

**COMMUNITY LED EFFORTS**

# Develop backbone resources

## OBJECTIVES

To improve the reach, impact, efficiency and effectiveness of community-led HIV education.

## CURRENT ISSUES

- Established HIV community-led efforts have been highly successful in achieving HIV prevention, testing and treatment results across a range of populations and localities, and have prevented a generalised epidemic;
- Those strengths notwithstanding, Australia faces a number of challenges:
  - the dominant narrative in Australia regarding HIV is out of date. This directly affects our capacity to address HIV as it conceals the urgency with which governments need to make new prevention strategies and testing methods accessible, causes people at risk of HIV to discount the possibility of their risk and therefore inquire about the tools available

- to prevent HIV, contributes to stigma and discrimination, and contributes to misinformed responses to HIV by community and health professionals; and
  - current efforts are not at sufficient scale to reach those at risk of acquiring HIV. This includes making new prevention strategies accessible, increasing testing frequency among key populations and supporting immediate linkage to care for people newly diagnosed with HIV and retention in care and treatment adherence among those already living with HIV.
  - The majority of community-led HIV organisations are small in size with a small

- education team. In general, they are staffed by individuals who are specialists in working with one population or delivering one aspect of community-led work (such as delivering educational workshops) but may lack expertise in designing integrated programs, or in specific modalities (such as the effective use of online tools for behaviour change). As each organisation endeavours to meet the needs of local populations, there is a risk of duplication and inconsistency in messaging, rather than collaboration;
  - Together, these factors will limit our capacity to reach our goal of ending HIV transmission in Australia.

## PROPOSED ACTIVITIES

- Develop a nationally-coordinated package of HIV prevention, testing and treatment resources for local implementation. This package should be informed by a range of data, including epidemiological data, social and behavioural research, and international best practice on addressing HIV in key populations and should include:

- Program development and planning tools
- Health promotion campaign materials
- Session plans for community education activities across the range of key populations; and
- Session plans for information/skill development among allied workforces;
- Conduct an ongoing program of awareness raising through a communications strategy

- which incorporates:
  - Working with communications specialists to monitor current media coverage of HIV, and design strategic interventions to update the narrative across mainstream media, LGBTI press and new media; and
  - Collaboration between community-led HIV organisations to provide a coherent and contemporary narrative of HIV in Australia.

### COST-BENEFIT

This investment will deliver greater efficiency in community-led efforts, reduce any remaining duplication and reduce the potential for inconsistent messaging.

### ADDITIONAL INVESTMENT

\$10 million per annum across national community-led organisations

**COMMUNITY LED EFFORTS**

# Specialised programs for hidden populations

**OBJECTIVES**

To maximise the reach and relevance of HIV prevention, testing and treatment education to ‘hidden’ populations, including people with unsuspected HIV, late HIV presenters and those not being treated.

**CURRENT ISSUES**

- Despite the success of existing HIV prevention, testing and treatment efforts, there are significant ‘hidden’ populations who are at risk of not enjoying the benefits of current prevention and treatment science. These populations include gay men with infrequent HIV testing practices, people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, people who inject drugs who have less understanding of their personal risk of acquiring HIV, and people with HIV who have not been linked to care or have been lost to care;
- Improving understanding of HIV – including building capability for personal risk assessment – is a priority because:
  - ➔ these individuals are at risk of poorer long-term health outcomes

- ➔ both late diagnosis and late commencement of treatment are implicated in preventable morbidity and mortality for people with HIV; and
- ➔ these individuals are also at risk of HIV transmission, due to their unknown HIV status and/or their higher viral load. This undermines the public health investment in HIV prevention;
- At present, the bulk of HIV prevention efforts across Australia are concentrated on gay men and other men who have sex with men. This is appropriate in that the prevalence is highest among this population and the potential for health and economic impact is greatest. However, as the dominant epidemic is brought under control, these ‘hidden populations’ will account for a greater proportion of the health impact of HIV

- acquisition and/or untreated HIV;
- This is already being experienced with around a third of HIV diagnoses coming from outside the population of gay and other men who have sex with men, with lower uptake of treatment among people with HIV who are not gay men, and poorer access to Pre-Exposure Prophylaxis (PrEP) and self-testing among Aboriginal and Torres Strait Islander people;
- Reaching these populations will require highly nuanced programming, informed by the needs of each sub-population. This capacity and expertise does not exist across the sector to target the range of hidden populations and, indeed, a localised response to each hidden population would potentially duplicate effort across states and territories.

