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Australasian Society for HIV Medicine

PositiveLifeNSW
the voice of people with HIV since 1988

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BUILDING OUR COMMUNITY'S
HEALTH & WELLBEING

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NSW USERS & AIDS ASSOCIATION INC

 **Hepatitis**
NSW


**bobby
goldsmith
foundation**
practical emotional
financial support

Submission to:

**NSW Health on *Health Reform in NSW: A
Discussion Paper***

September 2010

General Comments

NSW is one of the only jurisdictions in the Western world that have stabilised the rate of HIV transmissions while comparable jurisdictions have seen significant increases. This has been the result of a strong partnership between government, researchers and community organisations working to prevent the spread of HIV, viral hepatitis and sexually transmissible infections (STIs). The key elements of this success have involved the government's commitment to funding prevention and health promotion programs from a central policy and programmatic level of decision making; by working within a partnership approach; and maintaining a population health framework in order to achieve stable rates of infections.

It is from this unique and exemplary experience that this joint submission finds its comments towards the *Health Reforms in NSW: A Discussion Paper*. The following key principles outlined in this submission make up the strengths of the NSW response in the fight against the spread of HIV, STIs, and viral hepatitis. This approach provides a good model for other areas in the current health reform process and this document aims to outline the elements that have led to the achievements seen in NSW in regards to HIV, STIs and viral hepatitis.

Involving affected communities has been essential in the success of preventing HIV and delivering services to these communities. We hope this evidence based approach will be maintained throughout the reform process.

Additionally, a broad concern for the partner organisations is the lack of clarity on where health promotion and prevention programs will sit throughout the reform process and how the new model will impact on the management of prevention and health promotion activities throughout the state of NSW.

While the discussion paper focuses necessarily on the clinical aspects of the health system, the document omits any consideration of other aspects of the health system. Specifically, community based health services delivered by NGOs, which focus on a social determinants of health framework when providing services to at-risk populations who may not approach clinical settings as their first point of contact.

This submission represents the views of key non-government organisations (NGOs) involved in prevention, health promotion, harm reduction, education, treatment and support and advocacy initiatives for NSW citizens who are at-risk of acquiring Human Immunodeficiency Virus (HIV), viral hepatitis, and Sexually Transmissible Infections (STIs), as well as NSW citizens who are living with or affected by HIV, hepatitis, and STIs and in need of appropriate, accessible health services free from stigma and discrimination.

These key NGOs are effectively engaged in community-based primary health care, particularly early intervention, prevention, harm reduction care and support, supported accommodation and health promotion activities and represent the broad HIV and blood borne viruses (BBV) sector in NSW as well as specific communities or

sections of the community who are at high risk of acquiring BBV, which include the gay, lesbian, bisexual and transgender (GLBT) community, people with HIV, sex workers, injecting drug users, and people with hepatitis.

The organisations represented within this submission are ACON, the Australasian Society for HIV Medicine (ASHM), the Bobby Goldsmith Foundation (BGF), Positive Life NSW, NSW Users & AIDS Association (NUAA), and Hepatitis NSW. Descriptions of the role of each of these NGOs can be found in the last section of the submission.

The partner organisations to this submission (here-after referred to as “the partner organisations”) welcome the opportunity to make a submission towards this very important matter that will affect the health of NSW residents and look forward to any opportunities for further dialogue with NSW Health in relation to any issues identified within this submission.

Inclusion of NGOs in the Reform Process

The partner organisations are concerned about the limited opportunities that have existed to date for our sector to participate in discussions on the health reform process. While we are encouraged by the consultations with clinicians, nurses and allied health professionals, a similar level of consultation with the health NGO sector has not occurred.

The *National Health and Hospitals Network* (NHHN) reforms raise important concerns for the health NGO sector as a whole. There are several NGOs in NSW that provide health services that need to be considered as an integral part of the health system, rather than as sitting outside of the health system.

