings, whether real or perceived, was deterrent to HIV testing. They

Table 3: How communities have adapted to changes in Australia's HIV epidemic

Key changes	How community adapted
	 established community testing sites and mobile testing in popular venues such as spas, night clubs and brothels. When rapid testing emerged in the early 2000s, HIV CBOs scaled up their outreach testing and counselling programs. These were largely staffed by volunteers from the community. They responded (Brown et al 2015; Kippax & Stephenson 2016). A survey of gay men found that 73 per cent preferred rapid testing over non-rapid testing and 56 per cent preferred testing in non-healthcare settings. (Yang et al 2014). When treatment as prevention emerged in 2009, HIV CBOs worked with public health officials to adapt their campaigns to emphasise the benefits of early diagnoses. They developed new guidelines on how often affected communities should get tested based on risk behaviours (key informant consultations; community organisation program evaluations; Kippax & Stephenson 2016).
Changes in biomedical prevention to	 HIV CBOs have played a key role raising awareness about PEP. They were among the first to identify and advocate against barriers which deterred people exposed to HIV from accessing PEP – such as the lack of community-friendly places to access PEP and stigma from heath workers when PEP is accessed in mainstream clinical settings. When PrEP studies first emerged in the early 2010s, affected communities looked to HIV CBOs for information and advice. HIV CBOs kept them updated with the latest research and responded as soon as there was robust evidence that PrEP was safe and effective. HIV CBOs have recognised that PrEP will not work without community and peer education. They have also recognised the need for increased education on STIs and linkage to care as PrEP use increases. Therefore they have been developing a range of education and other initiatives focused on PrEP (key informant consultations; community organisation program evaluations; Kippax & Stephenson 2016; Brown et al 2015).
Changes in the behaviours of affected communities	f public health messages of simple condom promotion would not be sufficient. HIV CBOs recognised that gay men were adopting their own strategies to minimise risk
Changes in l and policies	

Key changes	How community adapted
	• When laws and policies have changed, HIV CBOs have rapidly communicated these changes to key populations.
	• For example, when prostitution was decriminalised in New South Wales, community organisations worked with sex workers to assist them build understanding of the new laws and adopt safer practices in their work. They also capitalised on reduced restrictions to expand health promotion services (key informant interviews; community organisation program evaluations; Kippax & Stephenson 2016; NSW Ministry of Health 2016).
	 Internet dating sites and smartphone apps have had a large impact on the sexual practices of many gay and bisexual men.
	• HIV CBOs have used gay male dating websites, escort websites and others to reach out to community members and offer information and services. They have also worked with website owners to add health promotion information to these websites (Race 2015; Kippax and Stephenson 2016).
Changes in technology	• HIV CBOs have started delivering many services online. This allows them to efficiently reach a much larger community (community organisation program evaluations; Kippax & Stephenson 2016).
	• The Sex Worker Outreach Project (SWOP) has been particularly effective at this. Cameron Cox, CEO, SWOP said that internet and smartphone technologies had totally changed the way they deliver many services:
	<i>"Our male project is all online. Our project for private female sex workers is almost entirely online. Our trans project is some street outreach and some home visits, otherwise they drop in or we contact them online."</i>
	 Community organisations have worked closely with epidemiologists to identify new populations affected by HIV. They have often been the first to respond.
Changes in the populations affected by HIV	• HIV CBOs have developed distinct programs for Aboriginal and Torres Strait Islander populations, migrant populations and workers who travel frequently to high prevalence countries. These programs are often run by staff and volunteers from the community (community organisation program evaluations, key informant interviews).
	 Key examples of these programs are discussed in more detail below.

From local to national: community responses to HIV and mobility

From the mid-2000s, the number of migrants from Sub-Saharan Africa living in the state has grown considerably. These communities experienced an epidemic different to the national epidemic. The WA AIDS Council was among the first to identify and reach out to the Sub-Saharan African community. The state Government was able to capitalise on the WA AIDS Council's community embeddedness to fund a rapid response at the community level, which continues today.

The WA AIDS Council drew on this experience to advocate and inform the national response to HIV and mobility issues. In 2013 and 2014, the WA Council partnered with social researchers, public health officials and other HIV CBOs to develop an **HIV and mobility roadmap for action in Australia**. This roadmap outlined a national research and action agenda to address HIV issues for people from high prevalence countries and their partners, travellers and mobile workers (Crawford et al 2014).

The WA AIDS Council was a key instigator of this work and continues to be at the forefront of the response in this area (key informant interviews; Crawford et al 2014).

A long-standing response: community programs for Aboriginal and Torres Strait Islander populations

Since the first phase of the epidemic, HIV CBOs have worked effectively with Aboriginal and Torres Strait Islander populations (Feacham 1995). Research has shown that partnerships between mainstream health services and community controlled HIV and Aboriginal organisations has been particularly effective in the prevention and treatment of HIV, STIs and other health concerns for young Indigenous people (Mooney-Sommers et al 2009).

As incidence has changed, so has the community response. Many HIV CBOs have recruited Indigenous staff and developed services and programs for Indigenous populations. The AIDS Council of NSW, for example, has a dedicated sexual health service for LGBTI Aboriginal and Torres Strait Islander populations (key informant consultations; community organisation program evaluations; ACON 2015).

3.4.2 The inherent features of HIV CBOs will enable them to be adaptable

HIV CBOs have a number of inherent features that enables them to adapt to changes in the epidemic. As a result, they are often able to respond more rapidly and effectively than non-community based NGOs and mainstream health providers. These features are described below.



Community embeddedness

Section 3.2.1 of this report described how community organisations are embedded within affected communities. Peer-reviewed research undertaken for the W3 Project strongly supports the finding that community embeddedness enables HIV CBOs to be adaptable (Brown & Reeders 2016). Key informants interviewed stressed that this was

a key feature that differentiated HIV CBOs from other organisations and enabled them to be adaptable. Being embedded means that community organisations are often the first to identify changes in the epidemic and the first to adapt to these changes. Key examples which have been discussed in previous sections include the rise of incidence among people travelling from high prevalence countries and changing patterns of drug and condom use among gay men.

Community embeddedness has enabled community organisations to maintain a focus on community and social outcomes in response to advances in biomedical prevention and treatment

To be adaptable community organisations need to be deeply connected at the grassroots level with the people affected by HIV. - Key informant consultation

options. According to Kippax and Race (2015), this has been critical for ensuring the response does not become too 'medicalised.' They stress that medical interventions need to be aligned with the needs and interests of affected communities in order to be effective. Otherwise technological potential will not be realised or could lead to harmful and unintended consequences.