**PROPOSED ACTIVITIES**

Develop a nationally-coordinated and evidence-informed package of HIV education resources for local implementation. This package should include identification of the modes of communication most relevant for each population, development of messaging that has both reach and impact in those populations, and support for the capacity of local services to conduct local activities and assist individuals who require education, testing and support as a result of the campaigns.

**IMPACT**

- Reduced delay in time between seroconversion and HIV diagnosis, and HIV diagnosis and linkage to care;
- Increased testing among members of ‘hidden populations’; and
- Increased HIV prevention behaviours among members of ‘hidden populations’.

**COST-BENEFIT**

This investment will reduce the prevalence of undiagnosed HIV infection and the pool of untreated HIV infection.

**ADDITIONAL INVESTMENT**

\$3million per annum

**COMMUNITY LED EFFORTS**

# Stigma and discrimination

## OBJECTIVES

To reduce HIV stigma and discrimination-related barriers to testing, treatment and care.

## CURRENT ISSUES

- HIV-related stigma and discrimination continue to be a central part of the lives of many people with HIV across Australia. That stigma is driven by a range of factors, including outdated notions of HIV and misinformation about transmission and transmissibility;
- HIV-related stigma and discrimination is experienced in a range of settings, including the gay community, the general community, health care settings, government agencies, workplaces and mainstream and on-line media;

- The effects of stigma and discrimination are multifaceted:
  - ➔ HIV-related stigma and discrimination is a source of significant harm in the lives of individuals, causing both a decline in wellbeing and quality of life (through social isolation, shame, anxiety and depression) and in physical wellbeing (social isolation is correlated with poorer adherence to HIV treatment).
  - ➔ At a population level, stigma and discrimination present a barrier to people

presenting for regular testing, engaging with health care providers regarding risk behaviours, and sustaining contact with health care and treatment adherence. These factors in turn pose a risk to our public health goals of reducing HIV transmission;

- Despite the substantial body of knowledge about the prevalence, nature and impact of HIV-related stigma there has been limited investment to date in innovative activities to address stigma and discrimination.

## PROPOSED ACTIVITIES

- Develop interventions that build individual resilience among people with HIV, so that individuals can withstand stigma and discrimination where it does occur;
- Develop strategies to address systemic factors that perpetuate stigma and discrimination, including policies and laws that regulate key populations and have an adverse impact on those populations;

- Publish an annual report on HIV-related stigma and discrimination, and document activities to combat HIV stigma and build resilience of PLHIV;
- Develop an evidence-informed programmatic response to HIV-related stigma and discrimination that:
  - ➔ engages communication specialists to design a sophisticated, integrated

communications package targeting (general and gay-specific) community settings, mainstream media and online channels;

- ➔ builds on recent efforts to address HIV-related stigma and discrimination in clinical settings;
- ➔ supports local workforces to design local interventions that address context-specific stigma and discrimination.

## IMPACT

- Improve the health, wellbeing and quality of life of individuals with HIV;
- Reduce barriers to testing, treatment and retention in care.

## COST-BENEFIT

This investment will contribute to the prevention of poorer health outcomes among people with HIV, thereby reducing pressure on primary care and public health, and reduce late diagnoses and the health care costs associated with late HIV diagnosis.

## ADDITIONAL INVESTMENT

\$400,000 per annum

**COMMUNITY LED EFFORTS**

# Safe sex and Australian travellers

## OBJECTIVES

- To prevent new HIV infections; and
- To improve uptake of testing and treatment among those who may acquire HIV while travelling.

## CURRENT ISSUES

- Over 8 million Australians depart the nation each year to travel overseas. This includes individuals travelling for leisure, work and visiting the country of their birth;
- Australians travelling overseas face unique risks in relation to HIV: they may be travelling to a context (either a country or a specific community within a country) with a higher prevalence of HIV, be less inhibited and more inclined to risk-taking while travelling, and assume that behaviour that is low-risk in Australia is low-risk overseas;
- While complete data is not available, it is well-established that mobility is implicated

- in around 50% of new diagnoses among heterosexuals; and that there are sub-populations of gay men who are at heightened risk of HIV acquisition when travelling, including Asian gay men;
- Moreover, travellers may not be aware of the range of strategies that could reduce their risk of HIV acquisition, including condom-protected sex and Pre-Exposure Prophylaxis (PrEP);
- Australians who acquire HIV in the context of travel are also at risk of later diagnosis and therefore delayed access to treatment and care. They may consider themselves personally at low-risk of acquiring HIV and therefore

- be less likely to request or be offered HIV testing at seroconversion, and they may be less knowledgeable about how to access testing, treatment and care either while travelling or upon return to Australia;
- Taken together, these factors can place individuals at risk of poorer health outcomes, and may increase the risk of onward transmission of undiagnosed HIV;
- Despite the role of mobility in HIV acquisition and delayed access to diagnosis and treatment, travellers are not currently a priority population for any part of the community-led or public health response.