The *COAG National Healthcare Agreement* stipulates that Australia’s health system should:

- (a) be shaped around the health needs of individual patients, their families and communities;
- (b) focus on the prevention of disease and injury and the maintenance of health, not simply the treatment of illness;
- (c) support an integrated approach to the promotion of healthy lifestyles, prevention of illness and injury, and diagnosis and treatment of illness across the continuum of care; and
- (d) provide all Australians with timely access to quality health services based on their needs, not ability to pay, regardless of where they live in the country.¹

¹ COAG, *National Healthcare Agreement: Intergovernmental Agreement on Federal Financial Relations*, (2007), p. A3, available at: http://www.coag.gov.au/intergov_agreements/federal_financial_relations/docs/IGA_FFR_ScheduleF_National_Healthcare_Agreement.pdf

The agreement also states: “the healthcare system will strive to eliminate differences in health status of those groups currently experiencing poor health outcomes relative to the wider community.”²

The HIV and BBV NGO sector in NSW, represented by the partner organisations, has demonstrated a strong ability to connect with the local communities they serve and often has a stronger focus on prevention of illness and disease with highly specialised and specific skills to work with marginalised population groups that experience lower health outcomes.

By working within a framework articulated in the NSW HIV/AIDS, STI and Hepatitis Strategies, and their related Implementation Plan for Aboriginal and Torres Strait Islander people, the partner organisations work with NSW Health, Area Health Services, researchers, clinicians and affected communities to identify priorities for reducing future infections among those populations considered at highest risk: gay men, people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal people, people who inject drugs, and sex workers.

The experience of NGOs aligns closely with the stated principles of the *National Healthcare Agreement*, which has been reaffirmed in the *COAG National Health and Hospital Network Agreement*. Reforms at both the NSW state and the Commonwealth levels would benefit from a stronger engagement with NGOs in the health sector in the reform of health systems to achieve the aims and principles stipulated in the *National Healthcare Agreement*, and the *National Health and Hospital Network Agreement*.

As stated in the discussion paper *Health Reforms in NSW*, there is “[c]oncern that if community health and other services are separated from hospital based services, there is the potential to fragment patient care”. The inclusion of health NGOs in the planning, policy and programming processes are important to bring a community perspective and to ensure patients do not fall through the cracks between different service providers. Community based peer organisations are also important organisations to engage with marginalised communities. In the development of health reforms, communication and coordination between Local Hospital Networks and NGOs will need to be ensured.

The experience of NGOs in the health sector are also a rich source of information regarding the operation of specific programs and the likely impact on these specific programs under particular reforms. The partner organisations have a strong history of providing direct service delivery, health promotion, harm reduction, education and policy development in the areas of HIV/STIs and viral hepatitis. We are keen to bring this expertise to discussions about health sector reform.

We encourage the NSW Government to consult and engage with the partner organisations, and other relevant NGOs, in this reform process so that the strong

² *Ibid.*

outcomes achieved in the prevention of HIV, STI and viral hepatitis can be strengthened and sustained.

Recommendations:

1. NSW Health to specifically consult with the partner organisations and other relevant NGOs as part of the National Health and Hospital Networks reform process.
2. NSW Health includes communication and collaboration requirements between health NGOs and Local Hospital Networks as a part of the health reforms.

A Partnership Approach

Since the advent of the HIV/AIDS epidemic in Australia, and NSW more directly, our sector, has worked within an effective partnership model to tackle the determinants that affect the transmission of HIV, viral hepatitis and STIs across the population groups most at risk. Principles developed in HIV, particularly partnership and engagement with affected communities, have been replicated across the sector as they have been demonstrated to be effective.

The success of this approach in NSW is evident in the stability of HIV transmission rates over the past decade, while all other jurisdictions in Australia and other Western nations have seen HIV transmission rates increase. The partner organisations are committed to ensuring that this response in NSW continues.

