



LGBTI Data

**'Developing an
evidence-informed
environment for
LGBTI health policy'**

Discussion Paper, 2013

A discussion paper outlining why diverse sex, sexual orientation and gender indicators should be included in:

- national, publicly funded health and other research;
- monitoring mechanisms including minimum data-sets (including mental health and suicide prevention); and
- the Australian Census.

National LGBTI Health Alliance

The National LGBTI Health Alliance is the national peak health organisation for a range of organisations and individuals from across Australia that work in a range of ways 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. Visit www.lgbtihealth.org.au for further information.

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The Alliance acknowledges the traditional owners 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.

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Introduction

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Recomendations

1) That the Australian Government fund a *National Sex, Gender and Sexual Orientation Research Methods Project* led by Australian Institute of Health and Welfare (AIHW) in partnership with Australian Bureau of Statistics (ABS), Australian Research Council (ARC), National Health and Medical Research Council (NHMRC), Department of Health and Ageing (DoHA), Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and other relevant bodies to explore and discuss the various issues involved in obtaining LGBTI data.

2) That the proposed *National Sex, Gender and Sexual Orientation Research Methods Project* publish standardised questions and response values for all LGBTI indicators (including but not limited to commonly used terms/indicators such as Sexual Attraction, Sexual Behaviour, Sexual Identity, Assigned Sex at Birth, Sex on current Birth Certificate, Gender Identity); a guide for researchers including lessons learnt from the AIHW-led study; an update to the NHMRC's ethics guidelines on research involving LGBTI people and an annual report of data that describes the population characteristics of LGBTI Australians.

3) Those Australian Government agencies include reference to LGBTI people within research funding grant guidelines, to promote an increase in LGBTI-related data.

4) That the Australian Bureau of Statistics consider increasing LGBTI data within the 2016 Census by reviewing the proposed amendments to the 2011 Census Questions 3 and 5, along with introduction of a question on sexual orientation and conduct a field test of those questions with input from suitably qualified individuals with LGBTI experience.

5) That the Department of Health and Ageing actively explore ways to increase LGBTI content in National Minimum Data Sets, particularly in the areas of Mental Health and Suicide Prevention.

Lesbian, Gay, Bisexual, Trans/transgender and Intersex (LGBTI!) Australians are often neglected in Australian research and monitoring mechanisms. The Census does not allow Australians to record their diverse sex, sexual orientation or gender identity. Most national population research in Australia does not collect LGBTI demographic information, indeed there is no collection whatsoever for intersex or trans/transgender people, and only limited collection for some level of lesbian, gay or bisexual people. Monitoring mechanisms, such as National Minimum Data Sets (NDMS), also fail to capture the necessary information to determine if existing policy initiatives are achieving their desired outcome of improving the health and wellbeing of LGBTI Australians. The ability to identify LGBTI Australians within monitoring and research will assist in ensuring fair government service is provided to all Australians, including LGBTI people.

In recent years, following decades of social and legislative reforms, LGBTI Australians have begun to be included in various health and other public policies, strategies, action plans, programs and initiatives. However, due to the lack of comprehensive data about LGBTI people within most general research, policy decision-makers have been forced to turn to smaller scale LGBTI-targeted studies for evidence to inform their policies. While uniquely valuable, these LGBTI-targeted studies often sample participants from within, and connected to, LGBTI communities. Accordingly, such statistics tend to represent the respondents rather than a holistic picture of LGBTI Australians, not all of whom are connected to the LGBTI communities. Sometimes this disconnection from the LGBTI community is a result of health conditions, while at other times LGBTI health issues may be exacerbated by disconnection from the community, which may be a source of information and support.

Research that purports to represent trans/transgender and intersex people often uses primarily clinical populations in settings that do not reflect the range of health and wellbeing needs across their daily lives. As discussed later in this document, empirical analyses of research on trans/transgender and intersex people may often contain inaccurate assumptions and employ methodological approaches that diminish their accuracy and usefulness.

This includes treating people's genders and bodies as inherently pathological, imposing terminology that disregards people's gender identities, and characterising people in ways that do not reflect their own understandings of their lives. Additionally, there are fewer studies that include trans/transgender responses and even less that are inclusive of intersex people¹.

This paper will discuss different types of indicators that could be used to capture LGBTI-related data. We will briefly discuss barriers to the inclusion of LGBTI-related data and argue why action is necessary to provide the best possible evidence for public policy making.

The paper lists known examples of Australian LGBTI data and proposes new areas where LGBTI data could be incorporated. The paper also notes activities of comparable countries where a better knowledge base about LGBTI people is available. The paper presents recommendations for Australian Government departments, agencies and authorities.

While recognising that there is no one-size fits all solution for all forms of data collection, the paper discusses some of the issues around collection of data generally. It is proposed that a more comprehensive discussion of the barriers and benefits pertaining to specific forms of data collection would occur as part of the proposed *National Sex, Gender and Sexual Orientation Research Methods Project*.

