



**Submission to:**

**NSW Health on the Draft Community  
Engagement Framework**

**November 2010**

## **General Comments**

As community based organisations that have strong partnerships with NSW Health, ACON, Hepatitis NSW (HNSW), Positive Life NSW, and the Bobby Goldsmith Foundation (BGF), welcome the opportunity to provide comment on the very important issue of community engagement.

As Australia's largest GLBT health and HIV/AIDS organisation, ACON has participated in several community engagement processes conducted by NSW Health on issues relating to people with HIV and the GLBT community. Similarly HNSW, as a member organisation, regularly contributes to and is part of ongoing dialogue between its stakeholders and NSW Health.

Community engagement is a central element of achieving success in health policy development and service delivery. This experience has been informed by the success of the HIV sector, through a partnership model with NSW Health, to stabilise HIV transmission rates in NSW.

We support the principles and approaches outlined in the draft *NSW Health Community Engagement Framework* (from here referred to as the *Policy*). The principles of "inclusiveness" and "advocacy" have been particularly important in achieving success in the HIV sector.

This approach is being modelled by HNSW around a community development approach aiming to impact on the numbers of people acquiring hepatitis across NSW.

This submission has a clear focus on communities affected by HIV and hepatitis and in the case of ACON; there is a strong focus around the importance of including the GLBT community in the Policy and by extension, community engagement processes. We also advocate for a community engagement approach to include people affected by hepatitis. These include people who inject drugs, people in custodial settings, people from culturally and linguistically diverse (CALD) backgrounds, and Aboriginal and Torres Strait Islander peoples, we note that some of these groups have already been included in the Policy.

## **Key Issues – Inclusion of people with HIV and hepatitis**

An area of NSW Health policy that has historically had and continues to have a strong element of community engagement has been the state's response to HIV/AIDS and increasingly to hepatitis. A strong partnership approach has been developed between community organisations, affected communities, the NSW Government and researchers. 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 countries have seen significant increases.

The principles established in the HIV sector, those of partnership and engagement of affected communities, have now been replicated in other sectors including the hepatitis sector. These principles have informed the understanding of government on the importance of engaging with affected communities in developing effective responses to public health issues.

It is therefore disappointing, that the sector that pioneered a strong partnership approach has not been included in the *Policy*. This is especially concerning as people with HIV/hepatitis, and communities at risk of HIV/hepatitis, such as gay men and other men who have sex with men (MSM), sex workers and injecting drug users are still marginalised in our society and have specific health needs to ensure their health and the public health's needs are met.

To ensure that the objectives outlined in the *Sixth National HIV Strategy* and related STI and Hepatitis strategies are not compromised by other health policies and programs, the inclusion of people affected by HIV/hepatitis is crucial to provide understanding of the impacts of other health policies. It should be noted that current NSW HIV, STI and Hepatitis C strategies refer to the involvement of affected communities. The inclusion of people affected by HIV/hepatitis in community engagement processes also offers an opportunity for all policies and programs to be aligned with the important public health objectives of preventing HIV, STIs and viral hepatitis.

We note that several engagement structures are already in place, such as the Ministerial Advisory Committee on HIV and other Sexually Transmitted Infections and the Ministerial Advisory Committee on Hepatitis. In addition to these high level consultative structures, the involvement of people affected by HIV/hepatitis more broadly would be beneficial.

To assist people affected by HIV/hepatitis to participate in community engagement processes, the following should be taken into consideration:

- The term “people” affected by HIV/hepatitis includes people living with HIV/hepatitis as well as communities that are at risk of HIV/hepatitis transmissions. The NSW and national HIV strategies identifies the following priority populations: including gay men and other men who have sex with men, people living with HIV, sex workers, intravenous drug users, people from culturally and linguistically diverse backgrounds, and Aboriginal and Torres Strait Islander peoples. The *Third National Hepatitis C Strategy* identifies the following priority population groups: people with hepatitis C, people who inject drugs, people in custodial settings, people from CALD backgrounds and people with hepatitis C with co-morbidities. The *First National Hepatitis B Strategy* people from CALD backgrounds, Aboriginal and Torres Strait Islander peoples and pregnant women with chronic hepatitis B.
- People affected by HIV/hepatitis may have had discriminatory experiences of the health system or have had their confidence breached by the health system, and thus may not be easily engaged in consultative processes.