Professionalism of staff including a new professional skillset around community engagement

Section 3.2.1 described the expertise and knowledge of HIV CBO. This enables them to engage with community and adapt to change (Brown & Reeders 2016). Community organisations are staffed and led by people who are now predominantly:

- from affected communities
- have strong skills in program administration and advocacy

"

• have a deep epidemiological understanding of the epidemic and medical interventions (key informant consultations; Adam et al 2011).

Of key importance is the expertise of the organisations in applying a community based approach. This has enabled community organisations to involve community members in the design and delivery of new programs (Mannell et al 2014). An example is the Victorian AIDS Councils program for sexually adventurous gay men. In response to rising incidence among this sub-population, rather than be prescriptive, the Victorian AIDS Councils asked them what support and services they needed. They then co-developed the Sexually Adventurous Men program which incorporated prevention and testing strategies that suited the lifestyle and needs of these men. Informants reported the program has led to greater adoption of risk minimisation strategies among this sub-population (key informant consultations).

AIDS Councils have been effective at using their professional skillset and infrastructure to support smaller community organisations representing specific populations. This is particularly important where a population is high risk but lacks professional skills and resources. For example, the AIDS Council of New South Wales (ACON) worked with local sex workers to establish the Sex Worker Outreach Project (SWOP) in 1990. Sex workers identified a need to form their own representative community organisation but lacked the professional capabilities and resources. With support from the Ministry of Health, ACON hosted SWOP in its offices and provided operational and governance until the project team were strong enough to operate independently. Today, SWOP is fully autonomous and the leading provider of outreach services to sex workers in New South Wales. SWOP has been particularly effective at identifying and supporting vulnerable migrant sex workers. Its success is evidenced by the fact that there have been no recorded cases of HIV transmission from sex workers to clients in New South Wales (NSW Health 2016; SWOP 2016).

AIDS Councils across Australia have provided similar professional support to small community groups representing a range of affected populations and sub-populations including:

- drug users
- young affected populations
- migrant populations.

This has enabled a rapid and effective response to specific changes within these communities (community organisation program evaluations; Kippax and Stephenson 2016; ACON 2016; Brown at el 2016).



Extensive networks of community organisations

AIDS Councils and other HIV CBOs do not operate in isolation but as part of broader community networks across the country. These networks are manifest formally through organisations such as AFAO, NAPWHA and the Scarlet Alliance, as well as informally through less visible grassroots networks (Kippax and Stephenson 2016).

These networks are a key feature that enables community organisations to be adaptable because it allows them to:

- identify trends in the epidemic
- mobilise responses from governments, health practitioners, researchers and other actors
- rapidly communicate new information to affected communities across the country and debate its implications

• rapidly implement new programs and services.

National and state level networks provide an efficient and cost-effective mechanism for government and others to interact with affected communities. Large community organisations interviewed for this report said that governments often sought their support to engage with affected communities through their networks.

"We ensure the positive community is aware of what the Commonwealth is doing and vice versa. This should stay. We need to keep up these communication channels.
 Communication between community organisations is essential.
 Key informant consultation

Democratic structures

Community organisations recognise that the affected populations they represent are far from homogenous. They have a diversity of epidemiology, social, health and other characteristics which cannot be addressed through a 'one-size-fits-all' approach. A key strength of community organisations is their ability to represent the diversity of needs. Peer reviewed research and key informants interviewed for this report found that this is critical to being able to adapt effectively to epidemiological, behavioural and other changes among affected populations (Brown & Reeders 2016).

Community organisations have informal and formal governance structures and mechanisms that ensure they are representative. Many community organisations require a certain number of a board and staff positions be reserved for community members. For example, 50 per cent of current board positions for the WA AIDS Council are reserved for members of affected communities and one position is reserved for a person living with HIV. Volunteers deliver a large proportion of outreach work and other services for community organisations and they are almost from affected communities (Feacham 1995).

Communities also have less formal democratic features that evolved organically. For example, many smaller community networks are derived from and almost entirely made up of members of the community, who respond directly to the requests and needs of their peers (key informant interviews).



Capacity to mobilise

HIV CBOs have a strong capacity to rapidly mobilise in response to changes in the epidemic. The features of community organisations allow them to mobilise in a number of ways:

- Their <u>community embeddedness</u> enables them to recruit volunteers from the community and mobilise action within communities and mobilise responses to sensitive issues, such as changes in male sexual practice and drug use.
- Their <u>professional skillsets</u> enable them to mobilise funds and resources quickly, and ensure response are cost-effective.
- Their <u>organisational networks</u> enable them to rapidly mobilise affected communities across the country.
- Their <u>democratic structures</u> enable them to mobilise a representative selection of affected populations, including hard-to-reach and highly vulnerable populations.

A key example of this capacity to mobilise is 'Ending HIV', a nation-wide campaign aimed at virtually eliminating new cases of HIV in Australia by 2020. The campaign focuses on significantly expanding prevention, testing and treatment across the country. It is jointly funded by governments and HIV CBOs. HIV CBOs have played a key role in mobilising affected community member from across the country to take part in the campaign. They have mobilised this response through social media, websites, frontline services delivery and on-the-ground networks. Independent research has found that in New South Wales, the 'Ending HIV' campaign has had an 82 per cent recall among gay men. This is one of the highest recall rates ever recorded for an HIV campaign. The campaign has also contributed to increased rates of testing across the state (ACON 2015; NSW Health 2016).

3.4.3 Despite previous success, there are risks that should be considered for HIV CBOs to continue to be effective and relevant

Australia is recognised internationally for the strength of its community response to HIV. However, the response has not always been effective and the capacity to evolve does not guarantee continued success.

HIV fatigue has hampered the response in the past and needs to be avoided.

The 2002 review of the third National HIV/AIDS Strategy found that HIV CBOs had made an important contribution to the strategy overall. However, it noted that HIV fatigue was impacting on the response:

"Some community participants (involved in the review) claimed that people who have been part of the response since the early years are experiencing a sense of 'exhaustion' and that this is resulting in the disengagement of many gay men from the response. They argued that this trend needs to be reversed as a matter of urgency, to preserve gay men's central place in the response" (Moodie et al, 2002).

HIV fatigue was a common experience in many developed countries at the time, particularly as HIV treatments meant HIV was no longer a death sentence. However, in Australia and elsewhere, community organisations have been able to re-energise their response and capitalise on new advances such as treatment as prevention and PrEP to mobilise their communities (Brown et al 2015).