## PROPOSED ACTIVITIES

- The most efficient modality for addressing travel-related HIV is via targeted communications saturating those settings relevant for travellers;

- This requires a concentrated effort with broad reach as opposed to highly localised responses;

- It is anticipated that the campaign would incorporate social media and traditional social marketing channels, with key messages including prevention, testing and treatment.

## IMPACT

- Reduce preventable infections;
- Improve uptake of testing and treatment among travellers who acquire HIV; and
- Reduce onward HIV transmission from people with undiagnosed HIV.

## COST-BENEFIT

This investment will contribute to the secondary prevention of poorer health outcomes among people with HIV, thus reducing pressure on primary care and public health, and reduce late diagnoses and the health care costs associated with late diagnosis.

## ADDITIONAL INVESTMENT

\$400,000 per annum

**COMMUNITY LED EFFORTS**

# Aboriginal and Torres Strait Islanders

## OBJECTIVES

To plan and implement an improved and sustained response to HIV and STIs among Aboriginal and Torres Strait Islander communities.

## CURRENT ISSUES

■ There have been slow but sustained increases among Aboriginal and Torres Strait Islander communities in Australia, such that HIV rates are now trending above the rate for non-Indigenous people for the first time in Australia's HIV epidemic. Rates of HIV diagnosis are higher in all areas (urban, regional and remote), with women, people who inject drugs and heterosexuals over-represented in diagnoses among Aboriginal and Torres Strait Islander people;

■ At the same time, rates of STIs (chlamydia, gonorrhoea, infectious syphilis and trichomonas, all of which are implicated in HIV transmission) are at all-time highs in Aboriginal and Torres Strait Islander communities;

■ It is well-established from overseas experience (particularly in Canada) that Indigenous communities are vulnerable to rapid increases in HIV because of younger age, poorer access to primary health care, very high background rates of STIs, higher

mobility, incarceration and drug use and lack of employment opportunity. These factors also make HIV extremely difficult to manage in Indigenous communities once it is established at any scale;

■ The impact of current activities notwithstanding, the response to HIV and STIs in Aboriginal and Torres Strait Islander communities is not of sufficient scale to reduce new infections and improve uptake to testing and treatment.

## PROPOSED ACTIVITIES

■ Unlike the broader HIV response, the response to HIV and STIs in Aboriginal and Torres Strait Islander communities should of necessity be highly localised, with nationally-coordinated backbone support, and as such informed by and responsive to existing conditions, rates of infection and vulnerability;

■ *The High-Level Summit to address HIV and other STIs* (Brisbane 2015) and other key consultation fora have identified the following priorities for action:

→ increasing the clinical and health promotion capacity of Aboriginal Community Controlled Health Organisations and non-Indigenous organisations to respond to HIV and STIs

in Aboriginal and Torres Strait Islander communities;

→ a national project to reduce sharing of injecting equipment among Aboriginal and Torres Strait Islander people, incorporating education and improved access to the means of prevention;

→ establish clinical and community surge capacity in areas that experience HIV outbreaks, including rapid testing, HIV case management, availability of Pre-Exposure Prophylaxis, Post Exposure Prophylaxis, clean injecting equipment and pharmacotherapy;

→ targeted health promotion in urban and regional areas addressing both HIV and STIs,

for: ➤ gay men and men who have sex with men; and

➤ heterosexuals, especially young people

→ ongoing support for Aboriginal HIV Awareness Week, the Anwernekenhe National HIV/AIDS Alliance and the biannual Anwernekenhe Conference;

→ research and evaluation to monitor behavioural risk factors, epidemiological trends, knowledge levels and patterns in access to services and to evaluate the impact of strategies implemented; and

→ sentinel surveillance to generate clinical and behavioural data.

## IMPACT

■ Improve health outcomes for Aboriginal and Torres Strait Islander people with HIV or at risk of HIV acquisition; and

■ Reduce the risk of onward HIV transmission from undiagnosed infection.

## COST-BENEFIT

This investment will substantially reduce the pool of individuals at risk of HIV and who have undiagnosed HIV and reduce the long-term clinical care costs associated with treating new infections.

## ADDITIONAL INVESTMENT

\$15 million per annum

**TECHNOLOGY**

# HIV Pre-Exposure Prophylaxis (PrEP)

**OBJECTIVES**

To maximise access to evidence-based biomedical HIV prevention in Australia.