- Many people affected by HIV/hepatitis experience a high level of stigma and discrimination in the community. It is crucial that their confidentiality is protected if they disclose that they are HIV positive or have hepatitis, a sex worker or intravenous drug user.
- HIV and hepatitis organisations can provide important support to participants affected by HIV and hepatitis to engage in consultative processes.

#### **Recommendations:**

1. That the *NSW Health Community Engagement Framework* includes specific discussions of the people affected by HIV and hepatitis under Section 3.2 of the document.
2. That the *NSW Health Community Engagement Framework* supports the inclusion of the people affected by HIV and hepatitis in all consultation processes of the Department of Health, its agencies and Local Health Networks.

## **Section 2 Inclusion of the GLBT community**

The GLBT community has historically been marginalised in most policy and programming consultations in NSW. With the exception of sexual health (and more recently alcohol and other drugs and mental health) policy and programs, where sections of the GLBT community were included, most other government policies and programs have not targeted the GLBT community in consultations and as a result have not specifically included the GLBT community or their health needs in health policy and programming.

Beyond HIV and sexual health however, there is a growing range of health issues that disproportionately impact on the GLBT community. Data and research are documenting and demonstrating the health disparities that many people in the GLBT community experience. For example, GLBT people were more than twice as likely to experience 'any mental disorder' according to an analysis of latest Australian Bureau of Statistics data.<sup>1</sup> Alarming, homosexual and bisexual people were more than three times more likely to have had an affective disorder (such as depression) compared to heterosexuals.<sup>2</sup> 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.<sup>3</sup>

With an increased understanding of the health disparities and barriers of access that the GLBT community experiences, we have seen an inclusion of the GLBT community not only in sexual health policies but also broader policies such as the *NSW Suicide Prevention Strategy 2010-2015* and the *NSW Dementia Services Framework 2010-2015*. The increased inclusion of the GLBT community in health policy is recognition that similar to other marginalised communities such as Aboriginal and Torres Strait Islander (ATSI) peoples, culturally and

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

<sup>2</sup> *Ibid.*

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

linguistically diverse (CALD) communities and people with disabilities, the GLBT community experiences inequitable health access and disparate health outcomes.

The Policy discusses the different experiences of ATSI and CALD communities as well as people with disabilities under “Strategic Directions 2” of the document. However, GLBT people as a specific population groups, have been omitted from this illustration. In order for future policy and service delivery programming to better engage and reach the GLBT community, the GLBT community must be included following a similar approach to that of ATSI and CALD communities and people with disabilities.

To assist the inclusion of the GLBT community in community engagement processes, the following issues should be taken into consideration:

- The impact of actual, perceived and historical discrimination has on the participation of GLBT people in consultative processes. Discrimination can lead to GLBT people not participating at all, or for those who are a part of the process to not disclose issues relating to their sexuality and how policies and programs impacts on people who are GLBT.
- Confidentiality of participants who do identify as GLBT need to be protected, especially in smaller communities, such as a rural, ATSI or CALD community.
- There is still a significant degree of stigma attached to being GLBT. Care should be taken to ensure that the language used by staff and participants do not stigmatise or exclude GLBT people.
- GLBT community based organisations, some of which already have strong partnerships with NSW Health, are a source of information during consultations, as well as organisations that can facilitate and support the broader GLBT community to participate in community engagement processes.
- A Ministerial Advisory Committee on GLBT Health and Safety (MACGLBT), as proposed by the GLBT community, would establish a process, similar to the one that has existed in Victoria for many years, for the GLBT community to provide information and assist NSW Health in developing policies to address the health disparities that is experienced currently by the GLBT community.