HIV CBOs have achieved strong outcomes but success is not automatic and effort to continuously evolve is required.

The 2002 review also found that a small number of organisations had lost focus on their mission which negatively impacted on their contribution to the response. This was partly due to being preoccupied with funding and position in the sector. They acknowledged the lack of evaluative data to measure the effectiveness of the strategy and recommended a greater focus on evaluation (Moodie et al 2012).

Bernard et al (2008) and some informants interviewed for this report expressed a similar sentiment.

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They emphasised Australia has had one of the most successful community responses globally, but that a small number of community organisations have not

"By becoming integrated into the health delivery system, CSOs (civil society organisations) risk losing their objectivity, thereby weakening the overall response. **CSOs must continue to play the role of societal watchdog**, being careful not to relieve governments of their duty to provide equitable and quality health services. Securing adequate resources while maintaining independent identities, ensuring quality interventions and meaningful involvement of communities, and addressing weak governance, and financial management structures while improving their own capacities to program funds to respond to clients changing needs are some of the dilemmas continue to affect many CSOs." ??

performed as well as others. They acknowledged this often reflected a lack of funding and loss of focus across the whole HIV partnership (informant consultations; Bernard et al 2008). Informants emphasised that all actors in Australia's HIV partnership need to maintain a strong focus on performance to ensure the response continues to be relevant and effective.

Competition for government funding is growing and corporate knowledge of HIV is slowly falling.

Government funding is becoming more competitive and increasingly tied to performance. Many leaders in the HIV CBOs support this but are concerned that, at the same time, knowledge inside government is diminishing. The corporate experience in HIV is reducing as public health officials involved in the early stages of the response retire or move to other areas. These trends are common across all jurisdictions in Australia as well as in other countries.

"

These challenges pose a dual dilemma for HIV CBOs. Community organisations need to place a greater emphasis on evaluation, demonstrating the effectiveness of their programs. They also need to maintain advocacy efforts to ensure government funding is directed to key needs within the community.

Community organisations need more sophisticated arguments to the health public sector to show that quantifiable measures of success are not the only form of evidence on HIV. - Key informant consultation

"

Informants interviewed for this report acknowledged these challenges and identified a number of imperatives for HIV CBOs, including the following:

- HIV CBOs need to re-examine their activities to ensure alignment with their visions
- They need to demonstrate to governments that HIV-positive people and other affected communities need to be involved in the roadmap to 'Ending HIV'.
- Like all funded organisations, they need continuously to rationalise and consolidate their services to be sustainable.
- They need to sustain efforts to secure funding from governments.
- They need to develop sophisticated arguments to show that quantifiable measures alone are not sufficient to measure the effectiveness of the community response. This may include the development of more relevant and useful quantitative and qualitative indicators.
- Some organisations may need to re-constitute themselves to be broader health-based organisations, responsive to the interacting health needs of their communities.

The experience of the response to HIV has lessons that are applicable across health promotion including: the need to harness community mobilisation and action; sustain participation and leadership across the partnership; commit to social and political structural approaches; and build and use evidence from multiple sources to continuously adapt and evolve."
 Brown et al 2015

3.4.4 Community based education and health promotion campaigns will ensure treatment as prevention and PrEP are effective.

There is growing consensus that treatment as prevention, PrEP and other biomedical advances mean it is now possible to eliminate almost all new HIV infections (UNAIDS 2014). Australia's Seventh National HIV Strategy sets the ambitious target to 'end new HIV infections in Australia by 2020 – with a 50 per cent reduction by 2017.' The NSW HIV Strategy 2016 – 2020 similarly set a goal to 'virtually eliminate HIV transmission in NSW by 2020' (NSW Health 2016). This reflects an international movement led by UNAIDS to end the AIDS epidemic by 2030 (UNAIDS 2014).

However, behavioural studies indicate that treatment as prevention and PrEP are also associated with a rise in risk behaviours such as condomless sex among gay men. This potentially undermines the effectiveness of PrEP as a tool to prevent new infections (Holt et al 2016). Holt et al (2016) conclude that treatment as prevention and PrEP must be accompanied by other interventions including education programs on condom use, if they are to achieve a substantial reduction in new HIV infections in Australia (Holt et al 2016). Kippax and Stephenson (2016) similarly argue that biomedical prevention technologies cannot be relied upon alone. They must be combined with a strong focus on education, campaigns and other initiatives that address the social practices of affected communities (Kippax & Stephenson 2016).

Holt et al (2016) have analysed behavioural surveillance systems and other data to develop two future scenarios for rates of HIV transmission in Australia. Under each scenario, PrEP uptake gradually increases to 15 per cent of men with casual partners in 2020. These two scenarios are depicted below in Figure 15. The first is an ideal scenario in which there is a decrease in the number of men who engage in high risk condomless sex who are not on PrEP. The second is a worst case scenario in which condom use declines as PrEP use increases and the number of high-risk men not on PrEP stays the same. These scenarios illustrate the importance of combining PrEP with other interventions that address risk behaviours (Holt et al 2016).

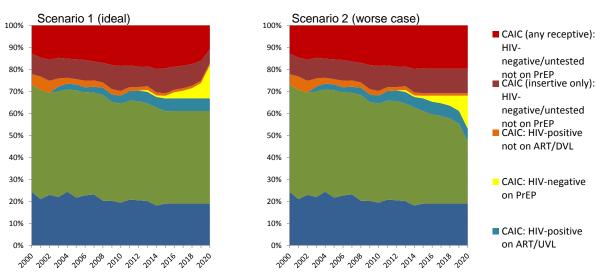


Figure 15 Scenarios depicting imagined impact of PrEP use on sexual practices with casual male partners, 2000-2020

Source: Holt et al 2016. CAIC = condomless anal intercourse with casual partners. UVL = undetectable viral load.

Community based organisations currently deliver a large proportion of education and health promotion, prevention and testing initiatives in Australia. It is critical that this work continues alongside biomedical prevention interventions if Australia is to achieve a major and sustained reduction in HIV transmission (Holt at al 2016; Kippax & Stephenson; 2016).

Appendix A Data collection plan

This appendix provides the data collection plan, which maps the key lines of enquiry and research questions to specific data sources.