**CURRENT ISSUES**

- Nationally, HIV infection rates have remained static over the past decade. In 2015 there were 1,025 HIV notifications, with gay and other men who have sex with men accounting for 68% of these diagnoses. This figure is consistent with the trend over the past decade;
- Behavioural data shows that consistent condom use is a mainstay of HIV prevention for a significant majority of gay men, but that there has been a rise in the proportion reporting unprotected sex over the past decade;
- This points to the need to diversify the means of prevention;
- Pre-exposure Prophylaxis (PrEP) is an evidence-based prevention tool that has the potential to break the cycle of HIV transmission among gay men in Australia. Evidence from the PROUD study, published in the Lancet, shows that for every thirteen

- people on PrEP, an HIV diagnosis is averted;
- In April 2017, Australian Health Ministers recognised PrEP as a crucial component for achieving Australia’s goal of virtually eliminating HIV by 2020;
- There is a substantial unmet need for PrEP, with modelling indicating that more than 31,000 men who have sex with men at high risk of HIV acquisition would be eligible for PrEP in Australia;
- Enhancing access to PrEP is essential if we are to achieve the HIV prevention goals of the National HIV Strategy. This will require making PrEP accessible and affordable for those at high risk of HIV, including enabling prescribing by all General Practitioners (as opposed to limiting prescribing to existing s100 HIV prescribers);
- At present, access to PrEP is variable across Australia, with some jurisdictions providing

- funding for trials of PrEP, while in other states and territories access is reliant on an individual’s capacity to pay for imported drugs. No jurisdictional trial is fully meeting need;
- Access to PrEP via the Pharmaceutical Benefits Scheme is vital to ensure sufficient access for key populations across Australia;
- The patented drug used for PrEP, Truvada, can be purchased on private script, but its cost is prohibitive;
- Two generic bio-equivalents supplied by Mylan and Lupin Generic Health have been registered on the Australian Register of Therapeutic Goods (ARTG);
- Mylan and Gilead have submitted applications to the Pharmaceutical Benefits Advisory Committee (PBAC) to have PrEP listed on the Pharmaceutical Benefits Scheme (PBS) at its 6-8 July 2017 meeting.

**PROPOSED ACTIVITIES**

- That PBAC broker a fair price for PrEP that enables a positive recommendation for its listing on the PBS; and
- Following a positive recommendation from the PBAC, that the Australian Government ensure PrEP is accessible through the PBS as quickly as possible.

**IMPACT**

- Reduce new HIV acquisitions;
- Reduce the costs of care (primary health care and public) and treatment associated with living with HIV.

**COST-BENEFIT**

The cost of providing PrEP under the PBS to those at high risk of HIV infection would be more than offset by savings from HIV infections averted.

**ADDITIONAL INVESTMENT**

As per PBAC advice

**TECHNOLOGY**

# HIV self-testing

## OBJECTIVES

To improve access to the full range of evidence-based HIV testing technologies for people at risk of HIV across Australia.

## CURRENT ISSUES

- Knowledge of status builds the capacity of individuals to, in the event of a negative result, minimise the risk of HIV acquisition or, in the event of a positive result, be linked to care to discuss treatment options and better understand the risks of onward transmission;
- Frequent, easy testing and early diagnosis are critical if Australia is to reach its target of virtually eliminating HIV transmission in Australia;
- HIV self-testing is identified in the National HIV Strategy as a tool that can simplify

the testing process and address access and acceptability issues such as cost, time and convenience;

- HIV self-testing has been endorsed by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine’s updated National HIV Testing Policy (February 2017);
- The Kirby’s Institute’s Frequency of Oral Rapid Testing at Home (FORTH) study has concluded that “HIV self-testing resulted in a two-times increase in frequency of testing in gay and bisexual men at high risk of infection,

and a nearly four times increase in non-recent testers, compared with standard of care, without reducing the frequency of facility-based HIV testing”;

- At present, HIV self-tests can be lawfully purchased online for personal use. However, as the TGA is yet to approve HIV self-tests for use in Australia, the quality and sensitivity of devices purchased online has not been assessed against Australian standards.

## PROPOSED ACTIVITIES

- That the Australian Government adopt an active posture on improving access to high quality HIV self-tests, through:
  - monitoring the environment for suitable candidates;
  - supporting the approval of HIV self-tests for purchase online;
  - supporting a regulatory environment and

regulatory process which provides individuals with access to high quality self-tests; and

- investing in the development of educational materials (such as online instructional videos) to guide use and interpretation of the device and to identify appropriate pathways to care in the event of an HIV positive result.

