Submission to the

McKeon Strategic Review

of Health and Medical Research

in Australia

30 March 2012

Acknolwedgements

The National LGBTI Health Alliance is the national peak health organisation for a range of organisations and individuals from across Australia that work to improve the health and well-being of lesbian, gay, bisexual, trans/transgender, intersex and other sexuality, sex and gender diverse (LGBTI) people and communities.

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The Alliance acknowledges the traditional custodians of country throughout Australia, their diversity, histories and knowledge and their continuing connections to land and community. We pay our respect to all Australian Indigenous peoples and their cultures, and to elders of past, present and future generations.

The Alliance also acknowledges our LGBTI Elders for their work and sacrifice on behalf of LGBTI Australians.

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Abstract. The significantly poorer health outcomes of LGBTI Australians as a group are largely due to discrimination and exclusion as key social determinants of health. The health issues, treatment options, and preventive health measures relating to the significant population of LGBTI Australians should become a priority in Australian health and medical research. Such research must take place in the Australian social context, become a standard part of all routine data collection and existing research projects, and become a priority in the commissioning of new research. Funding bodies should include diverse sexuality, sex and gender in funding application guidelines, and people with expertise in LGBTI health in panels that assess funding applications. Implementation of research findings could be facilitated by Government departments and agencies having an 'LGBTI Liaison' officer monitoring research, recommending changes to policy, and suggesting concrete measures to operationalise these policies. Governments and research bodies should include LGBTI representation on advisory groups. LGBTI organisations and individuals should be invited to participate in relevant policy reviews and service assessments, and be adequately resourced to participate and make submissions.

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Summary of Recommendations

Term of Reference 1.

The significantly poorer health outcomes of LGBTI Australians as a group are due to discrimination and exclusion as key social determinants of health. Thus in order to address the health issues of LGBTI Australians, research must take place in the social context they inhabit; ie within Australian communities. Data from other societies such as the US, UK and Canada are of limited value for working with a population whose health outcomes are largely socially determined.

Term of Reference 5.

Increasing numbers of individuals are reporting same-sex attraction, behaviours and relationships, a variety of diverse gender identities and expressions, and Intersex variations. Health and medical research into the unique and often highly complex health issues of these groups will increase in prominence and urgency, both in Australia and overseas, and so should be made a priority in Australia.

The strategic priority of health and medical research about Australia's LGBTI populations can be put into action in two main ways:

1. Including questions about diverse sex, sexuality and gender in *all* data dictionaries, routine data collections, and research projects (see Appendix A for some suggested options). Such categories could be aggregated for some forms of statistical analysis, particularly in longitudinal studies where comparability with previous iterations is an important consideration. Researchers who fail to include such questions should be expected to justify their exclusion.
2. Commissioning new research, both qualitative and quantitative, into the health and wellbeing of LGBTI Australians. Based on current reported research in Australia and overseas, the most urgent areas are:
    a. Ageing and Aged Care
    b. Mental Health and Suicide Prevention
    c. Alcohol, Tobacco and Other Drugs
    d. Primary care
    e. Overweight and Obesity
    f. Effects of long-term hormone use

Term of Reference 10.

The interaction of health and medical research with Government health policies and programs could be managed in the following ways to facilitate implementation of research findings:

- Government to identify LGBTI Australians as a 'special-needs' group, and target research funding accordingly.
- Education and training of health professionals to comprehensively include LGBTI health, with opportunities for advanced qualifications involving LGBTI health research.

- Funding bodies such as the NH&MRC, AIHW, ARC etc.
    - Include diverse sexuality, sex and gender in funding application guidelines.
    - Include people with expertise in LGBTI health and wellbeing in reference and advisory groups, and particularly in panels that assess funding applications.
    - Require funded research to make use of advisory or reference groups that include LGBTI representation.
- Government Departments and Agencies to have a position of 'LGBTI Liaison' filled by a staffer with expertise in LGBTI health and wellbeing. This role would involve monitoring research findings for material that is relevant to existing policies, such as the National Women's Health Policy and the National Male Health Policy, or which requires new policy initiatives, and making appropriate recommendations.
- Government Departments and Agencies to have LGBTI advisory or reference groups, or include LGBTI representation on existing groups.
- Notify LGBTI organisations of relevant policy reviews and service assessments, and adequately resource them to participate and make submissions.