	Research question			Data collection method		
Key line of enquiry		Research sub-question	Document review	Literature scan	Stakeholder	
1. What is the evidence that the	1.1 What is community	How is community control defined in the literature?				
community controlled HIV	control (and not CC) in HIV?	What are the key elements of community control in the HIV context?				
response has achieved better results (than	1.2 What evidence exists	What cohort evidence exists?				
sole reliance on non- community controlled	that compares the results achieved (CC vs non-CC)?	What evaluation evidence exists?				
responses) in the epidemic to date?	1.3 What evidence exists that demonstrates community control was an essential part of an effective overall system response?	What is the evidence that shows community control was essential to effective system wide responses?				
2. What are	2.1 How do the claimed features of the community based organisations contribute to the effectiveness of the response? (partnerships, trust and credibility, knowledge and expertise)	How valuable is the AIDS Councils understanding of, and embeddedness within communities?				
the features of the community based response that explain this difference?		How valuable is the AIDS Councils expertise, knowledge and intellectual property?				
		How valuable is the AIDS Councils credibility with mainstream providers (based on authority within the community)?				

		How valuable is the AIDS Councils expertise in education (including media) and service delivery?		
	2.2 What other features are described in the evidence?	What other features unique to the community based response contributed to the effectiveness of the community based response?		
		How valuable have any other identified features been in explaining the difference between community based and non-community based responses?		
		What are the costs (direct and indirect) associated with an AIDS Council education- community campaign		
	2.3 What are the cost- benefit advantages (or disadvantages) in the community controlled response?	What are the costs (direct and indirect) associated with an AIDS Council testing program?		
		What is the impact/reach (community member contacts, referrals, outcomes)?		
		What are comparative costs and impact/reach figures for non-community controlled activities?		
	3.1 How has the HIV epidemic changed over time?	What have been the changes in incidence?		
		What have been the changes in prevalence?		
3. How has		What have been the changes in survival?		
the epidemic and the health needs of the communities changed?		What have been the changes in risk behaviour?		
		What have been the changes in treatment?		
	3.2 What are the other	What are the other health needs that disproportionally affect the AIDS Council's communities?		
	health needs affecting AIDS council's communities?	How does the work of AIDS Councils responding to these other needs assist in the effectiveness of AIDS Council responses to HIV?		

4. How can	4.1 What are the costs and potential downfalls of community control			
governments be confident that the community based response will	4.1 What evidence is there that AIDS councils have changed their strategy and service offering to meet changing needs?	How have AIDS Councils adapted their strategy and service offering over time?		
be effective?	4.2 What features enable community based	What is it about governance that makes community based organisations adaptable?		
	organisations to be adaptable (to continue to be effective)?	What is it about other features that make community based organisations adaptable?		

Appendix B List of stakeholders consulted

This appendix provides the stakeholders who Nous consulted as part of the data collection for this project.

Stakeholder group	Stakeholders
AIDS Councils	 AIDS Council of New South Wales (ACON) Victorian AIDS Council (VAC) Western Australian AIDS Council (WAAC) AIDS Action Council ACT
Government	 Dr Kerry Chant, Chief Health Officer, NSW Health
Researchers	 Kane Race, University of Sydney Niamh Stephenson, University of New South Wales Bridge Haire, The Kirby Institute Garrett Prestage, The Kirby Institute Martin Holt, University of New South Wales Sue Kippax, University of New South Wales Gary Dowsett, La Trobe University Graham Brown, La Trobe University
Other stakeholders	• Bill Whittaker
Other HIV CBOs	 Australian Injecting & Illicit Drug Users League (AIVL), Craig Cooper Sex Workers Outreach Program (SWOP), Cameron Cox National Association of People with HIV Australia (NAPWHA), Aaron Cogle

Appendix C Case studies

This appendix provides three case studies of selected AIDS Council services and programs that demonstrate the value of the community based response. The case studies outline the following programs:

- the Sexually Adventurous Men's (SAM) Project developed by the Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC), People Living with HIV/AIDS Victoria (PLWHA), and the Australian Research Centre in Sex, Health and Society (ARCSHS)⁷
- Talk, Test, Test, Trust developed by ACON⁸
- M Clinic developed by the Western Australian AIDS Council (WAC)⁹

⁷ Information in the SAM case study was sourced from: 1) Living Positive Victoria 2015, 'SAM (Sexually Adventurous Men) Project', Date accessed: 26 May 2016. Available at: <u>http://www.livingpositivevictoria.org.au/programs/sexually-adventurous-men-project</u> 2) Victoria AIDS Council 2011, 'Down an' Dirty website launch', Date accessed: 26 May 2016. Available at: <u>http://www.vac.org.au/down-an%E2%80%99-dirty-website-launch</u> 3) Spina, A, Brown, G & Johnston K 2012, The Sexually Adventurous (SAM) Project Evaluation Report, publisher unknown, s.l.

⁸ Information in the Talk, Test, Test, Trust case study was sourced from: O'Leary A 2007, 'Beyond condoms: alternative approaches to HIV prevention', Springer Science and Business Media; s.l.

⁹ Information in the M Clinic case study was sourced from: Western Australia AIDS Council 2015, 'M Clinic', Date accessed: 26 May 2016. Available at: <u>http://www.waaids.com/what-we-do/m-clinic.html</u>

	Sexually Adventurous Men Project
Jurisdiction	Victoria
Service type	Community development and engagement
Summary	The Sexually Adventurous Men (SAM) Project consists of community development and engagement activities. It aims to increase the visibility of safe sex culture as defined by sexually adventurous communities. It has a particular focus on reducing HIV transmission.
Detailed description	Research suggests men who may be more sexually adventurous may be at greater risk of HIV infection. It also suggests sexually adventurous men are more likely to use risk minimisation strategies as alternatives to condom use, such as serosorting, strategic positioning and use of viral load and other clinical markers.
	In recognition of this, the Victorian AIDS Council/Gay Men's Health Centre (VAC/GMHC), People Living with HIV/AIDS Victoria (PLWHA), and the Australian Research Centre in Sex, Health and Society (ARCSHS) developed the SAM Project.
	The SAM Project is comprised of many different initiatives. This includes: partnerships with groups, venues and parties to promote safe sex information; events and launches to raise awareness and disseminate safe sex messages; production and distribution of safe sex posters and other educational resources and promotional materials; and development and maintenance of educational and awareness raising websites, videos and other material.
	It is supposed to be driven, guided and delivered by sexually adventurous men for sexually adventurous men.
	The SAM Project has achieved broad reach into the target community of sexually adventurous men in Victoria. Through the SAM Project, VAC/GMHC distributed almost 1,300 posters at 33 events, 11,000 resources at 60 events and almost 50,000 safe packs at 43 events.
Outcomes	The SAM Project achieved extensive reach due to the effective partnership approach. The SAM Project involved twelve partnerships between community organisations, community members and gay and party venues. The SAM Project has been positively received by the target community, who found the materials engaging, innovative, informative and appropriate.
Advantages of the community based approach	The SAM Project was able to achieve extensive reach into the SAM community as the organisations that delivered it are embedded with the SAM community and have a deep understanding of the context and issues. This means the design and implementation of the SAM Project met the needs of the community and was an acceptable and meaningful method of health promotion.
	VAC, GMHC and PLWHA are expert at service delivery with the target community , as demonstrated through their proven track record with similar programs (i.e. health promotion activities within LGBTI and other communities).