- Use self-testing as a pathway to educate

individuals about HIV prevention, and the benefits of care for people newly diagnosed with HIV.

- Support any future recommendation from the Medical Services Advisory Committee (MSAC) to publicly fund accessibility to HIV self-testing devices for key HIV populations and individuals at high-risk of HIV.

## IMPACT

Increase the frequency of testing, including among non-recent testers, to facilitate earlier diagnosis of HIV acquisition and earlier engagement in care

## COST-BENEFIT

- Reducing the time between seroconversion, diagnosis and treatment will improve individual health outcomes and reduce the risk of onward HIV transmission;
- More frequent testing has the potential to increase awareness and engagement with HIV prevention tools if self-tests are accompanied by appropriate prevention materials.

## ADDITIONAL INVESTMENT

\$0

**TECHNOLOGY**

# Rapid HIV testing

## OBJECTIVES

To improve access to the full range of evidence-based HIV testing technologies for people at risk of HIV across Australia.

## CURRENT ISSUES

- Testing is critical as it enables an individual to know their HIV status;
- Knowledge of status builds the capacity of individuals to, in the event of a negative result, minimise the risk of HIV acquisition or, in the event of a positive result, be linked to care to discuss treatment options and better understand the risks of onward transmission;
- Frequent, easy testing and early diagnosis are critical if Australia is to reach its target of virtually eliminating HIV transmission in Australia;
- There are significant benefits to facility-based testing, including access to a skilled and knowledgeable health professional who conducts a risk assessment, and provide customised information about prevention and access to treatment and care;
- However, there are barriers associated with facility-based testing, including the delay of several days or more between test and result, practical barriers such as time and financial constraints and concern about judgement from clinicians;
- Rapid HIV testing, by contrast, provides an opportunity to significantly increase frequent routine testing among key populations and for any individual who may be at risk of acquiring HIV. Rapid HIV testing returns results within 10-20 minutes and can be peer-led rather than clinician-driven;
- The current service system is not configured to capitalise on the opportunities presented by rapid HIV testing.

## PROPOSED ACTIVITIES

Seek a sponsor to initiate an application to the Medical Services Advisory Committee (MSAC) for public funding of an ARTG-registered product.

### IMPACT

- Improve the health, wellbeing and quality of life of individuals with HIV;
- Reduce barriers to testing, treatment and retention in care.

### COST-BENEFIT

This investment will contribute to the prevention of poorer health outcomes among people with HIV, thereby reducing pressure on primary care and public health, and reduce late diagnoses and the health care costs associated with a late HIV diagnosis.

### ADDITIONAL INVESTMENT

As per Medical Services Advisory Committee advice



**WORKFORCE**

# Community Workforce

## OBJECTIVES

To strengthen the community-led response through targeted workforce development that incorporates knowledge transfer and skill development.

## CURRENT ISSUES

- The workforce is the engine-room for the community-led response and is dispersed across Australia’s eight states and territories, and diverse populations and different modalities (including community education workshops, social marketing campaigns, outreach and community mobilisation);
- This workforce is highly skilled and specialist and relies on the HIV sector to provide

access to ongoing, role-relevant workforce development;

- The organisations that employ the community workforce are by their nature constrained, particularly in the smaller jurisdictions, in developing the knowledge and skills of their employees in the highly-specialised aspects of their work. Consequently, new staff are often required to ‘hit the ground

running’ with limited induction and have only periodic access to skill development that is deeply relevant to their work responsibilities;

- As such, national workforce development has the greatest potential to reach critical mass and to support cross-facilitation and skill development across workers located across Australia.

## PROPOSED ACTIVITIES

- Fund a biennial National HIV Health Promotion Conference, bringing together the diverse community workforces from across Australia. This conference would provide a regular opportunity to bring networks together to distribute current knowledge, including knowledge on HIV epidemiological, social

and behavioural research and knowledge on international best practice HIV health promotion, as well as practical skill development on strategies to achieve behaviour change and measure outcomes;

- This National Conference would be complemented by on-line training and regular

networking among practitioners, including webinars on more specialised aspects of HIV prevention, testing and treatment work with key populations, dissemination of current research, and peer support for the translation of critical advances in prevention science into health promotion/education practice.

## IMPACT

A highly skilled workforce will deliver world class HIV prevention, testing and treatment education initiatives.

## COST-BENEFIT

Over time, investment in the workforce will result in more impactful prevention, testing and treatment activity and ultimately contribute to a reduction in new infections and an increase in testing and uptake of treatment.

