



Dr Linda Kurti
Urbis
by e-mail
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Dear Dr Kurti

The National Hepatitis B Alliance (NHBA) represents a broad range of organisations in Australia working in the area of chronic hepatitis B. As a group, we are concerned that there is no current nationally coordinated response to chronic hepatitis B. To effectively respond to the needs of the estimated 200,000 people with chronic hepatitis B living in Australia, there is a clear need for national leadership.

The purpose of the NHBA is to exchange information and work collectively in improving the response to hepatitis B in Australia. As a consequence we see it as absolutely essential that there is national leadership in relation to hepatitis B and that a strategic, national response is developed and adopted across jurisdictions through Australian Health Ministers Advisory Council.

Advanced liver disease, liver cancer and death are all well recognised consequences of untreated hepatitis B. Early intervention, monitoring and treatment all improve health outcomes. Hepatitis B is significantly different from hepatitis C in the populations affected, its pathogenesis, transmission and epidemiology. There is a significant need in hepatitis B to see prevention as a health improvement strategy for people living with chronic hepatitis B, rather than as a primary prevention which is a very high priority with hepatitis C. Accordingly engagement with the health workforce must be an important feature of any hepatitis B strategy. While vaccination is available in Australia for hepatitis B, the greatest burden of hepatitis B is among non-Australian born individuals who have not received the benefit of vaccination.

The attached document responds to the specific issues put by Urbis and the Alliance collectively and its individual members welcome the opportunity to participate more fully in the development of a National Hepatitis B Strategy. For further information please contact Rae Neill NHBA@hepatitis.org.au

Kind regards

on behalf of the NHBA

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ALLIANCE MEMBERS LIST

- Advancing the Clinical Treatment of Hepatitis B Virus (ACT-HBV) •Association for Prevention and Harm Reduction Program (ANEX) •Australasian Hepatology Association (AHA)
- Australian Council of Chinese Medical Association (ACCMA) •Australian General Practice Network (AGPN) •Australian Liver Association/Gastroenterological Society of Australia (ALA/GESA)
- Australian Research Centre in Sex, Health and Society (ARCSHS) •Australasian Society for HIV Medicine (ASHM) •Hepatitis Australia (HA) •Cancer Council Australia (CCA)
- Ethnic Communities Council of Queensland (ECCQ) •Multicultural HIV/AIDS and Hepatitis C Health Services (MHAHS) •National Centre in HIV Epidemiology and Clinical Research (NCHECR)
- National Centre in HIV Social Research (NCHSR) •NSW Refugee Health Service (RHS) •St Vincent's Hospital Melbourne (SVHM) •The Cancer Council New South Wales (CCNSW)
- Victorian Infectious Diseases Reference Laboratory (VIDRL)

REVIEW OF THE NATIONAL STRATEGIES (2005-2008) FOR HIV/AIDS, HEPATITIS C,
SEXUALLY TRANSMISSIBLE INFECTIONS AND ABORIGINAL AND TORRES STRAIT
ISLANDER SEXUAL HEALTH AND BLOOD BORNE VIRUS

Urbis has been contracted by the Department of Health and Ageing to review the four National Strategies (2005-2008) for HIV/AIDS, hepatitis C, sexually transmissible infections and Aboriginal and Torres Strait Islander sexual health and blood borne viruses.

We are very interested in your perspective regarding the current governance and implementation of the Strategies, as well as the content of the Strategies. For that reason we are providing this template with several key questions; please respond to as many of the following questions as you can, referring to whichever Strategy(ies) are relevant to your knowledge and experience.

Please note that your comments will remain confidential to our research team and your comments will not be directly attributed within the final report, unless we first obtain your permission to do so. Should you have any further comments, concerns or questions about the research process, please contact the lead evaluator, Dr Linda Kurti, at Urbis on (02) 8233 9947, or lkurti@urbis.com.au.

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A. Review of Strategies

A1. In your view, what have been the **main achievements** of the work auspiced through the 2005-08 Strategy/ies?

In spite of an estimated 200,000 people infected with chronic hepatitis B in Australia, there has been little nationally coordinated response to this health issue. From the perspective of people working with issues related to hepatitis B, there has been very little progress in the current strategic response or advisory bodies except the establishment of a hepatitis B working-group within the Hepatitis C Committee.