It should be noted however that the inclusion of LGBTI indicators in any data set is likely to face barriers to all respondents providing accurate answers. Unlike other demographics collected (e.g. religion, ethnicity etc) a person who is LGBTI may not be known by people around them. Many LGBTI people may have faced discrimination by both individuals and institutions, indeed in some cases discrimination is seen as continuing to be enshrined in law. It is understandable therefore that LGBTI people may personally view their identity as private and may elect not disclose this information. This may be a particular issue in settings where the respondent fears the impact of disclosing, is concerned by stigma or discrimination. It may also occur where the collector of information has not adequately explained why the information is needed or how it will be used.

¹The National LGBTI Health Alliance uses "LGBTI" as a recognisable acronym to collectively refer to identities and experiences that include lesbian, gay, bisexual, trans/transgender and intersex people and other sexuality, sex and gender diverse people and communities, regardless of their term of self-identification.

This paper may also refer to "same-sex attracted" people as a collective referral to lesbian, gay and bisexual people, in addition to "sex and/or gender diverse" people as a collective referral to trans/transgender and intersex people. It is noted that intersex is distinct from trans/transgender and that individuals may not personally associate with such terms. For example SistaGirls is a term used by many Indigenous people who do not identify with the gender with which they were given by others. Members of this community may or may not associate with the terms trans or transgender.

Legislative and Social Reforms

LGBTI data collection methods often do not distinguish between the labels people use about themselves and the labels other people might use about them. People who are classified as transgender by others may self-identify simply as women or men. For example, someone who was assigned male at birth and whose documents list her sex as 'M' - may select woman as her gender and 'F' as her sex on a survey and not identify themselves as transgender. Similarly, intersex people may select male or female as their sex rather than nominating themselves as intersex.

There is a range of initiatives to reduce barriers for accurate responses including:

- improved and anonymous collection methods;
- clearly articulating how answers will be utilised and why they are being asked;

- the ability to select more than a single option and provide more than one response;
- questions that distinguish between identity and descriptors of behaviour/ attraction/ experience.

It is important to note that while a range of initiatives may be undertaken to mitigate barriers to collecting effective data, it is important to understand that for a range of reasons information may never be 100% accurate. An appreciation of the likely underreporting should be kept in mind when analysing and reporting on these data.

Australia acknowledges and endorses the diversity of its citizens, including people of diverse sex, gender and sexual orientation. In recent decades there have been socio-cultural advances in the inclusion of lesbian, gay, bisexual, trans/transgender and intersex (LGBTI) issues within public policy.

While it could be said that much of the focus of reforms over the past decades has been on same-sex attracted people (lesbian, gay and to a limited extent bisexual), there has also been limited progress for people of diverse sex (intersex) and/or gender identity (trans/transgender).

Up to April 2012, legislative and associated reforms include:

- decriminalisation of homosexuality² in (1972-1997);
- equalisation of age of consent laws³ (1975 – 2003; exc QLD);
- Removal of homosexuality from the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* (1973)
- World Health Organisation removing 'homosexuality' from International Classification of Diseases (ICD-10) (1990)
- introduction of equal opportunity and anti-discrimination laws at state⁴ (and soon federal⁵) levels of government for LGBT people (no protections for intersex people currently exist but are proposed in Tasmania⁶);
- recognition of some same-sex couples⁷:
 - as domestic/ defacto partners (all states and Commonwealth), or;
 - as a civil partnership / registered relationship (QLD, NSW, ACT, VIC, TAS)
 - within Family Law (Commonwealth)

- same sex parenting reforms⁸ including:
 - recognition of lesbian mothers on birth certificates (all states);
 - access to artificial reproductive treatments (all states except SA);
 - recognition as parents in family law (Commonwealth);
 - access to altruistic surrogacy (NSW, ACT, VIC & WA);
 - access to adoption for individual LGBTI people (QLD, NSW, ACT, VIC, TAS & WA);
 - access to step-parent adoption for same-sex partners (NSW, ACT, VIC, TAS, WA);
 - access to same-sex couple adoption (NSW, ACT, WA).
- advances in recognition of diverse sex/gender in documentation including:
 - access to updated birth certificates following gender affirmation treatment for trans/transgender people in limited circumstances⁹ (all states) and correction of mistaken sex in terms of intersex people
 - access to Australian Passports¹⁰ in a person's affirmed sex or gender, without the requirement of sex reassignment surgery, and with a new 'X' category for people's whose sex is indeterminate, unspecified or intersex.
- Recognition for all LGBTI people as a special needs group under the *Aged Care Act 1997*.



LGBTI data needed to inform decision making

LGBTI Australians have begun to be included within government and non-government policy frameworks. This includes broad health strategies and plans,^{11 12 13 14 15 16 17} as well as specific LGBTI policies, initiatives or programs.^{18 19 20} However there has been little work completed to actively secure LGBTI data to better inform relevant decision making.

Without the inclusion of LGBTI data in reporting mechanisms and research it is challenging to determine the effectiveness of such initiatives. Further, without greater LGBTI data allocation of future resources/initiatives may be hindered.