Introduction: Who we are

The Alliance is the national peak health organisation for a range of organisations and individuals from across Australia that work together to improve the health and well-being of lesbian, gay, bisexual, transgender, intersex and other sexuality, sex and gender diverse people (LGBTI)[1] and communities. Formed in 2007, the Alliance includes the major providers of services for LGBTI people in Australia, with 67 Member Organisations and more than 50 individual member drawn from each State and Territory.

Alliance Members have come together to work collaboratively to improve the health and wellbeing of LGBTI people, their carers, families, and communities by:

- supporting evidence-based decision-making through improved data collection covering sexuality, sex and gender identity;
- developing policy and advocating with a national voice on LGBTI health and wellbeing issues;
- seeking increased commitment to health services for LGBTI people and communities;
- building the capacity of our members to work with and for LGBTI people, their carers, families, and communities.

Key areas of work for the Alliance include: Ageing and aged care; alcohol, tobacco and other drugs; disabilities; health and human rights; mental health and suicide prevention; monitoring and research; primary care; relationship recognition; sex and gender diversity; sexual health; and violence, homophobia and transphobia. The Alliance's website (www.lgbtihealth.org.au) provides a wide range of resources, including copies of policy submissions, media statements, governance information and LGBTI health information.

We welcome the opportunity to comment on the Strategic Review of Health and Medical Research.

Why we are interested in this Strategic Review?

Lesbian, gay, bisexual, transgender and intersex (LGBTI) people make up a significant proportion of the Australian population: 9% of adult men and 15% of women report either same sex attraction or some sexual experience with the same sex (Smith et al. 2003); up to 1:1,000 people may be transgender (Department of Health 2008, Olyslager & Conway 2007); and up to 1:200 intersex (Diamond 2004, Blackless 2000). LGBTI people are part of all population groups, including Australians living in rural and remote areas, indigenous communities, and in culturally and linguistically diverse populations.

Many LGBTI people lead healthy and fulfilling lives contributing to their families, local communities, workplaces and society as a whole. Nevertheless, the experience of dealing with marginalisation and stigmatisation often impacts on LGBTI people's health. For example, we know that LGBTI people have disproportionately negative mental health outcomes in comparison with the rest of the population, including depression and suicide (Rosenstreich 2011). The use of alcohol, tobacco and other drugs is also higher than the wider population (AIHW, 2011).

Research demonstrates that these negative outcomes are not due to sexual orientation, sex or gender identity as such, but rather are related to the social determinants of health. In particular, these include the discrimination, social exclusion and isolation experienced by LGBTI Australians, and the failure of generic

[1] The Alliance uses 'LGBTI' to cover lesbian, gay, bisexual, trans/transgender, intersex and other sexuality, sex and/or gender diverse people. Other groups and previous Alliance documents may use these and/or other initials in a different order.

health interventions and prevention strategies in this country to be inclusive of LGBTI people and their needs (Couch et al. 2007, Dyson et al. 2003, Hillier et al. 2005).

The general success of Australia's response to HIV/AIDS has been achieved in part by accurate surveillance data and research – including social and cultural research grounded in an understanding of the social determinants of health – developed in partnership with communities and service providers (National LGBTI Health Alliance 2009). Similarly the complex and sometimes unique health problems of LGBTI Australians cannot be met without timely and comprehensive health and medical research.

Matters for Review

1. Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector?

> Term of Reference 1: The need for Australia to build and retain internationally competitive capacity across the research spectrum, from basic discovery research through clinical translation to public health and health services research.