"It's been designed by and includes men like in our community. And talks about things that I and my friends will discuss. Its got people we know, like members of our community."

(participant of focus group conducted as part of the 2012 SAM Evaluation by Spina, Brown and Johnston)

Talk, Test, Test, Trust

Jurisdiction	New South Wales
Service type	Education campaign
Summary	Talk, Test, Test, Trust is an education campaign targeted at gay men in relationships. It aims to provide realistic educational material to gay men to address unprotected anal intercourse within gay relationships.
	The cumulative impact of the HIV epidemic meant gay men in relationships needed to talk about their HIV status in order to safely stop using condoms. ACON designed an education campaign – 'Talk, Test, Test, Trust' – to advise gay men on how to negotiate safe sex with their partner. It provides a guide for men on how to safely stop using confirms within a relationship.
Detailed description	The 'Talk, Test' part of the slogan refers to the need for both men to get tested and be honest about their results. The 'Test, Trust' part of the slogan refers to the need for both men to get tested again three months later, before they stop using condoms.
	ACON provided additional advice in campaign material on a variety of ways to talk about getting test and test results.
Outcomes	An evaluation found the campaign added to gay men's understanding of how to safely negotiate unprotected sex within their relationships. The campaign achieved broad reach into the target community. According to one evaluation, 80% of the target group surveyed were aware of and understood the campaign.
Advantages of the community based approach	ACON's knowledge of the gay community and connections with community venues supported increased the reach of the campaign within the target population. ACON was able to widely distribute campaign materials in community venues across NSW. The community's trust in and respect of ACON as an organisation and its purpose meant those who viewed the campaign was more meaningful and resonated more strongly within the gay community (compared with campaigns delivered by other service providers not embedded within the community).
"The issue of condom use within gay relationships is a complex one, and it is certainly a challenge to convert this into an easily understood campaign capable of attracting the attention of gay menACON has succeeded in doing this very well"	

this very well."

Evaluation of the TTTT HIV/AIDS Education Campaign (Mackie, B 1996)

	M Clinic
Jurisdiction	Western Australia
Service type	HIV and sexually transmitted infection (STI) screening
Summary	M Clinic provides free, confidential, non-judgemental STI testing & treatment and rapid HIV testing for men who have sex with men.
Detailed description	 M Clinic is a health clinic in Peth, Western Australia that caters exclusively to men who have sex with men. M Clinic uses a peer based model that combines clinical service provision with health promotion. It provides rapid HIV testing, a full range of STI testing and treatment, and vaccinations for hepatitis A and B and human papillomavirus. M Clinic also undertakes in health promotion activities that aim at reducing the transmission of HIV and STIs. M Clinic is designed, implemented and delivered by the Western Australian AIDS Council (WAC).
Outcomes	 Between 2012 and 2015, M Clinic diagnosed 25% of all HIV cases diagnosed amongst gay and bisexual men in Western Australia. Over this period, the number of HIV tests conducted at M Clinic each year increased by 84% (from 1,337 to 2,472). Over 4,000 patients are registered at M Clinic. Over 600 new patients access the clinic each year, with 18% of having not been tested previously. New patients attending the service as a result of a word of mouth referral increased from 31% to 53%. Over 70% of M Clinic patients self-assessed as being at high risk of acquiring HIV (in 2015).
Advantages of the community based approach	M Clinic has achieved significant reach within social and sexual networks. M Clinic patients are increasingly likely to know other M Clinic patients socially and sexually. The increasing rate of word of mouth referral suggests M Clinic is embedded and connected to the community of gay and bisexual men. M Clinic is an efficient and effective vehicle around which to centre the establishment of PrEP in WA, as it becomes increasingly embedded and connected to the community it serves.

"Whereas the clinic was originally established primarily to increase sexual health screening capacity for gay and bisexual men in WA, growing scale and market share presents unique opportunities for health promotion through social media and peer education to a highly engaged audience"

Appendix D Inserts for tender documents

This appendix provides a summary of this report that AFAO and AIDS Councils can use in future tender documents.

The value of community control in Australia's HIV response: Summary of Nous Group Findings

Nous Group was asked to conduct an independent analysis of evidence on community responses to HIV

In early 2016 AFAO and the AIDS Councils commissioned independent consultants, the Nous Group (Nous) to assess the evidence for the HIV sector's belief that the success of the Australian HIV story in the past and into the future relies on a strong community based response, at the centre of the Australian response.

AFAO and Australia's State and Territory AIDS Councils were keen to have an objective and documented account of the strength and continuing salience of their core value proposition in this changing environment. The epidemic is undergoing another major change, with the implications of treatment based prevention coming into focus. Much of the familiarity of the Australian HIV history within public health and funding organisations has fallen away.

In addition, government departments are tendering many more public health functions competitively and there are non-community embedded non-government organisations (NGOs) now claiming an ability to work with HIV affected communities, including the lesbian, gay, bisexual, transgender and intersex (LGBTI) communities.

Nous' research methodology was structured and robust

Nous used four key lines of enquiry (KLEs) to structure data collection and analysis activities. These were:

- 1. What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?
- 2. What are the features of the community based HIV response that explains any difference?
- 3. How has the epidemic and the health needs of communities changed?
- 4. How can governments be confident that the community based response will continue to be effective?

Nous focused on identifying existing evidence that described the features and value of community based responses to the HIV epidemic in Australia. Nous used complementary data collection methods to source a breadth of information and data and triangulate findings (where possible). The data collection methods included:

- a review of AFAO and AIDS Council documentation
- a literature scan of peer reviewed and grey literature

• interviews with AIDS Councils and other key informants (other HIV CBOs, government and researchers).