Below we discuss a few areas where an enhanced dataset may help to inform Government work:

Public Policy, particularly health

There is some inclusion of gay and lesbian people within nationally significant health data; however there remains no mention of people of diverse sex and/or gender identity. The decision to include (or not include) LGBTI Australians in particular policies is often made on the basis of the available data. In areas such as mental health,²¹ sexual health,^{22 23} and drug and alcohol usage,²⁴ there is significant national evidence of health disparities faced by same-sex attracted people. However in areas such as general health research,²⁵ socio-economic data,²⁶ mortality data-sets,²⁷ morbidity data-sets,²⁸ same-sex attracted people, continue to be excluded from national statistics. In all these areas trans/transgender people and intersex people have not been included.

Planning for LGBTI services

To better target future initiatives, enhanced data is required. Following the removal of same-sex discrimination in over 85 Commonwealth laws, the Federal Government have increased the number of both targeted and inclusive services for LGBTI populations such as mental health capacity building²⁹ and aged care community packages.³⁰ However, the lack of geography-based demographic information on LGBTI people may inhibit the ability to develop sophisticated program initiatives for these populations.

LGBTI Consumers – business needs to know

LGBTI consumers are niche markets for many businesses.^{31 32 33} Access to data on geographical locations, income, household, family and other general data from the census would be of enormous benefit to companies seeking to pitch their advertising spend towards this niche market.

Human Rights Monitoring

The draft exposure of the National Human Rights Action Plan³⁴ identifies the need to better collect data for the monitoring of human rights. Specifically under the target of “freedom from discrimination” the Action Plan notes that “*The Australian Government will amend data collection to allow for or encourage disclosure of sexual orientation and gender identity to establish a better evidence base for service provision and policy development*”.³⁵ It remains unclear if this action item will include consideration of inclusion within the Australian Census and if the action item will extend to include people of diverse sex.

Given the increasing demand by governments and other organisations for data on LGBTI health, the National LGBTI Health Alliance believes it is necessary for Australia’s research and statistics agencies to review the current lack of data and determine strategies for full inclusion.

The National LGBTI Health Alliance acknowledges the small but significant increase in national data available regarding sexual orientation over the past decade (Mental Health, Drug and Alcohol, Sexual Health and same-sex couples in the Census). While these data sets may be improved upon through the diversification of LGBTI identifiers, we more urgently draw attention to the lack of data available on trans/transgender or intersex people.

LGBTI / Sex, Gender and Sexual Orientation

Lesbian, Gay, Bisexual, Trans/transgender and Intersex Australians are not a single group of people that may be viewed as a single category. There are three distinct categories of demographics that may identify LGBTI Australians – sexual orientation, sex, and gender identity. Even amongst these three categories of demographics, it is important to note the distinction between how people self-identify and how others may label them. Accordingly, it is important to consider not only the category of questions that need to be asked but also the limitations on responses available to answer these questions.

There are a multitude of combinations across the concepts relating to sex, gender and sexual orientation. A man who was assigned ‘female’ at birth may or may not identify as trans, even when others would classify him as ‘a trans man’. He may have a sexual orientation of gay, bisexual, or straight, or be same-sex attracted and yet identify as heterosexual. A lesbian may also identify as intersex but list her sex as female.

There are multi-faceted issues to consider when collecting LGBTI data. This does not mean, however that researchers should abstain from collecting LGBTI data, or limiting data to the simplest categories of “identity”.

An approach to these complex issues may be for researchers to critically assess which concepts associated with sex, gender and sexual orientation are most applicable to their particular area of research:

- Is the reason for asking purely for demographics where perhaps ‘sexual identity’ (gay, bi, lesbian) along with options for diverse responses for ‘gender identity’ (trans/transgender) and ‘sex identity’ (intersex) may be appropriate?*
- Is knowledge of ‘sexual attraction’ instead of ‘sexual identity’ labels (gay, bi, lesbian etc.) more appropriate when discussing young people, still forming their identity, that sometimes can be fluid?³⁶*
- When looking at the biological health of Australians, consider the benefits of knowing someone’s biological history by asking their ‘assigned sex at birth’, their ‘sex*

listed on their current birth certificate’ and/or their ‘current gender identity’?

- In areas where health may be impacted by “minority stress”,³⁷ such as mental health or alcohol and other substances, are questions relating to levels of ‘attraction’ more beneficial than questions related to ‘identity’?*
- Are questions relating to ‘behaviour’ more appropriate than ‘identity’ or ‘attraction’ when looking at sexual health?*
- When looking at sexual health for transgender and intersex people, are questions about gender ‘experience’, ‘history’, ‘expression’, or ‘characteristics’ more appropriate than ‘gender identity’ or ‘sex’?³⁸*

Sex and Gender

Gender is a social construct that is generally understood in Australia as being “masculine” and “feminine” or of being a “man”, a “woman”. However, there are a number of Australians who fall outside this ‘binary’. It is important to remember that some populations and communities in Australia have come from societies that traditionally recognise more than two genders. For example, one society in Indonesia recognises five genders. In South Sulawesi, the third largest island of Indonesia, the Bugis society recognises the genders calalai, calabai and Bissu in addition to women and men. In Thailand, several gender categories are recognised beyond woman and man, such as kathoey, phuying praphet song and phet thi sam.