LGBTI Australians have significantly poorer health across the board than the general population, and a number of health areas where they are a particularly vulnerable, 'at-risk' group (AIHW 2011, Hillier et al 2004, Couch et al 2007, Pitts et al 2006). This is not due to sexuality, sex or gender identity in and of themselves, but rather due to discrimination and exclusion as key social determinants of health (Wilkinson & Marmot 2003). Therefore, in order to address the health issues of LGBTI Australians, research must take place in the social context they inhabit, the various domains of social space which impact on their health and wellbeing; ie within *Australian* communities. Data from other societies such as the US, UK and Canada are of limited value for working with a population whose health outcomes are largely socially determined.

3. What are the health and medical research strategic directions and priorities and how might we meet them?

> Term of Reference 5: Likely future developments in health and medical research, both in Australia and internationally.

Increasing numbers of individuals are reporting same-sex attraction, behaviours and relationships, a variety of diverse gender identities and expressions, and Intersex variations, both in Australia and internationally (Smith et al 2003; Couch et al 2007). Given the unique and often highly complex health issues of these groups, and the relative lack of reliable Australian research data about them, health and medical research about LGBTI Australians should definitely be a high priority.

In the Australian Study of Health and Relationships (ASHR) conducted in 2001/2002, 2.5% of the 19,307 respondents identified as something other than heterosexual (Smith et al 2003, p. 139). By comparison, in the 2010 iteration of the National Drug Strategy Household Survey (NDSHS), 3.3% of the 26,000 people surveyed identified as something other than heterosexual (AIHW 2011, p. x). This represents an increase of 0.8% over an eight year period. Whether this is attributable to the increasing willingness of non-heterosexual people to so identify in data collections where their anonymity is assured, or to an actual increase in the number of same-sex attracted Australians, it is evidence that this is a significant segment of

the population. As registered marriage is not currently available to same-sex couples in Australia, any questions about relationship status should be worded to be inclusive of same-sex relationships. Similarly questions about kin relationships should be inclusive of same-sex, intersex, and gender diverse parents, and non-biological kinship networks.

There are no reliable estimates at this time for the numbers of intersex, transgender and other people of diverse sex and gender. The International Statistical Classification of Diseases and Related Health Problems, 10th Revision, identifies 116 biological variations under the term 'Intersex'; only twenty appear on Australian lists of reportable birth defects, while many intersex variations are only detected later in life (WHO 2010). Various groups supporting sex and gender diverse people in Australia are reporting increasing demand for health services for trans and intersex people, such as GPs, psychologists, psychiatrists, endocrinologists, and surgeons, putting existing services under severe strain, and resulting in many seeking treatment overseas (e.g. Longhurst 2012). The treatment of people of diverse sex and gender will become increasingly widespread and sophisticated and will need to become a research priority.

The strategic priority of health and medical research about Australia's LGBTI populations can be put into action in two main ways:

1. Including questions about diverse sex, sexuality and gender in *all* data dictionaries, routine data collections, and research projects (see Appendix A for some suggested options). Such categories could be aggregated for some forms of statistical analysis, particularly in longitudinal studies where comparability with previous iterations is an important consideration. Researchers who fail to include such questions should be expected to justify their exclusion.

2. Commissioning new research, both qualitative and quantitative, into the health and wellbeing of LGBTI Australians. Based on current reported research in Australia and overseas, the most urgent areas are:
    a. Ageing and Aged Care
    b. Mental Health and Suicide Prevention
    c. Alcohol, Tobacco and Other Drugs
    d. Primary care
    e. Overweight and Obesity
    f. Effects of long-term hormone use

4. How can we optimise translation of health and medical research into better health and wellbeing?

Term of Reference 10. Ways in which health and medical research interacts, and should interact, with other Government health policies and programs; including health technology assessments and the pharmaceutical and medical services assessment processes.