## ADDITIONAL INVESTMENT

\$250,000 per annum

**WORKFORCE**

# Clinical Workforce

## OBJECTIVES

- To facilitate uptake of biomedical prevention;
- To broaden the base of clinicians able to facilitate HIV prevention, testing and treatment in the community; and
- To support and maintain clinicians with a specialist interest in HIV medicine, including HIV trained and accredited s100 highly specialised drugs prescribers.

## CURRENT ISSUES

- The HIV clinical workforce is vital in facilitating access to timely prevention, testing and treatment among people at risk of and living with HIV. Clinicians are uniquely placed to support individuals to assess personal risk, undergo regular testing, make informed decisions about prevention strategies and engage in treatment and care;
- As such, sustaining and expanding the HIV clinical workforce is an essential element of achieving our shared goal of ending HIV transmission;
- The workforce is relatively small, and includes highly skilled and specialised HIV clinicians, general practitioners, sexual health physicians, and nurses;
- Given the size, diversity and geographic dispersal of the workforce, it is vital that initiatives targeting the workforce are coordinated and strategic; and that mainstream agencies (such as Primary Health Networks) are assisted to take up an appropriate role in a way that complements rather than duplicates efforts;
- In addition, modest investment in continuing initiatives such as timely and responsive policies and guidelines and clinical advice around HIV testing, HIV Pre- and Post-Exposure Prophylaxis and HIV management will provide the backbone to state- and territory-based initiatives to upskill the clinical workforce;
- There is also a need to explore new models of care, particularly to facilitate access in areas where there is a shortage of medical practitioners and where there may be other barriers to engagement or retention in care (such as low levels of knowledge, or high levels of stigma and discrimination);

## PROPOSED ACTIVITIES

- Develop backbone resources (such as curriculum, training materials and clinical information) that support local workforce development initiatives
- Conduct national workforce development activities that facilitates information exchange and provides education, training and support
- Develop nationally standardised policies and guidelines including the National HIV Testing Policy, Pre- and Post-Exposure Prophylaxis, and treatment and management guidance and guidelines.

## IMPACT

- Improved knowledge and capacity of the health workforce to contribute to ending HIV transmission
- Increased information exchange without unnecessary replication of existing effort.

## COST-BENEFIT

- Improved primary and secondary prevention and care
- Increased access points to prevention and care services
- Expansion of the range of health care providers able to contribute to ending HIV transmission.

## ADDITIONAL INVESTMENT

\$350,000 per annum

**WORKFORCE**

# Involvement of people with HIV and affected communities

**OBJECTIVES**

To maximise the relevance and appropriateness of HIV prevention, testing and treatment education, health promotion, policy and clinical care.

**CURRENT ISSUES**

■ The meaningful involvement of people with HIV and affected communities has been central to Australia’s HIV response for over thirty years. Unlike other countries, Australia has been able to harness the insights, knowledge, goodwill and skills of people with HIV and affected communities to ensure programs and services are relevant, accessible and able to achieve their desired impact for both individuals and public health;

■ This has included a sustained commitment to the meaningful involvement of people with HIV at all levels of the response, from local HIV and sexual health services engaging a client representative, through to the role of community organisations representing the collective experience of people with HIV;

■ While the role of an individual able to tell their personal story is vital and often represents a very rich source of learning for the audience, it is important that this individual story-telling

is complemented by representative roles – that is, by community advocates and community organisations that are able to move beyond an individual’s story to speak with authority about patterns in the experience of communities and to make recommendations informed by the trends across sub-populations. This includes being able to advocate for and inform the health system about the full diversity of lived experience and the need for tailoring to that experience.

**PROPOSED ACTIVITIES**

■ Commit to the greater involvement and meaningful engagement of people living with HIV and affected communities in all aspects of the response to HIV across Australia, including:

→ **Acknowledgement:** Research and practice findings which draw upon the experiences of people with HIV and affected communities to acknowledge the contributions made;

→ **Participation:** Projects requiring community guidance or input, including research projects, to include community participation, including the representation people with HIV;

→ **Leadership:** Support initiatives such as the *Positive Leadership Development Institute* to operate within each state and territory at least once per annum;

→ **Monitoring and accountability:** All HIV organisations to undertake a Meaningful Involvement of People with HIV audit and report their findings;

→ **Policy and practice:** All HIV organisations to have in place a contemporary *HIV in the Workplace* policy that includes protocols for HIV disclosure and privacy provisions in the workplace;

**IMPACT**

Maximise the reach and effectiveness of services and programs.

**COST-BENEFIT**

The greater involvement and meaningful engagement of people with HIV and affected communities will ensure programs and services are relevant and accessible, thereby improving uptake of prevention, testing and care, and supporting long-term retention in care.