This strength is also noted in NSW Health's Consensus Statement, *A Think Tank: Why are HIV Notifications Flat in NSW 1998 – 2006?* which acknowledges that the infrastructure, investment, and intensity of an effective partnership between government, clinicians, researchers and the community has contributed to containing the significant spread of HIV.³

Further, our work within this practical and effective partnership model means our sector has built particular knowledge and experience, largely attributed to the comprehensive and sustained financial and non-financial support given by the State Government to the NSW HIV/AIDS program.⁴ This has encouraged a more direct relationship in regards to our funding and performance agreements with NSW Health, through the AIDS and Infectious Diseases Branch, and has ensured alignment between our work and relevant state health strategies is clear.

The partner organisations have partnerships that extend beyond that with the NSW Government. Our partners also include university research centres, health professionals (such as general practitioners and medical specialists), other NGOs and peak bodies, as well as the affected communities themselves.

³ *Ibid.*

⁴ NSW Health AIDS and Infectious Diseases Branch, 2007, *The Impact of HIV/AIDS in NSW, Mortality, Morbidity and Economic Impact*, p. 6.

The success of the partnership approach in NSW should be considered in the development of Local Hospital Networks and broader reforms. A strong relationship between NGOs, Local Hospital Networks, Medicare Locals and other service providers will be crucial in maintaining the successes achieved in NSW in the areas of HIV, STI and viral hepatitis prevention, treatment and care and support.

We feel it is important to highlight that many of us are community organisations that work within peer based models. This is important because it means we provide unique services that cannot be duplicated by clinical settings and non peer based organisations. We are able to access at-risk communities because we are, in fact, part of the affected and most at risk communities and we are experts in our fields. This unique placement means our peer based programs and services build credibility and trust with population groups who may otherwise feel apprehensive about approaching mainstream services. The success of this model in NSW can be attributed, for example, to one of the lowest rates of HIV amongst people who inject drugs in the world.

This discussion paper outlines the structure of the Local Health Network Governing Council but does not include NGOs as fulfilling any necessary roles within the Governing Council and/or selection committees.

While the paper does suggest the selection process should aim to achieve “diversity objectives” in line with “cultural backgrounds that are prominent in the LHN’s community,” we believe relevant health NGOs should be included as representatives on the Governing Councils of Local Hospital Networks.

Recommendations:

3. NSW Health recognises in its health reform documents the importance of a strong partnership with the NGO sector.
4. NSW Health includes relevant health NGOs on the Governing Councils of Local Hospital Networks.

Equity

The principle of equity in the health system has been affirmed in the *National Healthcare Agreement*, with “all governments agree[ing] that the healthcare system will strive to eliminate differences in health status of those groups currently experiencing poor health outcomes relative to the wider community.”⁵

This is an extremely important issue to the partner organisations. Notably, not all members of the community we serve – namely, gay men and men who have sex with men (MSM), lesbian, transgender, bisexual and intersex people; people who inject drugs; sex workers; those living with Hepatitis C or B; those living with co-infection;

⁵ COAG, *op. cit.*

people who are drug dependent or engaged in drug treatment; and people living with HIV – have shared equally in the health gains made in the broader community.

NGOs, especially community based and peer based organisations, have the unique advantage of not only understanding the communities they serve, but also being a part of the communities they serve. This positions them as a key partner in delivering improved health services to marginalised communities that experience differential health outcomes. Indeed, this was recognised in the *Close the Gap* initiatives to address the disparity between Indigenous and non-Indigenous health.

To reflect the principle of equity throughout the reform process, NSW Health needs to ensure active engagement with these communities, and formally recognise the ability and unique place of community based and peer based organisations that have a proven track record of successful engagement with these communities.

Recommendation:

5. NSW Health include the principle of equity and eliminating health disparities between different groups as a principle in reform documents and recognise the role of community based NGOs in this process.