The interaction of health and medical research with Government health policies and programs could be managed in the following ways to facilitate implementation of research findings:

- Government to identify LGBTI Australians as a 'special-needs' group, and target research funding accordingly.
- Education and training of health professionals to comprehensively include LGBTI health, with opportunities for advanced qualifications involving LGBTI health research.
- Funding bodies such as the NH&MRC, AIHW, ARC etc.
    - Include diverse sexuality, sex and gender in funding application guidelines.

    - Include people with expertise in LGBTI health and wellbeing in reference and advisory groups, and particularly in panels that assess funding applications.
    - Require funded research to make use of advisory or reference groups that include LGBTI representation.
- Government Departments and Agencies to have a position of 'LGBTI Liaison' filled by a staffer with expertise in LGBTI health and wellbeing. This role would involve monitoring research findings for material that is relevant to existing policies, such as the National Women's Health Policy and the National Male Health Policy, or which requires new policy initiatives, and making appropriate recommendations.
- Inclusion of LGBTI issues in policies should be accompanied by concrete measures to operationalize these policies.
- Government Departments and Agencies to have LGBTI advisory or reference groups, or include LGBTI representation on existing groups.
- Notify LGBTI organisations of relevant policy reviews and service assessments, and adequately resource them to participate and make submissions.

Appendix A – Sample survey items.

1. Sexuality

Text Box 1: Sexuality-related questions in the Australian Study of Health and Relationships
(Smith et al 2003, p. 139).

Ascertainment of sexual identity, attraction and experience among men.
(After question on occupation)

Question: Do you think of yourself as . . .
(Interviewer reads out categories 1 to 3 with numbers. Interviewer codes 'normal' as 1. If 1, 2 or 3 and also 'Queer', interviewer codes as 4.)
1. Heterosexual or straight
2. Homosexual (gay)
3. Bisexual
4. Queer
5. Not sure; undecided
6. Something else/other (interviewer types in response as well as code).
9. Refused

Question: Which of these six statements best describes you? I will read them out and ask you to please just give me the number.
1. I have felt sexually attracted only to females, never to males.
2. More often to females, and at least once to a male.
3. About equally often to females and males.
4. More often to males, and at least once to a female.
5. Only to males, never to females.
6. I have never felt sexually attracted to anyone at all.
9. Refused.

In the next question when we say 'sexual experience' we mean any kind of contact with another person that you felt was sexual. It could be kissing or touching, or intercourse, or any other form of sex.

Question: Which of these statements best describes you? Again I will read out the list and you tell me the number.
1. I have had sexual experience only with females, never with males.
2. More often with females, and at least once with a male.
3. Equally often with females and males.
4. More often with males and at least once with a female.
5. Only with males, never with females.
6. I have never had any sexual experience with anyone at all.
9. Refused.

2. Sex and Gender

Text Box 2. Suggested questions to obtain data about Transgender and Intersex people.

ZZ1. Sex and Gender Identity.

Question: What was your sex assigned at birth (i.e. the sex recorded on your birth certificate)?
1. Female
2. Male

Question: What is your sex now?
1. Female
2. Male
3. A mixture of male and female
4. Intersex

Question: Do you think of yourself as . . .
1. Female
2. Male
3. Both female and male
4. Neither female nor male
5. Not sure; undecided
6. Something else/other (please specify)

3. Relationships

Text Box 3. Suggested question about relationship status that clearly includes cohabiting relationships.

Relationship Status.
Question: Which one of the following best describes your *present* relationship status? (Mark one response only)

1. Never partnered
2. Partner has passed away
3. Separated from partner
4. Living with partner
5. Partnered but living in separate residences

Text Box 4. Suggested questions about marital and relationship status with a separate question about cohabiting relationships.

