



Submission to:

NSW Health

On:

Promoting the generation and effective use of
population health research in NSW: A
Strategy for NSW Health 2011-2015

November 2010

About ACON

ACON (formerly known as the AIDS Council of NSW) was formed in 1985 as part of the community response to the impact of the HIV/AIDS epidemic in Australia. Today, ACON is Australia's largest community-based gay, lesbian, bisexual and transgender (GLBT) health and HIV/AIDS organisation. ACON provides information, support and advocacy for the GLBT community and people living with or at risk of acquiring HIV, including sex workers and people who use drugs.

ACON is home to the Lesbian and Gay Anti-Violence Project (AVP), the Community Support Network (CSN), the Positive Living Centre (PLC) and the Sex Workers Outreach Project (SWOP). ACON has its head office in Sydney as well as branches in the Illawarra, Northern Rivers, the Hunter region and the Mid North Coast.

General Comments

ACON welcomes the opportunity to comment on the draft *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* (the Strategy). As a community based organisation that has a strong history of engagement with researchers, community based research and its contribution to the development of an evidence base, ACON welcomes the opportunity to provide input towards the development of a population health research strategy in NSW.

As Australia's largest GLBT health and HIV/AIDS organisation, ACON strongly supports the partnership approach outlined in the Strategy. The success of working within a partnership approach in the HIV sector has been largely attributed to the stabilisation of HIV transmissions in NSW, specifically between governments, researchers, community based organisations and affected communities in the health sector. This partnership approach has proved to offer significant benefits to the public health of the residents of NSW beyond HIV and a similar model could be developed in other health areas.

ACON believes priority population groups should be explicitly addressed in the Strategy to ensure quality population health research builds an evidence base and targets population groups in NSW most at risk of lower health outcomes. Marginalised groups do not share the same health outcomes as the general population, and it is only by collecting demographic information and disaggregating data that health inequities can be identified and addressed appropriately.

As a community based organisation, we recognise the importance of building relationships between researchers and affected communities to ensure that targeted and relevant research is produced. Additionally, working directly with research bodies means that health policy development and program planning continues to be evidence based and that new and emerging issues continue to be at the core of organisational planning processes.

Community based organisations can also act as important facilitators of research and have a unique position in their capacity to have contact with affected communities by virtue of being placed within the community itself. Building formalised and collaborative partnerships between NSW Health, researchers and community based organisations has the potential to contribute to building robust and evidence based public health policy in NSW.

Key Issues

Inclusion of specific priority populations

While it is encouraging that the Strategy states that population groups can be identified as priority populations for research, as the leading body, NSW Health should bridge the gaps in research in order to address existing health inequities faced by specific population groups in NSW and this is best addressed by explicitly identifying population groups within the Strategy.

The GLBT community has historically been excluded from public health research, beyond the context of HIV and sexually transmissible infections (STIs). Other population groups such as Aboriginal and Torres Strait Islander communities and people from culturally and linguistically diverse (CALD) backgrounds have also historically experienced exclusion in population health research. However, in recent years they have been recognised as priority population groups due to the growing evidence that as marginalised communities these groups face a range of barriers in accessing adequate health services which ultimately lead to significantly lower health outcomes than the general population.

There is mounting evidence that GLBT people experience higher rates of mental health issues, have higher rates of drug and alcohol use and are significantly under-screened for cancers. GLBT people continue to face more health disparities than faced by the general population but have yet to be recognised as a priority population group beyond HIV and sexual health related research.

According to a recent analysis of Australian Bureau of Statistics data, GLBT people were more than twice as likely to experience 'any mental disorder'.¹ Alarming, homosexual and bisexual people were more than three times more likely to have had an affective disorder (such as depression) compared to heterosexuals.² Suicide Prevention Australia also estimates that the rate of attempted suicide is 3.5 to 14 times higher for the GLBT community than the general population.³

The disparities in health outcomes experienced by the GLBT community are often compounded by the invisibility of GLBT people in research. Given that most mainstream

¹ Australian Bureau of Statistics, *National Survey of Mental Health and Wellbeing*, (2007).

² *Ibid.*

³ Suicide Prevention Australia, *Position Statement: Suicide and self-harm among gay, lesbian, bisexual and transgender communities*, (2009), p. 2.

health research does not gather demographic data relating to sexual orientation or gender identity (as opposed to age, sex, geographical location etc), the results from important and large-scale health research exclude the trends and behaviours, and potential access related barriers that lead to the health disparities experienced by GLBT people.

It should be noted that population health research in the area of HIV and sexual health has successfully incorporated sexual orientation, gender identity and HIV status indicators. Research in this area has also targeted members of the GLBT community, mainly gay men and other men who have sex with men (MSM), given their over representation in HIV data in epidemiological research. However, it is imperative that GLBT people are included more broadly in health related research as there are a host of health and wellbeing related issues facing the GLBT community beyond infectious diseases that impact on this population group.

The explicit inclusion of the GLBT community as a priority population group, with other recognised priority population groups, would strategically align this research strategy to other NSW Health strategies. These include *Healthy People NSW: Improving the health of the population* which states respecting diversity as an a necessary approach to improving health outcomes, as well as other strategies including the *NSW Suicide Prevention Strategy* and the *NSW HIV, STI and Hepatitis Strategies*.

Recommendations:

1. That *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* include GLBT communities as a priority population group.
2. That all NSW Health funded research include sexuality and gender identity indicators as a part of their demographic data sets.

