



BUILDING OUR COMMUNITY'S
HEALTH & WELLBEING

Submission to:

**Strategic Review of Health and Medical Research in
Australia**

March 2012

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), 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.

Our response to this review

Australian researchers have led the way and are highly valued internationally for their work in the field of HIV and their innovative work researching sexuality and sexual behaviours. This has been achieved in part through the integration of sexuality indicators throughout the breadth of research that has been undertaken. This has enabled Australia to implement and deliver a world leading response to HIV.

However the willingness to engage with issues of sexuality and health impacts is less evident across the broader field of health research. Sexuality questions have not been included in most broad population based research, nor have they been included in most longitudinal studies of health. This has an impact on the policy making ability of government and service providers. It has also limited the ability of government and services providers to utilise an evidence based approach to improving the health outcomes for GLBT communities.

There are two main areas of concern when it comes to the inclusion of sexuality indicators in research: a lack of inclusion of sexuality questions in population wide health surveys; and a lack of routine collection of sexuality data in service provision. The latter is important as service related data sets are often important sources of secondary data for a range of health related studies and research. This is a significant deficit in our national knowledge base and is a major limitation to our ability as a nation to respond effectively to the health and medical challenges faced by GLBT communities.

Sexuality data has been included in a small number of research projects. Where data has been collected: The Australian Longitudinal Study on Women's Health (ALSWH); National Survey of Mental Health and Wellbeing (NSMHW); National Drug Strategy Household Survey; it shows a clear health inequity for GLBT people. The NSMHW showed, for example, that GLBT people were more than twice as likely to experience 'any mental disorder' and that homosexual and bisexual people were more than three times more likely to have had an affective disorder (such as depression) compared to heterosexuals¹.

However, the capacity to respond to these issues, when they are identified, is severely limited by the inconsistent nature of inclusion in other major studies and lack of collection of sexuality indicator

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

data on key health service data sets. The data that would come from the collection of this information has been shown to be useful when it comes to the Australian response to HIV. In NSW this data has helped in maintaining a stable rate of HIV transmission over the past 12 years, whilst other jurisdictions have continued to see increases.

Overseas jurisdictions are increasingly taking sexuality questions and indicators into account when developing health service and research agendas. Recently the Congress of the United States of America (US) recognised this in the *Affordable Care Act* and the US Government addressed it in *Healthy People 2020*, their national plan for reducing health disparities. Similarly, the Fenway Institute in the US has recently released two policy briefs specifically looking at the importance of gathering this data in clinical settings. The Williams Institute at the University of California, Los Angeles has also produced reports on best practice strategies to ask questions on sexuality in a broader range of research settings. Copies of these briefs are attached for your information.

ACON believes that this review provides an important opportunity to respond to the health inequities of a significant minority and for Australia to continue to demonstrate leadership in an increasingly recognised field of health research internationally. The inclusion of sexuality indicators is a low cost way to translate health research outcomes into improved health policies and practices.

ACON has written to AIHW about increasing the consistent collection of sexuality indicators in the research in which it is involved. The response was that the AIHW "did not see a policy imperative in collecting this information as a matter of course, and noted the difficulty of collection accurate information from those receiving a wide range of services". However, the experience to date of those studies in Australia which have included such questions is that it is perfectly feasible and possible to address these issues - often regarded as sensitive or personal - in general population health research and service provision. We also believe that the data that is available from the limited number of broad based research projects that do collect sexuality indicators has shown significant health disparities. When these existing disparities are viewed in the framework of the social determinants of health, we believe that there is enough evidence to warrant the inclusion of sexuality questions in a broad range of health and medical research.

We therefore believe that it is time for Australia to act on this issue and for key research bodies such as the National Health and Medical Research Council, Australian Institute of Health and Welfare and Australian Research Council to increase awareness of the importance of collecting this data, educate and support researchers around the feasibility of data collection and to promote appropriate strategies to collect this data, thus ensuring the availability of adequate data to better define the extent of the health disparities facing this population and inform an appropriate health policy and service response.

Recommendations:

1. That the data dictionaries produced by the National Health and Medical Research Council, Australian Institute of Health and Welfare and Australian Research Council, including the National Health and National Community Services and National Housing Data Dictionaries are updated to include indicators of sexual orientation and gender identity.

2. That the National Health and Medical Research Council, Australian Institute of Health and Welfare and Australian Research Council issue policy positions explaining the importance of including sexuality, sexual orientation and gender identity indicators in data. These should be promoted and circulated widely by the research bodies to all grant recipients, current and future, and outline how to go about inclusion.

3. That the Australia Bureau of Statistics lead a national consultation in partnership with National Health and Medical Research Council, Australian Institute of Health and Welfare and Australian Research Council on the updating of the data dictionaries and the policy position on the collection of sexuality, sexual orientation and gender identity indicators.