In contrast to gender, sex is presumed to be a natural fact that describes whether someone is biologically “female” or “male”. Medical evidence documents that many people’s bodies have natural variations that differ from “male” or “female”. These variations to the conventional assumptions about “female” or “male” biology can be made based on a wide range of physical differences including chromosomes, hormonal levels, hormone regulation and processing, genital configuration, gonads, body hair distribution, chest appearance, and/or other physical characteristics. Interestingly, up until the mid-1800’s anatomical diagrams from leading medical experts did not distinguish between the current two sex model, instead opting for a one sex model³⁹. Clearly, over time, societal understanding of the biological sex and its practical uses have evolved.

Sex indicators are one of the most common demographic items contained in research. However, it is unclear if all respondents conceptualise a distinction between sex and gender when completing research surveys. It is necessary therefore for this distinction to be clearly understood by researchers before looking

at the issues surrounding sex and/or gender. Further, as people's biological sex characteristics may not match their official (or legal) 'sex' consideration of the specific question being asked should be considered. This distinction between generalised 'sex' categories and specific biological characteristics is particularly important when considering the statistics relating to health where a person's biological characteristics (and not necessarily their 'sex' identity or classification) is the key indicators sought after. These distinctions may be important even for non-biological research that relates to intersections between biology and social determinants of health.

Further it should be noted that sex and gender are often conflated in legislation where man or woman is used (gender), basing the determination of gender on evidence contained within a birth certificate or other document which are based on a person's sex classification (being male or female). This presents a range of issues for trans/transgender and intersex people and those of diverse sex and gender.

Some overseas research guidelines have indicated the limitations of restricting responses to a single gender category and suggested that the addition of an 'other' category does not result in an increase of available data. In addition, people who have non-binary genders (i.e., genders other than the binary two options of woman or man) may not necessarily identify as transgender, and people with multiple genders (i.e., woman and man, woman and genderqueer) are unlikely to be recorded accurately by statistical recording methods that restrict the selection of more than one gender category. Thus methodologically sound LGBTI research can reduce underreporting by demonstrating an awareness of this diversity. Scientifically accurate LGBTI research design is based on an understanding of the distinction between how people label themselves and how other people might assume they identify.

There is no known guideline on categories of gender in research, by any leading research body in Australia. Sex according to the Australian Health Data Dictionary⁴⁰ is defined as *"The biological distinction between male and female, as represented by a code."* Contained within the Dictionary are permissible values of "male", "female" and "intersex or indeterminate". This definition assumes that people's assigned sex label automatically matches how they would label their own sex, which as discussed previously may not be the case.

A similar definition is used by the Australian Bureau of Statistics' Sex Standard⁴¹, which is currently being reviewed by ABS. In the current version (1999) of the sex standard recording of transgender people is recommended as being either male or female along with recording of ICD 10 AM codes in clinical settings. Intersex identification is permitted, but recommends it only be used perinatal and hospital morbidity collections. The Alliance sees a range of practical and technical issue with the current approach outlined in the standard and

along with other interested parties will make submissions to the ABS consultation process⁴².

There has been very little investigation of how best to collect gender and sex in research, however consideration of the available literature should be made in any approach in this regard.^{43 44}

What is Intersex?

Intersex is defined by the Australian Health Data Dictionary as "Intersex or indeterminate, refers to a person, who because of a genetic condition, was born with reproductive organs or sex chromosomes that are not exclusively male or female or whose sex has not yet been determined for whatever reason".⁴⁵ Intersex people may have chromosomal, hormonal or anatomical differences that are nonetheless commonly seen as male or female, both or neither.

Some intersex people may identify their sex as "female" or "male". There are a number of different medical diagnoses associated with intersex bodies, although it is important to distinguish between intersex biological variations themselves and the medical conditions that people with intersex biological variations may experience. Many intersex people object to intersex bodies being described in some medical approaches as inherently disordered and see their intersex differences as a natural variations. This means for collection of data that intersex people may identify their "sex" as a wide range of options from "male", "female" "intersex", "indeterminate" or simply seek to not respond to the question, and that people's responses are unlikely to be consistent with the classification they might be given by others. There is limited research on the number of intersex births, but widely quoted is the figure of a minimum of 1.7% of live births.⁴⁶

While the Australian Health Data Dictionary may permit the recording of intersex, it discourages coding intersex for people over 90 days old. In most situations, sex markers are then overwritten with values of "male" or "female", with no historical reference to the original determination of intersex. In addition, one major source of information about the sex of Australian births is the Births Deaths and Marriages Register in each state. These registers do not allow birth certificates of babies to be issued with sex markers other than male or female.