Nous found strong evidence that community based organisations were and will continue to be critical to the success of Australia's ongoing HIV response

Nous set a high standard of assurance for its test of the HIV sector's hypothesis. To be prepared to endorse the proposition, the Nous team sought strong evidence for each of the four Key Lines of Enquiry. That is, there not only needed to be strong evidence that the community based response had been essential in Australia's success to date. The Nous team also sought strong evidence to explain exactly why the features of the response to date had placed the community based sector so centrally in the response.

In addition, the Nous team sought a clear and evidence based understanding of changes in the epidemic, through its key transformational changes, including the current impact of biomedical treatments as a powerful form of prevention and intervention. The Nous team's test was to understand the changes in the epidemic, in order to understand the basis of the continuing claim for salience from the community based sector.

Finally, the Nous team explored evidence to support an assurance to government (and the sector's own communities) that the community based HIV sector will remain agile and relevant to the evolution in the HIV epidemic in Australia and to other health issues confronting its communities.

On all of these measures, against each of these tests, the Nous team was satisfied that the evidence examined did indeed support each of the propositions needed to support the overall hypothesis. Nous is confident that HIV community based organisations have played a key role in a world leading HIV epidemic response and are well placed to continue this success.

At the core of this assurance is the ability of these community embedded organisations to know the issues and trends within the affected communities; to be able to talk frankly and effectively to members of the affected communities who would not necessarily engage with mainstream health services; and to access the substantial professional expertise they have also gained to form strong partnerships with mainstream health services.

Below is a summary of the Nous team's findings.

KLE 1: What is the evidence that the community controlled HIV response has achieved better results (than sole reliance on non-community controlled responses) in the epidemic to date?			
Finding	Description		
Community based HIV organisations are part of a strong partnership network between government, health practitioners, researchers and HIV affected communities.	 There is no standard definition for 'community control' in existing literature. However, key elements define community based responses, elements which have enabled these organisations to play a pivotal role in the overall response to HIV in Australia. Community based responses are: initiated, designed and implemented by the community responsive to the evolving needs of the community often enacted through partnership with mainstream organisations dependent on community for authority. 		

Table 4: Summary of findings

There is strong evidence that compares the results achieved by community based HIV organisations to non-community organisations.	 Community based responses have been more effective than traditional public health approaches. Case studies can be used to demonstrate their comparative effectiveness, such as: Australia's success in responding to HIV versus other countries that did not use a community led response (and were less successful). The increased infection rates in Queensland and Victoria when the HIV partnership between government and supporting communities broke down. 	
There is evidence that community based HIV/AIDS organisations were key contributors to the overall response.	 Australia responded to HIV through a partnership model, which is widely credited as the reason for Australia's success in responding to the epidemic. Community based HIV/AIDS organisations play a distinct role in the overall partnership response. 	
KLE2: What are the features of the community based HIV response that explains this difference?		
Finding	Description	
HIV CBOs have unique	 HIV CBOs are embedded within their affected communities, which supports a deep understanding of the contemporary issues and effective solutions. A number of examples demonstrated how HIV CBOs were aware of behavioural and athen shares are in the UV and emission of a black of the target demonstrated how HIV CBOS were aware of behavioural and athen shares are in the UV and emission of a black of the target demonstrated how HIV CBOS were aware of behavioural and a black of the target demonstrated how HIV CBOS were aware of target demonstrated how HIV CBOS were aware of target demonstrated how HIV CBOS were aware of target demonstrated how HIV CBOS were aware demonstrate	
features that enable them to provide trusted, relevant and efficient services and programs.	 other changes in the HIV epidemic and able effectively to address these changes arising ahead of other health organisations. HIV CBOs have attained unusually high levels of professional knowledge in specific domains, which informs successful service delivery. 	
	 HIV CBOs typically have high credibility with mainstream service providers, government agencies, researchers and other stakeholders based on their professionalism and authority within the affected communities. 	
The combined value of HIV CBOs unique features place them in an advantageous position to respond to the HIV epidemic and other emerging health threats.	 HIV CBOs have permissions that many other public service organisations do not have. HIV CBOs work in partnership and collaboration with a broad range of organisations. HIV CBOs are recognised as leaders within their respective fields of expertise. 	
Programs and services delivered by HIV CBOs are cost effective.	• Overall, existing evidence shows AIDS Councils services and programs are cost effective when compared to other approaches. This is due to: their access to community intelligence and cultural knowledge; the cost-benefits of volunteers; greater reach; self-generated funds; and efficient data and information collection.	
KLE3: How has the epidemic and the health needs of communities changed?		
Finding	Description	
Australia's HIV epidemic has been characterised by a strong community response and can be historically grouped into three phases.	 There have been three phases in Australia's epidemic. Each is marked by significant changes in prevention and treatment options. In each phase, HIV CBOs have led efforts to respond to the changing needs and requirements of communities affected by HIV. 	
New communities of people affected by HIV are emerging.	 New diagnoses have been rising among some Aboriginal and Torres Strait Islander communities New diagnoses have been rising among people who travel to and come from countries of high HIV prevalence 	
New health threats are emerging in HIV affected communities.	 HIV interacts with numerous other health issues and affected communities increasingly focus on a range of these other health concerns. These include: STIs, 	

	hepatitis and sexual health; mental health and alcohol and drug use; and comorbidities and aged care.
Non-health issues also have a large impact on the lives of communities affected by HIV.	 These include: legal and policy issues; the re-emergence of politician led homophobia; and stigma and discrimination.
KLE4: How can governments be confident that the community based response will continue to be effective?	
Finding	Description
There is strong evidence that AIDS Councils have changed their strategies and will continue to adapt to meet changing needs.	 HIV CBOs have a strong track record of adaptability. As Australia's epidemic has changed, HIV CBOs have effectively adapted their responses and they are continuing to do so.
The inherent features of HIV CBOs will enable them to be adaptable.	 These inherent features are community embeddedness, professionalism of staff, extensive networks, democratic structures and the capacity to mobilise.

In summary, given the findings of this report, AFAO and Australia's AIDS Councils can effectively demonstrate that:

- they operate differently from other organisations who work in the HIV sector and this results in in a more effective response to HIV
- there are particular features that characterise how they operate that allow them to successfully
 engage with communities.

How are AIDS Councils different from other organisations that work in the HIV sector?

The key differentiating factor of AIDS Councils and other HIV CBOs is that, as organisations, they understand and are embedded in HIV affected communities. This allows them to design and develop more meaningful and successful services and programs targeted at these communities. Other organisations might deliver services to HIV affected communities however, their understanding of community needs and issues is not as strong, and thus their services not as tailored to or meaningful for the community. In addition, HIV affected communities have had a long-standing relationship with AFAO and AIDS Councils, which has fostered a sense of trust and respect.