The development of the National Hepatitis B Needs Assessment, which was not funded with government support, and the inclusion of hepatitis B in the Australasian Viral Hepatitis Conference has been two of the positive steps to getting hepatitis B onto the agenda but this was achieved outside the strategies framework.

A2. When the next iteration of Strategies is developed, what **key approaches and activities** need to be retained?

The next iteration of the strategies need to include specific strategies to reduce the burden of hepatitis B on the community and particularly people infected with chronic hepatitis B. Two choices for accomplishing this could included using the framework developed for hepatitis C and developing specific strategies within the framework which address hepatitis B related needs, or the development of a specific hepatitis B strategy with a broader consultation process. As with the response to HIV/AIDS and hepatitis C, the response to hepatitis B needs to include a partnership approach. The partners involved in this response need to include representatives of communities most affected by hepatitis B such as communities from culturally and linguistically diverse backgrounds and Indigenous communities, and representatives of health care workers most involved in addressing hepatitis B related illness. This is a significantly reworking of the current stakeholders, as these stakeholders have not previously been supported to participate in the partnership.

A3. In the next iteration, what **key changes** would you like to see?

The establishment of a National Hepatitis B Strategy which is resourced, coordinated and responsive to the unique nature of hepatitis B.

Hepatitis B is predominantly a disease experienced by people born outside Australia and hepatitis B rate remain extremely high in Aboriginal and Torres Strait Islander Communities. There needs to be an active and sensitive approach to these individuals so that they can be screened for progressive hepatitis B disease, monitored and treated optimally. The National Hepatitis B Needs Assessment found that the lack of systemic pre and post diagnostic test discussion and the lack of adequate resources available for people with hepatitis B meant that many people with hepatitis B are not responding effectively to their infection.

There is considerable concern that discrimination and stigma may make these individuals and their families hard to reach and for that reason it is important that any strategies involve affected communities and their culturally specific supports such as media, professional and cultural associations.

The strategy should be totally separate or included as a separate schedule within a broader viral hepatitis strategy which could have 2 x separate and resourced schedules, one for hepatitis C and one for hepatitis B.

B. Review of the governance and implementation of the Strategies

B1. What have been the **key strengths or limitations** of the existing committee and subcommittee structure and membership (2005-08)?

The existing committees have been dysfunctional from the outset as they have comprised a number of people with no expertise in the issues and little commitment to engage with organisations which work in the areas or communities most affected by the specific viruses. We have seen in the past that a lay person can act as a strong advocate for an issue this was demonstrated in the 1980s when Ita Buttrose was appointed head of NACAIDS. But in that role she immersed herself in the response to HIV and was supported by people with skills in the area. In the current committees there have been a number of people who have no understanding of the issues at hand and who have made no attempt to engage.

The Committees have not been resourced to undertake work which could be used to lead and inform the national response, and have not engaged with organisations within the sector who could assist in the development of strategy and strategic responses. Support to the members has been non-existent and this has meant that work has not progressed. One example of the impact of this lack of resourcing is found in the extended development time for the Hepatitis C Prevention, Treatment and Care: Guidelines for Australian Custodial Settings. This document took almost 7 years to develop; was to be a key platform for addressing hepatitis C related issues within correctional settings, and required broad consultation to ensure its effectiveness. The lack of resourcing for this process has meant that the document does not have the credibility nor impact on a group of people within the community who were identified as being a key priority group within the National Hepatitis C Strategy.

Rapid turn around in key staff within the department has meant that corporate history has been lost and there has been such a high level of frustration amongst committee members that there is a fear good people will walk away.

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There has been confusion as to the role of the committees their relationships to each other and the activities of states and territories.

If the strategies: viral hepatitis, HIV/STI and Aboriginal and Torres Strait Islander STI and BBV health are to remain linked then ATSI health strategies should be included in each of the condition-based strategies.

B2. What are your top-priority suggestions for improvement in the governance process?

Clear Terms of Reference and purpose. The committees should comprise experts who can provide strategic advice. There should also be greater engagement with other key government ministries or jurisdictions such as AusAID, Immigration, Corrections, Education, Attorney Generals etc and a mechanism for cross fertilisation.

Funding for a secretariat and a budget or role in priority setting.

Greater inclusion of research expertise, via the inclusion of relevant research and workforce development experience on each of the committees.

Making viral hepatitis a National Health Priority should be a strategic aim for the Committee. This will put viral hepatitis on the broader national agenda and will cause divisions of general practice to include viral hepatitis on their training and support agenda.