In Victoria however, the Common Client Data Dictionary⁴⁷ distinguishes between the code "indeterminate" and "intersex" in its responses to the sex indicator. Victoria notes that the value of "indeterminate" may only be assigned to babies less than 90 days old. However, in Victoria, the term "intersex" is a value that may be used throughout someone's life.⁴⁸ This is inconsistent with the advice in the Australian Health Data Dictionary. It is not known however in practice how intersex is recorded in Victoria, however we would submit the Victorian approach is closer to a more

appropriate model for LGBTI Australians. Further we note that the ACT's Law Reform Council recently recommended the inclusion of a third category of sex/gender should be included and that this may further inform the collection of sex in Australia.⁴⁹

For some intersex people, they may discover their intersex variations at later points in their lives, where others may be aware of their intersex difference throughout their life. Accordingly, there is no known source of health-related information about intersex people in Australia. There may also be unique challenges with obtaining accurate information about intersex people at all life stages.

It is important to note however that intersex people do not enjoy the broad protection or recognition under the law that many gay, lesbian, bisexual or transgender people do. In the area of discrimination laws for example, a binary definition of sex (i.e. protecting only "males" or "females") provides no protection under existing sex discrimination laws.

What is trans/transgender and gender identity?

Trans/transgender as an umbrella term refers to someone whose assigned gender does not match their gender identity. Over the course of their lifetime, this cohort of individuals may embark up on a journey of social, legal, and/or medical 'gender affirmation' (formerly referred to as 'transition'. Despite the mainstream popularity of terms like 'female to male' and 'male to female', people who seek gender affirmation are typically motivated by the need to affirm their self-designated gender. The term 'transition' may sometimes be inappropriate when describing people who have a non-binary gender or no gender at all.

Trans/transgender is currently classified as a "Gender Identity Disorder" in the American Psychiatric Association's (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) as at the time of this paper, although the APA is currently preparing the DSM-5. Many trans/transgender individuals and allied professionals, including psychological professionals, object to trans/transgender being treated as a psychiatric disorder and call for all diagnostic categories that treat trans/transgender people's genders as mental pathology (e.g., Gender Identity Disorder and the proposed Gender Dysphoria diagnosis) to be removed from the DSM.^{50 51 52 53}

² The National LGBTI Health Alliance uses "LGBTI" as a recognisable acronym to collectively refer to identities and experiences that include lesbian, gay, bisexual, trans/transgender and intersex people and other sexuality, sex and gender diverse people and communities, regardless of their term of self-identification.

This paper may also refer to "same-sex attracted" people as a collective referral to lesbian, gay and bisexual people, in addition to "sex and/or gender diverse" people as a collective referral to trans/transgender and intersex people. It is noted that intersex is distinct from trans/transgender and that individuals may not personally associate with such terms. For example SistaGirls is a term used by many indigenous people who do not identify with the gender with which they were given by others. Members of this community may or may not associate with the terms trans or transgender.

We note however that trans/transgender is not appropriate in research where a wide range of self-identification labels may occur. Such labels includes, but are not limited to trans man, trans woman, GenderQueer, transsexual, trans* and any number of other culturally specific terms that do not have direct English language equivalents, such as kinnar (sometimes called hijra) (Indian), fa'afafine (Samoan), and kathoey (Thai). Where issues of non-conforming genders are a key outcome of the research, we would encourage more diverse language is used to be all encompassing. For example, some kinnar from India, would identify under a response category of "trans/transgender" and some would be more likely to select "female" when looking to answer a question in relation to sex/gender.

.....
A fictitious scenario to highlight the complexities of recording diverse sex/gender

At birth, Bob is issued a birth certificate identifying Bob as male. When filling in a research form at age 15, Bob marks sex = male and gender = man.

At age 18, Bob commences living publicly as a woman and begins using the preferred name of Mary. Over the next five years Mary identifies as sex = male but gender = "Gender Queer" (a term of increasing popularity amongst younger people that is similar to but distinct from transgender).

At age 23, Mary begins to identify on research forms as sex = female and gender = woman. Other people might consider her sex as male and her gender as transgender and researchers may not consider the difference between their perception and Mary's responses.

At age 30, Mary has surgery to construct female genitals and legally changes her birth certificate to show her sex as female. Mary's sex and gender on forms are the same as when she was 23, but some researchers may now be more likely to identify her research responses in a way that is consistent with Mary's own responses.

Note: The above scenario is designed to give a brief snapshot of the complexities on capturing trans/transgender in research. It is not intended to be representative of all people who transition. Indeed many will identify as their chosen gender (in this case woman) before the transitioning process begins.
.....

Sexual Orientation

The above scenario is not necessarily representative of trans/transgender people, but is an illustration of how the journey undertaken by a trans/transgender person may elicit different responses at different times during their journey. They may have completed or be in the process of “gender affirmation”—moving to live in accord with their gender identity in social, legal, and/or medical contexts (formerly referred to as transitioning). They may choose not to transition. During or at the conclusion of the individual’s unique transition process, a trans/transgender person may see their gender identity as strictly “woman” or “man” or continue to identify as “transgender”.

At points along their journey, their gender identity may not match how others would classify their biological sex, and may also be inconsistent with the legal sex on documents such as birth certificates, passports or drivers licenses. This self-identification as a “man” or a “woman” regardless of their biological history can cause significant challenges when trying to identify trans/transgender people within research.

What is possible to capture in research?