This respectful, trust-based relationship supports the ongoing link between AIDS Councils and affected communities, which has and continues to be a critical part of the overall health system response to HIV. Without AFAO and AIDS Councils' links into affected communities, our understanding of the epidemiology of the virus and social behaviours of communities would not be as strong. In turn, the response to epidemiological changes would not be as rapid or meaningful (as evidenced in international jurisdictions which did not leverage the community response).

Another key differentiating factor of AFAO and Australia's AIDS Councils is their strong relationships and networks with mainstream providers, government agencies, researchers and other stakeholders. Throughout their history, they have effectively worked alongside and in partnership with mainstream providers, governments and academics to respond to the epidemic. Their ability to establish and maintain these effective working relationships to enact a 'partnership response' is consistently cited as a critical success factor in Australia's HIV response.

What features of AIDS Councils allow them to successfully engage with communities?

AIDS Councils possess a number of features that allow them to successfully engage with affected communities. These features are unique to AFAO and AIDS Councils. They are:

- Embeddedness in and understanding of affected communities. AIDS Councils are embedded within their affected communities, which supports a deep understanding of contemporary issues and effective solutions. Due to this, AFAO and AIDS Councils provide targeted, acceptable and meaningful health promotion and prevention services. This embeddedness also means AFAO and AIDS Councils are able to respond more rapidly than governments and mainstream health services to the changing needs of their communities.
- Knowledge and expertise in service delivery. AIDS Councils have attained unusually high levels of professional knowledge in specific domains, which informs successful service delivery. The expertise and knowledge of AIDS Councils workforces supports them as leaders in their communities and the sector more broadly. This individual and organisational knowledge and expertise means AIDS Councils are expert at the delivery of successful services and education and media campaigns.
- **Credibility with mainstream providers**. AIDS Councils typically have high credibility with mainstream service providers based on their authority within the affected communities. AIDS Councils' strong credibility with these other stakeholders who work in the HIV sector also contributes to the ongoing partnership, as others recognise the benefits AIDS Councils bring to the partnership approach.

Combined, these features mean AFAO and Australia's AIDS Councils are distinctly positioned to interact with and deliver services within HIV affected communities across Australia. AIDS Councils can efficiently assess changes in the HIV epidemic and social behaviours and effectively respond with acceptable, targeted programs, services and campaigns. This is a comparative advantage over other non-government, government and private sector providers, who rely on AIDS Councils for links into HIV affected communities.

In conclusion, the evidence supports AFAO and the AIDS Councils' claim that they have a unique and strong relationship with HIV affected communities

In conclusion, the Nous team would reinforce the claim of AFAO and Australia's AIDS Councils that they have a specific and strong relationship with the HIV affected communities. For those interventions that require mobilisation of those communities, or groups within them, it is pragmatic and evidence based to utilise the capability of these organisations.

Nous would also echo the view put to our team by AFAO and the AIDS Councils that they understand the motive to broaden engagement of other NGOs. Indeed, other NGOs becoming more supportive and effective, for example, with LGBTI, sex worker or drug user communities is a welcome development for a range of service offerings. However, for public health measures which require community action, especially relating to the most intimate of behaviours that are central to community identity, the evidence is strong that genuine community based organisations have a distinctive position.

Selected key findings for tender documents



HIV community-based organisation (HIV CBOs) have unique features that differentiate them from other non-government organisations¹⁰ AFAO and Australia's AIDS Councils are embedded within their communities. This allows them to provide more targeted and acceptable campaigns and services, respond

¹⁰ See page 5 for references and further information

more quickly to change in the HIV epidemic, foster a greater trust in their organisations (within their communities) and provide services other organisations cannot provide due to sensitivities.

AIDS Councils and other HIV CBOs have a high level professional knowledge and expertise. This includes a deep epidemiological understanding, longitudinal knowledge of the epidemic, health and social programing expertise, health promotion expertise and expertise from networks between HIV CBOs.

AIDS Councils and other HIV CBOs typically have high credibility with governments and mainstream service providers, based on their professional expertise and authority within affected communities. This is evidenced by their central role in the health system response to HIV for the past three decades.

Collectively, these features enable HIV CBOs to be effective and differentiate them from other organisations.



There are specific elements of the community-based response that have been critical to the successful HIV response in Australia¹¹

Community control is essential to the success of AFAO and Australia's AIDS Councils. Community based responses are initiated, designed and implemented by members of the target community. They are responsive to the evolving needs of community and

dependent on community for their authority. They are often enacted through a partnership with government, health practitioners, researchers and HIV affected communities. Collectively, these elements have been critical to the success of Australia's response to HIV over the past three decades. It is these elements that distinguish the response of AIDS Councils and other HIV CBOs from non-community controlled responses.



Community based responses to HIV have been more effective than traditional health approaches¹²

Evaluations of community based HIV programs show they are cost effective, well targeted and achieve significant behaviour change. AIDS Councils and other HIV CBOs are more effective at accessing hard-to-reach populations than non-community

controlled organisations, and are able to use their networks to rapidly and efficiently reach large proportions of the community. They are also more effective at building credibility and trust with communities, resulting in greater behavioural change.



Community based programs are cost-effective¹³

Evaluations show that programs and services by AIDS Councils and other HIV CBOs are cost effective compared to other approaches. This is due to their access to community intelligence and cultural knowledge, the cost-benefits of volunteers, greater reach due to sites of intervention and peer-based workforce, application of self-generated funds

to augment government funded service delivery, and the efficiency of data and information generated through community connectedness.

Other services providers would require additional costs to achieve the same reach that HIV CBOs do because they lack the community networks and are not embedded within communities.

¹¹ See page 13 for references and further information

¹² See page 15 for references and further information

¹³ See page 28 for references and further information



A high quality HIV partnership has been a critical feature of the successful HIV response in Australia¹⁴

AFAO and Australia's AIDS Councils have played a vitally important role in the HIV partnership between governments, clinicians, academics and other HIV CBOs. They have provided the link with affected communities to ensure the response has been

accessible and informed by epidemiological trends, community attitudes and behaviours. Australia's HIV partnership model is widely credited as the reason for Australia's success in responding to the epidemic compared to other developed countries. There is clear evidence that within Australia, states with high quality and well-funded partnerships, such as New South Wales, have achieved far higher reductions in new infections than states with poorly functioning partnerships.