**ADDITIONAL INVESTMENT**

\$0.

**DATA, RESEARCH AND EVALUATION**

# Unlock access to big data

## OBJECTIVES

To strengthen the national evidence base underpinning HIV prevention, testing and treatment initiatives.

## CURRENT ISSUES

- There is a range of critical data that can inform HIV prevention, testing and treatment efforts across Australia including Pharmaceutical Benefits Scheme and the Medicare Benefits Scheme data;
- At present, access to this data has been through the efforts of jurisdictions rather than

a uniform national effort to generate analytics and insights to inform the national response;

- Improved access to this data, and regular linkage of that data to existing jurisdictional data sets (including, for example, hospitalisation data) would generate actionable, population-level insights into

current trends in HIV treatment coverage and retention in care across Australia. This would include insights into access to testing, treatment and care among ‘hidden populations’ such as Aboriginal and Torres Strait Islander people with HIV and overseas-born populations.

## PROPOSED ACTIVITIES

- Convene a national roundtable on HIV-related data linkage to create dialogue and agreement regarding privacy protections, protocols and controls acceptable to people with HIV and affected communities;
- The Australian Government to make a determination that all data held by its agencies that could usefully inform the HIV response be made available to states and territories and to the community-led response. This should

be done in such a way as to maintain strict protections for individuals’ privacy;

- Commit to providing de-identified line-listed PBS data on a quarterly basis (100% sample) for HIV treatment and Pre-Exposure Prophylaxis, including demographics, provider type, dispensing location and jurisdiction;
- Undertake regular data linkages as a quality assurance (as opposed to research) activity, linking national HIV notification data with

Pharmaceutical Benefits Scheme, Medicare Benefits Scheme and hospital datasets;

- Include data linkages with hospital morbidity datasets to determine Aboriginal and Torres Strait Islander status, and processes to conduct more timely linkages in the future. During this process, determine Aboriginal and Torres Strait Islander status from hospital morbidity datasets and establish processes for more timely linkages in the future.

## IMPACT

Strengthening data systems and data architecture will produce more accurate, complete and timely data, that in turn will improve the capacity of the workforce to deliver tailored and impactful interventions.

## COST-BENEFIT

A more tailored response will increase the impact of HIV prevention efforts and result in an increase in testing and retention in care.

## ADDITIONAL INVESTMENT

\$0.

## DATA, RESEARCH AND EVALUATION

# HIV Surveillance

### OBJECTIVES

To strengthen the national evidence base underpinning HIV prevention, testing and treatment initiatives.

### CURRENT ISSUES

- Australia's HIV evidence-base consists predominantly of epidemiological data, community-based behavioural surveillance and the broader body of research regarding effective practice and effective interventions with priority populations;
- Tracking practices as they emerge, responding to new threats and evaluating the impact of current strategies requires access to complete, accurate and timely epidemiological and behavioural data;
- Timeliness is particularly important as leaps in prevention, testing and treatment science create opportunities and imperatives for rapid

- responses;
- At present, there is variation between states and territories as to the completeness and timeliness of epidemiological surveillance;
- There are also significant gaps in community-based behavioural surveillance:
  - some jurisdictions, such as the Northern Territory, have no routine community-based behavioural surveillance;
  - routine data on trends in some key cities and regional areas (including Hobart, Newcastle and other urban and major regional centres) – even areas with a high concentration of priority populations – is virtually non-existent

- there is poor coverage of key populations, particularly non-gay identified men who have sex with men, sex workers and heterosexuals (particularly those from high prevalence countries and women).
- There are serious gaps in the timeliness and completeness of data for Aboriginal and Torres Strait Islander communities. This must be resolved as an urgent national priority;
- Taken together, these limitations constrain the capacity of researchers, programmers and educators to respond to threats and monitor progress.

### PROPOSED ACTIVITIES

- Convene a national roundtable on the epidemiological, behavioural and social data routinely required to inform and monitor progress toward the goals of the *National HIV Strategy*, and implement national reforms;
- Anticipate and advance reforms including:
  - conducting regular data linkages of HIV notifications and Pharmaceutical Benefits Scheme and Medicare Benefits Scheme data to strengthen HIV care cascades for sub-populations;
  - creating an online data portal for access to quarterly HIV data on demand; or including

- HIV in an existing data portal, such as the National Notifiable Diseases Surveillance System;
- developing special HIV data reports periodically for each key population;
- producing quarterly PrEP dispensing reports to track uptake by population and location;
- expanding community-based surveillance to include coverage of the Northern Territory and key populations currently not covered (gay and bisexual men living in regional areas, people from culturally and linguistically diverse backgrounds, transgender people, heterosexual

- people from at-risk populations and sex workers), including strengthening the funding and collaborative arrangements between federal and state governments and community organisations to produce sustainable data; and
- identifying opportunities to gather qualitative data on behaviours, knowledge and risk practices among 'hidden populations';
- As part of that process, reform the architecture that delivers data and surveillance, with a stronger emphasis on collaboration with those who are charged with implementation of the *National HIV Strategy*.