It may be necessary therefore to identify an individual’s “Assigned Sex at Birth”, “Sex on Current Birth Certificate” and “Gender Identity” to capture a holistic view of people of diverse sex and gender. If such an approach is adopted, each question should be accompanied by explanatory text to ensure broad understanding of the question’s meaning. Where this statistically valuable three-question approach is not possible, and a single question is required, another approach may be to ask a question about a person’s Sex/Gender that clarifies the designation as referring to

how respondents label themselves and not how others or official documents may label them. When using a single question, it will increase data quality and accuracy to permit the selection of multiple response choices with the option of freeform text.. It should be noted that a single question approach is no longer reflects best practice guidelines for sex and gender data collection. In 2009, the Trans Data Position Paper published by the Office for National Statistics, which is the executive office of the UK Statistics Authority, noted the limitations of a single question approach with use of an “other” box and included a guideline that used three separate questions⁵⁴. Likewise, the current academic discussion in the US led by the Williams Institute on how best the US Department of Health and Human Services should ask questions on gender identity has identified the complexities involved in this process⁵⁵. Thus the use of a single question approach, even with multiple selection options and an “other” box, should only be used after careful consideration of the alternatives.

Alternatively, framing the question in terms of an individual’s lifetime, (e.g. during your lifetime, have any of the following broad terms been used by you or by others to describe you? “Male”, “Female”, “Trans/transgender/transsexual” “intersex”) with the ability for multiple responses, may provide insight into the existence of people with diverse sexes and/or genders.

As part of the paper’s recommendations, it is proposed that further investigation, testing and recommendations of standardised research questions be developed. We therefore do not propose specific examples at this stage, but the Alliance has expertise to provide clear suggestions about question approaches upon request.

Sexual Orientation is made up of at least three aspects of a person’s sexuality: identity, behaviour and attraction. It is not simply categories of heterosexual, homosexual (gay or lesbian) and bisexual. Nor is sexual orientation merely variants of a scale from “exclusively” gay through to “somewhat” gay to “exclusively straight”. Sexual Orientation has three core components, each different to the other, which collectively make up a person’s sexual orientation:

Sexual Identity – refers to the self-identified label that a person may choose to describe themselves. Common identities include heterosexual/straight, homosexual/gay/lesbian and bisexual. Note: these may change over time.

Sexual Behaviour – refers to the types of sexual experiences/encounters a person may have. This may be consistent or inconsistent with their sexual identity, that is to say a man having sex with a man may *identify* as heterosexual and may or may not feel attracted to people of both sexes.

Sexual Attraction – refers to attraction a person may feel regardless of their sexual identity or the behaviour/sexual experiences they may have had. “Same-sex attracted” is an important term, particularly in relation to younger people and others who may feel sexually attracted to people of the same sex but have not yet formed a self-identified sexual identity.⁵⁶

A national survey of 10,173 men and 9,134 women, the Australian Study of Health and Relationships⁵⁷, found that “relatively few Australians reported a sexual identity other than heterosexual. However, both same-sex attraction and homosexual experience are more common than homosexual or bisexual identity would suggest”⁵⁸.

While only 1.6% of male respondents identified as gay/ homosexual and 0.9% identified as bisexual, 8.6% of respondents reported some level of same-sex attraction or

homosexual experience. For women, 0.8% identified as lesbian and 1.4% identified as bisexual; yet 15.1% of women recorded some same-sex attraction or homosexual experience.

This study shows that asking questions on sexual attraction or sexual behaviour reveals an additional 6.1% of men and 12.9% of women who may share similar experiences to those who identify as lesbian, gay or bisexual. This principle of disparate figures between attraction, experience and identity is comparable to other countries.⁵⁹

Due to perceived lack of benefit of asking multiple questions on a single ‘demographic’ factor like sexual orientation, researchers may limit the number of questions to a single question. It is necessary however to assess which of the three indicators (identity, behaviour or attraction) is the most appropriate to include and not simply include sexual identity.

Individuals at the time of participating in research or data collection may acknowledge their same-sex attraction, but may not self-identify as lesbian, gay or bisexual for a range of reasons. These include not yet assigning themselves a sexual identity⁶⁰, using other identity labels⁶¹, or self-identifying as heterosexual, but having levels of same-sex attraction and/or behaviour.

In the field of HIV research, there is a wide body of knowledge about “men who have sex with men” that may have similar sexual health challenges to those who identify as gay or bisexual. The principles of “identity vs. behaviour” learnt through years of research within the HIV/STI field, as well as lessons learnt about “attraction vs. identity” within the field of same-sex attracted and gender-questioning young people⁶², are applicable and informative to a wide range of research incorporating LGBTI people.

Collecting LGBTI data – discussion of challenges

From the Health Care professional’s perspective

The Alliance’s MindOUT! Project, Phase 1 research⁶³ of mainstream mental health services found that only 60% of respondents believed their staff members would “*feel confident and be competent in sensitively and appropriately asking questions to identify a LGBTI person’s sexual orientation and gender identity.*” In the same survey, 79% felt staff would treat LGBTI clients with sensitivity but only 31% of organisations would consider LGB/TI as a specific group for the purposes of organisational planning.