Prevention

While a focus on clinical care is important, transitioning to Local Hospital Networks at an area health level, does not only impact on clinical services, but equally on prevention and health promotion services. There is a risk, when addressing the health system to only focus on the clinical and acute care aspect, and overlook the impacts that such reforms will have on prevention and health promotion. It is important to integrate discussions on where prevention and health promotion programs will sit in order to plan for effective strategic responses that in the long term will work to alleviate pressures on the overall clinical and acute care health system.

The importance of prevention and health promotion has been demonstrated by the efficacy of the NSW response in the prevention of HIV and hepatitis C. An estimated 44,545 cases of HIV were avoided as a result of the various prevention initiatives in NSW in the period 1981 to 2005. The return on investment from the NSW Health AIDS and Infectious Diseases Branch in funding HIV prevention programs equated to a direct cost-benefit ration of 1:13. That is, for every \$1 invested in HIV prevention in NSW, there has been a saving of \$13 in clinical care costs to the NSW Government.

The results are similar for injecting drug use, with estimates that for every \$1 invested in needle and syringe programs (NSPs), more than \$5 were returned in healthcare cost-savings in the short term (10 years) and an estimated aversion of 32,050 new HIV infections and 96,667 new hepatitis C infections.⁶

⁶ National Centre in HIV Epidemiology and Clinical Research, *Return on Investment 2: Evaluating the cost-effectiveness of needle and syringe programs in Australia*, University of NSW, (2009), p. 8.

These prevention efforts, such as health promotion, peer education and needle and syringe programs are important elements of an effective health system. In addition to sexual health, prevention and health promotion will have an increasing importance as the population ages and to reduce the burden on the health system as a whole into the future. The current lack of clarity and focus on prevention in the health reforms should be remedied.

The HIV, viral hepatitis and STI program has been an effective program due to the centralised funding commitments of NSW Health towards prevention; this should be increased and expanded across other preventative health areas.

Recommendations:

6. NSW Health maintains and increases a focus on prevention and health promotion in reform documents.
7. NSW Health increases funding for prevention and health promotion activities to maintain the funding ratio between prevention and health promotion, and more clinical based health services.

State-wide Policy and Programming

Although the management of hospitals will be decentralised to Local Hospital Networks, other policies and programs, where appropriate, should continue to be managed on a state-wide basis.

For policies and programs that have worked well being managed more centrally, such as the HIV, STIs and BBV and NSP programs, there is a significant risk that decentralisation will have a negative impact and put at risk the world renowned outcomes achieved over a sustained period.

Much of the HIV program and NSPs service marginalised communities. These marginalised communities often require specialised services, such as peer education and support, as well as other health promotion activities to improve their health. A decentralised approach is less likely to deliver effective specialised services that tailor to the specific needs of at-risk communities.

Although there is a strong evidence base to support HIV prevention programs and NSPs, there is still stigma associated to these programs and the communities these programs work with. Due to stigma and a lack of specific knowledge around these areas, a decentralised approach may hinder the ability to deliver evidence based policy and programming decisions that specifically impact on communities at-risk.

Retaining decision making powers around such policies and programs at a state level provides the best opportunity for best practice standards in these areas to be developed and implemented.

Under a new health and hospital framework for NSW it is integral that sufficient flexibility continues to exist across funding and policy mechanisms in order to respond to new and emerging issues, including across geographic areas. The good heritage that has existed between the NSW government and our partner organisations over the years has meant direct results through evidence-based policy and program development, efficient administration, sound planning and timely reporting; all contributing to the efficacy of prevention and population based programs in NSW.

The partner organisations value the relationships we share with NSW Health and believe very strongly that our work in this way contributes to the achievement of state strategic goals by effectively reaching priority populations at-risk of HIV, STIs, and viral hepatitis under this framework.

Recommendation:

8. NSW Health maintain centralised policy and programming functions relating to the HIV, STI and BBV program, including NSPs.

Conclusion

The *National Health and Hospital Networks* reforms are an opportunity to improve our health system. However, the partner organisations are concerned that elements of the reform process may jeopardise crucial and effective elements of the current health system and erode the great gains achieved in the area of HIV, STI and viral hepatitis prevention.