Community responses holistically address the multitude of health and non-health issues that impact affected communities and the epidemic more broadly¹⁵

AFAO and Australia's AIDS Councils have specific services and programs that respond to other health issues, such as sexually transmissible infections, co-morbidities, alcohol and substance use, mental health and aged care. They also support strong campaigns

and advocacy targeting non-health issues, such as legal and policy issues, and stigma and discrimination.



AFAO and Australia's AIDS Councils have a strong track record of adaptability and distinct features that will enable them to continue to $adapt^{16}$

Throughout the epidemic, AFAO and Australia's AIDS Councils have adapted their strategies and programs in response to changes, such as advances in prevention, testing and treatment, changes in the behaviours of affected communities, changes in

laws and policies and the emergence of new populations affected by HIV. AFAO and Australia's AIDS Councils have inherent features that enable them to be adaptable, including community embeddedness, professionalism of staff and skillset around community engagement, extensive networks of community organisations, democratic structures and the capacity to rapidly mobilise responses.



AFAO and Australia's AIDS Councils are critical to ensuring treatment and prevention and PrEP are effective and 'ending HIV'¹⁷

Behavioural studies show advances in biomedical prevention and treatment technologies must be accompanied by education, campaigns and other initiatives to be effective. AFAO and Australia's AIDS Councils currently deliver a large proportion of

education and health promotion, prevention and testing initiatives in Australia. It is critical that this work continues alongside biomedical prevention interventions if Australia is to achieve a major and sustained reduction in HIV transmission.

¹⁴ See page 6 for references and further information

¹⁵ See pages 37-38 for references and further information

¹⁶ See page 40 for references and further information

¹⁷ See page 48 for references and further information

Appendix E Other health issues for communities affected by HIV

E.1 PrEP and associated health issues

PrEP is a once-a-day pill that can be taken by HIV-negative people to prevent infection of HIV. It is designed for high-risk populations such as gay men who are highly sexually active. The drug marketed for PrEP, *Truvada* is not yet subsidised in Australia and costs around \$9,000 to purchase. However, Australia has one of the highest numbers of large-scale PrEP trials in the world. HIV CBOs have recruited thousands of gay and bisexual men to participate in these trials (Swannell 2016).

There is growing consensus in Australia and overseas that PrEP has the potential to dramatically reduce HIV transmission - particularly among gay men. According to one key informant, "PrEP is a game changer for gay men". There is also growing interest in PrEP among at risk populations. The number of HIV-negative and untested gay men who said they were willing to use PrEP grew by 32 per cent between 2013 and 2015 (de Wit et al 2016).

Interest in PrEP is highest among gay men who are occasionally having condomless sex which means that it offers opportunities for an increased focus on STIs.

HIV CBOs are advocating for an increase in the accessibility and affordability of PrEP and have begun efforts to mobilising high risk communities around PrEP. They have also stressed that the introduction of PrEP needs to be combined with the provision of guidance and advice to targeted populations to inform, support and maintain their decision making regarding their use of PrEP. This is critical to mitigate the risk that poor adherence practices or diminishing other health protective behaviour undermines the potentially powerful gains from access to PrEP (key informant consultations).

E.2 Sexual health, STIs and blood-borne diseases

STIs are a public health concern and also increase the risk of HIV transmission. The advent of alternative risk minimisation strategies among gay men, such as PrEP and negotiated safe sex strategies may increase risk of contracting an STI. Surveys show that knowledge of STIs among affected communities is generally high but many people do not get tested sufficiently regularly (de Wit et al 2016).

Gay men, particularly those who have HIV or inject drugs are at greater risk of hepatitis C. A national survey of gay and bisexual men found testing for hepatitis C was common but that many men only had a moderate understanding of hepatitis C and its treatment. The survey also showed that a majority of respondents wanted gay-specific hepatitis C services (de Wit et al 2016).

Affected communities are diverse and have different sexual health needs, both within and between their communities. They also have different levels of access to sexual health information and services.

E.3 Mental health and alcohol and substance use

Mental health issues and alcohol and substance use can have serious health impacts. They can also impact on HIV treatment adherence and engagement in risk behaviours. LGBTI communities are

identified in numerous mental health strategies as having particularly high risk of mental illnesses and suicide (NSW Mental Health Commission, 2014; DHHS, 2015).

Affected communities face specific mental health concerns that may be related to HIV or specific circumstances of their community. There is increasing demand for targeted mental health services for these communities. Some HIV CBOs are responding with targeted programs. For example, ACON also provides mental health and ageing services and support to the LGBTI community, including people living with HIV (ACON 2015).

Alcohol and substance use are a health concern for many affected communities. Some people engage in overlapping risk behaviours, such as drug use and condomless sex. A survey of gay men showed that undiagnosed HIV-positive gay men were more likely to report injecting drugs or otherwise using drugs than HIV-negative men (de Wit et al 2016). Patterns of alcohol and drug use can change rapidly as new social practices and drugs emerge. For example, the Australian Injecting and Illicit Drug Users League (AIVL) has noticed an increase in heroin use following the crackdown by law enforcement authorities on methamphetamines. HIV CBOs have shown a strong ability to respond to quickly these changes with health promotion initiatives that are targeted, have a wide reach and respect the agency of those targeted (Brown et al 2015; Kippax & Stephenson 2016).

E.4 Co-morbidities and aged care

Advances in HIV treatment have greatly improved the length and quality of life for people living with HIV and reduced the side-effects of taking HIV treatment. However, co-morbidities continue to affect many HIV-positive people, particularly those who were diagnosed late or have been living with the virus for a long period of time. A 2005 study of people living with HIV found they experienced a range of non-HIV co-morbidities with varying degrees of severity. The most common co-morbidities were hepatitis C, pulmonary disease, high blood pressure, high cholesterol and obesity (Weiss et al 2010). There is concern in Australia and abroad that with advances in prevention and treatment medications, comorbidities are being neglected in these communities (key informant interviews; Weiss et al 2010).

As HIV-positive people live longer, the demand for aged care will increase. Many older people living with HIV will have specific health concerns related to the virus and being on HIV treatments for a long period of time. Treatment adherence can also become more of a concern as people age. Some HIV CBOs are concerned that aged care services may not have adequate knowledge or capabilities to care for older people living with HIV. There is also a fear that there is a risk of stigma and discrimination if aged care workers are not provided adequate information on HIV and affected communities (key informant interviews).

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