ZZ3. Marital/Relationship Status.
Question: Which one of the following best describes your *present* relationship status? (Mark one response only, in either A or B)

A. Registered Marriage
1. Never married
2. Widow/Widower
3. Divorced
4. Separated but not divorced
5. Married
6. Married but living in separate residences

B. De facto, living together, civil union
1. Never partnered
2. Partner has passed away
3. Separated from partner
4. Living with partner
5. Partnered but living in separate residences

References

AIHW Australian Institute of Health and Welfare (2011), *2010 National Drug Strategy Household Survey report*. Drug statistics series no. 25. Cat. no. PHE 145. Canberra: AIHW. http://www.aihw.gov.au/publication-detail/?id=32212254712&tab=2 [Accessed 15/03/2012].

Blackless, Melanie, Anthony Charuvastra, Amanda Derryck, Ann Fausto-Sterling, Karl Lauzanne and Ellen Lee (2000) How Sexually Dimorphic Are We? Review and Synthesis. *American Journal of Human Biology*, 12:151-166.

Couch, Murray, Marian Pitts, Hunter Mulcare, Samantha Croy, Anne Mitchell and Sunil Patel (2007) *TranZnation – a report on the health and wellbeing of transgender people in Australian and New Zealand*. Australian Research Centre in Sex, Health and Society, La Trobe University. Melbourne.

Department of Health (2008) *Trans: A practical guide for the NHS*. Department of Health. London. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089941 [viewed 16/4/2011].

Diamond, Milton (2004) Pediatric Management of Ambiguous and Traumatized Genitalia. *Contemporary Sexuality*, 38(9): i-vi.

Dyson, Sue, Anne Mitchell, Anthony Smith, Gary Dowsett, Marian Pitts and Lynne Hillier (2003) *Don't ask, don't tell. Report of the same-sex attracted youth suicide data collection project.* Australian Research Centre in Sex, Health and Society, La Trobe University. Melbourne.

Hillier, Lynne, Alina Turner and Anne Mitchell (2005). *Writing themselves in again: 6 years on - the 2nd national report on the sexuality, health & well-being of same-sex attracted young people.* Australian Research Centre in Sex, Health and Society, La Trobe University. Melbourne.

Longhurst, Toby (2012) 'Queensland Transgender Services at Risk', *QNews* 13 January 2012. http://qnews.com.au/article/qld-transgender-services-risk [Accessed 13/01/2012]

National LGBTI Health Alliance (2009) *Australia: The Healthiest Country by 2020*. Submission to the Preventative Health Taskforce, January 2009. http://www.lgbthealth.org.au/sites/default/files/National-LGBT-Health-Alliance-Submission-Preventative-Health-Taskforce-Jan-2009.PDF [Accessed 30/03/2012].

Olyslager, Femke and Lynn Conway (2007*) On the Calculation of the Prevalence of Transsexualism*. Paper presented at WPATH 20th International Symposium, Chicago, Illinois, Sept 5-8 2007. http://ai.eecs.umich.edu/people/conway/TS/Prevalence/Reports/Prevalence%20of%20Transsexualism.pdf [viewed 16/4/2011].

Pitts, Marian, Anthony Smith, Anne Mitchell and Sunil Patel (2006) *Private Lives: A report on the wellbeing of GLBTI Australians*. Australian Research Centre in Sex, Health and Society, La Trobe University. Melbourne.

Rosenstreich, Gabi (2011) *LGBTI People: Mental Health and Suicide*. Briefing Paper. The National LGBTI Health Alliance, Sydney.

Smith, Anthony, Chris Rissel, Juliet Richters, Andrew Grulich and Richard de Visser (2003) Sex in Australia: Sexual Identity, Sexual Attraction and Sexual Experience Among a Representative Sample of Adults. *Australian and New Zealand Journal of Public Health*, 27(2): 138-145.

WHO World Health Organisation (2010) International Statistical Classification of Disease and Related Health Problems, 10th edition. http://apps.who.int/classifications/icd10/browse/2010/en#/Q50-Q56 [Accessed 30/03/2012]

Wilkinson, Richard and Michael Marmot (eds) (2003) *Social Determinants of Health – The Solid Facts. 2nd ed.* World Health Organisation, Geneva. http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf [Accessed 30/03/2012]