Partnership approach

ACON strongly supports the discussion of “partnerships and collaborative population health research” in the Strategy. ACON is also pleased with the strategic objectives outlined to promote the “use of research evidence in policy and practice.” The recognition of these objectives in the Strategy is fundamental to developing relevant and useful health research.

The successful partnership approach in the NSW response to the HIV epidemic has been largely attributed to the strong policy leadership of the AIDS and Infectious Diseases Branch (AIDB), NSW Health. The departmental management of the sector has meant that the partnership between the NSW government, researchers, community based organisations and affected communities has been enshrined and allowed to flourish under the strategic directions of NSW HIV and STI Strategies.

This approach in NSW has resulted in achieving strong results for NSW in maintaining a stable rate of HIV transmission over the past 12 years, whilst other States and Territories in Australia have continued to see increases. This achievement would not have been possible without the continued funding of targeted research of at risk communities, particularly amongst gay men and MSM, in order to build an evidence base that in turn informs policy and programming by policy makers and service providers.

An example of research produced under this framework is the *Sydney Gay Community Periodic Survey*, produced in partnership with the National Centre for HIV Social Research, the National Centre for HIV Epidemiology and Clinical Research, ACON, Positive Life NSW and NSW Health. This research project produces timely information about the sexual behaviour, HIV status, HIV and STI testing rates and drug use of gay men and MSM. The data informs policy and programming by service providers such as ACON in the development of education programs and health promotion campaigns.

This allows researchers to access affected communities for research, and enables research, policy and service delivery to be strongly inter-linked and informed by each other. This model should be considered in other areas of health service delivery to better develop collaborative research that is relevant for at risk communities and to better inform policy development and service delivery.

Recommendation:

3. That *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* support partnership approaches between government, community organisations and researchers across NSW Health programs.

The participation of communities

The engagement of affected communities in the HIV response in NSW has produced strong results for the people of NSW. This engagement with affected communities has matured to enable community organisations to facilitate research mechanisms in the communities they serve.

An example of this is the development of research capacity within ACON. This capacity has resulted in the development of an ACON Research Ethics Committee, which provides an avenue for ACON and external research institutions such as the National Centre for HIV Epidemiology and Clinical Research, the National Centre for HIV Social Research and the National Drug and Alcohol Research Centre to better reach people living with HIV, the GLBT community, sex workers and people who use and inject drugs. The Committee also ensures that research engagement with these communities maintains the highest ethical standards as under the National Health and Medical Research Centre research guidelines.

This research capacity further allows for the dissemination of important data and information within ACON to inform policy and programming and enables ACON to be able to provide expert policy advice to governments and policy makers where possible. NSW Health, as a part of its strategy to “foster links and partnerships for collaborative population health research” should consider the opportunity of improving the research capacity of the community organisations it works with to facilitate important health related research.

The importance of community based and community driven research can be demonstrated by the bi-annual research project *Sydney Women and Sexual Health Survey* (SWASH). The project is the only piece of research that specifically targets lesbians and same sex attracted women to better understand the sexual health and health risks associated with this group of women. Unlike the *Sydney Gay Community Periodic Survey*, this research project is largely unfunded, however, follows a similar community based research approach based on the successes of the *Periodic Survey*.

This project, driven by researchers at the University of New South Wales (UNSW) and ACON, and has been ongoing since 1996, with initial funding from NSW Health. More recently, in order to continue the life of the project, the project has been supported by in kind donations from ACON and UNSW researchers to undertake the work. Over time this research has contributed to a growing evidence base around the sexual health of same-sex attracted women as well as the broader health risks faced by this group such as higher rates of tobacco, alcohol and other drugs use.

This data is invaluable for the development of important health promotion programs and resources that target this population of women. However, without a policy framework that positions the importance of funding population based health research at a government level, this project remains significantly limited in terms of resourcing, recruitment, data analysis and formal publication of results.

Recommendations:

4. That *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* develop opportunities to build the capacity of community organisations to partner with NSW Health in expanding their research relationships and capacity.
5. That NSW Health supports the generation of quality research that is relevant to community needs by commissioning population health research such as the *Sydney Women and Sexual Health Survey*.

Conclusion

ACON welcomes the development of *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* and support the approach and objectives outlined in the Strategy.

Due to the strong results that have been achieved through a partnership approach and the specific inclusion of marginalised communities in HIV research, policy and programming, ACON makes the following recommendations:

1. That *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* include GLBT communities as a priority population group that should be taken into consideration for all NSW Health funded research. This can be achieved for example by including sexuality and gender identity indicators as a part of gathering demographic data of research participants.
2. That all NSW Health funded research include sexuality and gender identity indicators as a part of their demographic data sets.
3. That *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* support partnership approaches between government, community organisations and researchers across NSW Health.
4. That *Promoting the generation and effective use of population health research in NSW: A Strategy for NSW Health 2011-2015* support funding to community organisations partnering with NSW Health to develop their research capacities.
5. That NSW Health supports the generation of quality research that is relevant to community needs by commissioning population health research such as the *Sydney Women and Sexual Health Survey*.

ACON would welcome further opportunities to discuss this submission with NSW Health. If you wish to receive any further information, please contact Veronica Eulate, A/Director, Policy, Strategy and Research on (02) 9206 2048 or email veulate@acon.org.au.