For this reason, the partner organisations recommend focusing on the key principles that have demonstrated efficacy in improving the health of NSW. A strong engagement and partnership with health NGOs will deliver improved policy and service delivery outcomes. A continued effort to address health equity should be paramount in addressing the continued health status disparities experienced by communities most at-risk, gay men, people from culturally and linguistically diverse (CALD) backgrounds, Aboriginal people, people who inject drugs, and sex workers.

As the demands on treatment and care services increase with an ageing population, an increasing focus will be required on prevention and health promotion to relieve the burdens of tertiary health services. To best deliver prevention and health promotion, this will require evidence based policy and programming decisions that are best made on a state-wide population level, with strong engagement from communities and the NGO sector.

We encourage NSW Health to consider these principles in the development of the Local Hospital Networks as well as in the broader design of health system reform.

If you have any questions please contact Veronica Eulate, Acting Director, Policy, Strategy and Research at ACON, on (02) 9206 2048 or email veulate@acon.org.au.

Recommendations

1. NSW Health to specifically consult with the partner organisations and other relevant NGOs as part of the National Health and Hospital Networks reform process.
2. NSW Health includes communication and collaboration requirements between health NGOs and Local Hospital Networks as a part of the health reforms.
3. NSW Health recognises in its health reform documents the importance of a strong partnership with the NGO sector.
4. NSW Health includes relevant health NGOs on the Governing Councils of Local Hospital Networks.
5. NSW Health include the principle of equity and eliminating health disparities between different groups as a principle in reform documents and recognise the role of community based NGOs in this process.
6. NSW Health maintains and increases a focus on prevention and health promotion in reform documents.
7. NSW Health increases funding for prevention and health promotion activities to maintain the funding ratio between prevention and health promotion, and more clinical based health services.
8. NSW Health maintain centralised policy and programming functions relating to the HIV, STI and BBV program, including NSPs.

Partner Organisations to this Submission

ACON is Australia's largest community-based gay, lesbian, bisexual and transgender (GLBT) health and HIV/AIDS organisation. ACON provides a range of information and services in the areas of HIV and STI prevention, HIV care and support, health promotion, advocacy, counselling, and housing. ACON also has a focus on issues such as mental health, alcohol and other drugs use, violence and ageing within the GLBT community via a harm minimisation framework to address issues that can contribute to risk behaviours which increase the possibility of HIV/STI 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.

The **Australasian Society for HIV Medicine** (ASHM) is a key partner in the Australian response to HIV, hepatitis and related diseases. It works closely with government, advisory bodies, community agencies and other professional organisations. The Society conducts a broad Education Program in HIV and viral hepatitis for medical practitioners, health care providers and allied health workers and manages a program of continuing medical education in HIV and viral hepatitis. It manages the NSW Workforce Development Program and is about to commence a program of clinical education in conjunction with Aboriginal Community Controlled Health Services in NSW.

The **NSW Users & AIDS Association's** (NUAA) is a not-for-profit NSW-based community controlled organisation advocating for people who use drugs, particularly those who inject drugs. The peak drug user organisation in NSW, NUAA was formed in 1989 in the face of a growing HIV epidemic. Funded primarily by the NSW Health Department, NUAA provides peer education, practical support, information and advocacy to people who use and inject illicitly, their friends, and allies. NUAA has often led the way in developing innovative approaches to peer education and community development, and has contributed to Australia having one of the lowest HIV rates amongst people who inject in the world.

Formed initially as a support group in 1991, **Hepatitis NSW** is the independent, community-based non-government health promotion charity funded by the NSW Health department since 1994 to provide information, support, referral, advocacy, workplace development and capacity building services for all people in NSW affected by hepatitis C. Striving to be representative of, supportive and accessible to people

affected by hepatitis C, Hepatitis NSW works actively in partnership with other organisations and the affected communities to bring about improvement in the quality of life, information, support and treatment for the affected communities, and to prevent hepatitis C transmission.