Many healthcare providers do not feel comfortable asking about sexual orientation as it is culturally seen as a private matter. It is important that any action to encourage greater capture of sex, sexual orientation and gender identity is balanced with increased training on how to ask these questions in a sensitive manner.

It is important however that services who ask questions around sex, sexual orientation and gender identity have a whole-of-organisation appreciation for LGBTI appropriate policies and procedures including privacy. Clients must be made aware of how this information may be used and if the data may be shared with other organisations.

From the researcher’s perspective

While the proposition to include sexual orientation, gender identity and diverse responses for sex is a simple one, the National LGBTI Health Alliance recognises that it presents a range of challenges in practice.

Perhaps the most critical of these is research funding. Each and every question/ response add additional costs and time to research projects - from the cost involved in collecting, through to the costs involved in analysing the data. Accordingly, the inclusion of any question is subject to a rigorous evaluation by research teams of the value of including the data.

While a researcher may desire to know the full suite of indicators for sexual orientation (attraction, behaviour and identity), sex and gender (assigned sex at birth, sex on current birth certificate, and gender identity), the costs of six questions may be prohibitive. In population size surveys, it is essential to consider whether survey items have been appropriately worded and tested. Lack of appropriate wording and testing is likely to present another cost and time barrier to the inclusion of LGBTI indicators.

In a previous version of the Human Research Ethics Handbook⁶⁴, the NHMRC identified some guidelines for research involving gay men and lesbians, however this information has not been updated in over 10 years, is no longer deemed current by the NHMRC and requires amendment to ensure the inclusion of transgender, intersex and bisexual Australians within its considerations.

It may also be a barrier that LGBTI people are not seen as disadvantaged groups, despite extensive evidence to document the stigma and discrimination experienced by LGBTI people. Therefore it is not seen as necessary by some to capture data about this group of individuals for reporting mechanisms. This is further enforced by the fact that currently, no mandated reporting requires this information.

Survey design will be an important consideration when addressing LGBTI data issues. For example, research shows that a person’s sex or gender should not be determined by data collectors⁶⁵ and that some trans women are misclassified as men who have sex with men (MSM) while trans men who have sex with men are excluded from the MSM category⁶⁶. Consideration in particular should be given to the process asked of trans/transgender or intersex people to respond in a survey. For those trans/transgender or intersex people who self-identify as women or men (which is thought to be the largest portion of the trans/transgender community), requiring classification by only responding using “transgender” or “other” can cause offense and reduce response rates⁶⁷. Another barrier to successful survey results may be the lack of assurances provided by the survey collector about confidentiality, anonymity, privacy and data usage/storage⁶⁸. International best practice, while still being developed, indicates that more than one question will be needed to successfully and appropriately collect sex and gender information.

We also note that there is a distinction between the collection of LGBTI data and the informed and appropriate analysis of data. Accordingly, sophisticated understanding of sex, gender and sexual orientation is required when considering how data collected through research are required to be coded, analysed, and reported.

National Sex, Gender and Sexual Orientation Research Methods Project

The National LGBTI Health Alliance recommends Australia’s research agencies support researchers through this process by undertaking a project to:

- *Explore updates of key research architecture to ensure they are LGBTI inclusive (data dictionaries, minimum data sets, funding policies etc.);*
 - *Outline the government and community need for LGBTI data to deliver upon policy and service demands;*
 - *Develop standardised questions and responses for LGBTI indicators in research (including focus testing of question suite in a variety of settings);*
 - *Recommending where particular question sets should be considered for research inclusion (including updates to succeeding iterations of established research);*
 - *Discuss technical aspects of how and why LGBTI indicators should be included in different types of studies (population health, targeted studies, longitudinal studies) and within particular fields of research;*
 - *Discuss how collection methods may impact information provided (privacy, anonymity and confidentiality);*
 - *Methodological challenges in the inclusion of such data, particularly where comparability to previous studies is a factor.*
-

From the respondent’s perspective

The Alliance recognises that disclosure of a person’s sex, gender identity or sexual orientation is a very personal decision. As such, disclosure will be impacted by a range of factors including the known context of the data collection; the level of privacy, anonymity and confidentiality perceived; and the knowledge of how and why the information will be used, along with other socio-cultural factors.

Additionally, the mode of collecting responses may impact upon levels of sexual orientation disclosure. In situations where research is collected by a researcher or questioner, there may be lower levels of disclosure for fear of discrimination or generally not wishing to “reveal” one’s identity to another person.

It is also possible that questions and response options are misunderstood by respondents, such as not declaring a same-sex partner due to the question label of “marital status” where the answer of “married” is seen by the same-sex attracted respondent as not being applicable to their partner.

Analysis of research data in the United States notes that self-identification of a person’s sexual orientation and a willingness to disclose a person’s sexual orientation, as lesbian, gay or bisexual, can be impacted by race, ethnicity, culture, age and geographical location.^{69 70}

People of diverse sex and/or gender may also not disclose their sex/gender histories and identities for a wide range of reasons. A person’s self-identification of their gender may also be impacted by the point of their transition at the time of the data collection.⁷¹

LGBTI people may be hesitant in disclosing their status, their gender/sex history or levels of same-sex attraction/behaviour for a wide range of reasons. However, careful design and testing of surveys, and ensuring adequate training of staff collecting, coding and analysing the data, should help to lower the non-response rate.