**Recommendations:**

3. That the *NSW Health Community Engagement Framework* includes specific discussions of the GLBT community under Section 3.2 of the document.
4. That the *NSW Health Community Engagement Framework* supports the inclusion of the GLBT community in all consultation processes of the Department of Health, its agencies and Local Health Networks.
5. That the *NSW Health Community Engagement Framework* supports the establishment of a Ministerial Advisory Committee on GLBT Health and Safety (MACGLBT).

### **Section 3 Inclusion of other peer groups**

An estimated 162,000 people were living in Australia in 2009 with chronic hepatitis B, about 60,000 of whom live in NSW. An estimated 325 deaths in 2009 in Australia were attributable to chronic hepatitis B infection.

An estimated 217,000 people were living in Australia in 2009 with chronic hepatitis C infection, including 46,000 with moderate to severe liver disease. In NSW this amounts to around 80,000 people of whom around 80% contracted it through blood-to-blood contact from sharing equipment used to inject drugs. The majority of those people no longer inject drugs.

As noted in the 2010 National Hepatitis B & C Strategies people most affected by hepatitis are often best placed to respond to its impacts. These communities are diverse and are made up of people from a range of backgrounds who either because of stigma and discrimination are often marginalised from health care services and treatment. This may be due to perceived judgements made around injecting drug behaviour or around institutionalized or overt racism.

Although communities affected by hepatitis are not one homogenous group their commonality comes from their shared experience of living with or being affected by hepatitis.

As noted earlier there are a number of community organisations and networks that would facilitate dialogue between NSW Health and communities affected by hepatitis. These include peer organisations such as Hepatitis NSW, NUAA (NSW Users and AIDS Association) as well as organisations such as Multicultural HIV/AIDS and Hepatitis C Service (MHAHS) and the range of Aboriginal Community Controlled Health Services, (ACCHS) through their NSW peak organisation, AH&MRC (Aboriginal Health and Medical Research Council).

### **Conclusion**

As the *NSW Health Community Engagement Framework* noted:

“There are groups of people who continue to remain marginalised in our society and as a result are not receiving appropriate health services in all circumstances. The barriers that contribute to marginalisation are often the same barriers that prevent their voices being heard when it comes to planning delivering health care.”

Similar to already identified communities such as Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, and people with disability; people affected by HIV and the GLBT community experience marginalisation in our society, and in our health system. To fulfil the statement that “Health care services need to address these barriers”, including people affected by HIV/Hepatitis and the GLBT communities in conversations, consultations and partnerships are the first steps.

## About US

**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.

**Hepatitis NSW** (HNSW) is an independent, community-based, non-government health promotion charity funded by NSW Health. We provide information, support, referral and advocacy for people affected by hepatitis C in NSW. We also provide workforce development and education services both to prevent the transmission of hepatitis C and to improve services for those affected by it.

We strive to be representative of people affected by hepatitis C and work actively in partnership with other organisations and the affected communities themselves to bring about improvements in quality of life, information, support and treatment, and to prevent HCV transmission.

**Positive Life NSW** is a community based NGO that has represented the interests of people living with HIV in New South Wales since 1988. We provide advocacy, peer support, HIV prevention and health education campaigns and resources that focus on the experiences of people with and affected by HIV. We work to promote a positive image of people affected by HIV with the aim of eliminating prejudice, isolation, stigmatisation and discrimination.

The **Bobby Goldsmith Foundation** (BGF) is Australia's oldest HIV charitable organisation and the only one of its kind. Founded in 1984, it provides direct financial and practical assistance, financial counselling, housing and employment support to people directly disadvantaged by HIV in New South Wales.

List of Recommendations:

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3. That the *NSW Health Community Engagement Framework* includes specific discussions of the GLBT community under Section 3.2 of the document.
4. That the *NSW Health Community Engagement Framework* supports the inclusion of the GLBT community in all consultation processes of the Department of Health, its agencies and Local Health Networks.
5. That the *NSW Health Community Engagement Framework* supports the establishment of a Ministerial Advisory Committee on GLBT Health and Safety (MACGLBT).

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