### IMPACT

Strengthening data systems and data architecture will produce more accurate, complete and timely data, which in turn will improve the capacity of the workforce to deliver tailored and impactful interventions.

### COST-BENEFIT

A more tailored response will increase the impact of HIV prevention efforts and result in an increase in testing and retention in care.

### ADDITIONAL INVESTMENT

\$400,000 per annum

**DATA, RESEARCH AND EVALUATION**

# Fund implementation research

## OBJECTIVES

To strengthen the national evidence base underpinning HIV prevention, testing and treatment initiatives.

## CURRENT ISSUES

- Australia has a long-standing commitment to producing world class research to inform our efforts to achieve the goals of successive national strategies;
- The quality and relevance of the research is a tribute to the skill and dedication of Australian HIV researchers and the collaborative relationship between the research centres and community-led organisations;
- The bulk of Australia’s HIV research investment is in epidemiological, behavioural and social research;
- There is now an urgent need to

complete that research with investment in implementation research – that is, research that is explicitly focussed on program design and implementation (as opposed to mapping trends in population behaviours); and that is both formative (that is, helps inform program development at the outset) and evaluative;

- Implementation research would provide intelligence on key questions such as ‘are our approaches effective?’ ‘what are gay men’s preferences in engaging with the service system?’, ‘how do we best target less engaged gay men in relation to PrEP?’ and ‘where else

should our efforts be focused to maximise impact?’;

- The required implementation research must be immediately responsive to community-led program needs and therefore must be embedded within the community-led response. This would involve formal partnership between a national community-led organisation and researchers, under community-led direction. Embedding implementation research in this way allows for rapid research response to questions and issues emerging from community programs and intelligence.

## PROPOSED ACTIVITIES

Fund and establish dedicated implementation research capacity that is embedded and controlled by the national community-led HIV response.

### IMPACT

Creating dedicated capacity for implementation research will generate data not currently available to the response, which in turn will improve the capacity of the workforce to deliver tailored and impactful interventions.

### COST-BENEFIT

A more tailored response will increase the impact of HIV prevention efforts and result in an increase in testing and retention in care.

### ADDITIONAL INVESTMENT

\$1.5 million per annum

**DATA, RESEARCH AND EVALUATION**

# Evaluation of programs

## OBJECTIVES

To create capacity to routinely evaluate programs and services, in order to maximise reach and impact.

## CURRENT ISSUES

- Evaluation is a key tool for ensuring that programs and services are appropriately tailored to the needs of key populations and at-risk individuals, and people with HIV;
- However, many organisations encounter a range of obstacles to routinely embedding evaluation into program and service delivery, including lack of expertise in the specific evaluation methodologies and tools

that produce program-relevant findings (for instance, formative evaluation or developmental evaluation), limited funding, past poor experiences with evaluations that have not produced relevant findings, and time constraints related to funding cycles that prioritise short term output reporting at the expense of longer-term monitoring of impact and outcomes;

- At an individual service level, this can undermine an organisation’s ability to adapt its services and programs to best meet client need;
- At a systemic level, this means that the sector does not have access to the full range of data needed to best focus its efforts.

## PROPOSED ACTIVITIES

Create a dedicated national evaluation team that is available to conduct evaluation at the following levels:

- micro level – that is, to evaluate the reach, impact and outcomes of specific initiatives (for example, a health education campaign targeting a specific population), to make

recommendations about upscaling, and to identify transferability to other localities and/or populations;

- meso level – that is, to evaluate specific streams and bodies of work, such as outreach with sex workers, or social media targeting gay men, with a view to assessing the current

relevance of that modality and making recommendations for the future use (or cessation) of that modality; and

- macro level – that is, to evaluate the health and economic impact of sub-programs within the Australian HIV response.

## IMPACT

Creating dedicated capacity for evaluation will generate data not currently available to the response, which in turn will improve the capacity of the workforce to deliver tailored and impactful interventions.

## COST-BENEFIT

A more tailored response will increase the impact of HIV prevention efforts and result in an increase in testing and retention in care.

## ADDITIONAL INVESTMENT

\$1.2 million per annum