The National LGBTI Health Alliance acknowledges that some data collection methods that do not provide participants with a sense of confidentiality and anonymity may result in participants not disclosing their sexual orientation or gender identity.

The Australian Census⁷² is collected every five years by the Australian Bureau of Statistics (ABS). The ABS's mission is to “assist and encourage informed decision making, research and discussion within governments and the community, by leading a high quality, objective and responsive national statistical service.”⁷³

Australia lacks the authoritative data on the number of LGBTI people that the Census, over time, would provide. For example, the Census would enable modelling of the number of LGBTI people in Australia to occur.

As the major source of socio-economic information on the Australian population, the Census provides crucial data on a range of individual characteristics (age, ancestry, family relationships, indigenous status, relationship status, education, employment, housing, languages spoken, income, voluntary hours, etc.) and collective information about education and qualifications, employment, income and unpaid work, cultural and language diversity, Indigenous people, disability and the need for carers, childcare, migration trends, and household and family characteristics.

The issue of including sexual orientation within the Census has been discussed for a number of years but with little actual investigation by the ABS of the issue^{74 75}. Lack of data about LGBTI people puts this cohort of Australians at a significant disadvantage in terms of enabling policy makers and service delivery agencies to accurately predict where resources including healthcare and education targeting the LGBTI population may be required. Only the Census would provide the ability to identify small target populations for accurate information to inform such government initiatives, as no alternative source of information is currently available or likely to be available in the near future. Further, businesses and other parties seeking to promote their products and services to LGBTI people are unable to utilise the Census data that would be commonly available for almost any other market segment of customers and clients. While it is arguable that inclusion of sexual orientation may be seen as an invasion of privacy, particularly due to the nature of face to face collection of the census, the recently introduced option for individual respondents to request an individual survey or complete their individual responses online mitigates many of these concerns. It should also be noted that in the early days of capturing indicators around a person's Indigenous heritage, similar concerns of appropriateness to be asked what was then deemed a personal issue were raised but subsequently resolved.

In addition, various research undertaken across Australia may link data to the Census to model their results on the Australian population, as does some existing resource allocation by government. The lack of Census data about same-sex attracted people and people of diverse sex and/or gender places this cohort of Australians at a distinct disadvantage for accessing targeted services.

Finally, as Australia's national statistics agency, ABS policies and approaches to the Census set a benchmark for other research. This is an important factor when seeking to compare the results of multiple sources of related data. Accordingly, the leadership that could be shown by the ABS through the Australian Census and ABS publications, in the area of sex, gender and sexual orientation identifiers is influential when seeking the broad inclusion of LGBTI indicators in research.

The Australian Bureau of Statistics has commenced public submissions into the 2016 Census.⁷⁶

As discussed later in the paper, national statistic bodies in comparable countries have investigated aspects of data collection on LGBTI people that is consistent with our recommendations.⁷⁷ We believe that the findings from these investigations should inform the ABS in their investigations and field-testing. We note that acceptability and understanding of terms and language may be specific to Australia and that Australian results may not be very consistent with international experiences. Accordingly, we do not believe the international investigations are grounds for Australia not to test and investigate its own approach to see its applicability in Australian research. Further, we note the additional descriptive text we proposed was not included in international field tests and that this may have had an impact on results. We also note the ABS's ability to include messages about questions in its media strategy, as was seen in various Census collections regarding Jedi as a religion.^{78 79}

Finally, we note that the previous collection method by which the Australian Census is filled in by a member of the household may decrease the likelihood of an LGBTI person declaring their sexual orientation or gender identity. This is further complicated by census collectors making the individual completing the census not feel at ease with declaring their sexual orientation or gender identity to a stranger, or in cases of regional/remote areas to a person known to them. This is of particular concern for younger people questioning their sexual orientation or gender identity where they have not yet disclosed this information to their parents with whom they live. However, with the increase of census collections occurring online, we note that this anonymity may, over time, increase the likelihood of disclosure.

Same-Sex Relationships

Since the 1996 Census, ABS data has allowed for same-sex couples to be identified as part of the Australian Census. Officially included in the 2011 Census Dictionary⁸⁰, the data is created using a combination of the respondent's sex⁸¹ and their declared “relationship in the household”⁸² between Person 1 and Person 2 etc.⁸³

There are many challenges with this current approach:

- The term “marital status”⁸⁴ does not include opportunity for same-sex couples married overseas to be recognized as married. Rather they are coded as “de facto” and from the 2011 Census onwards will be published as “relationship as reported”.
- Responses under “relationship in household”⁸⁵ frame their responses within the words “de facto partner of person 1”, which is not necessarily a term which is well understood.
- It only captures same-sex couples who are under the same roof on Census night. That is to say, it doesn't capture relationships across two homes or single same-sex attracted people.
- It only captures relationships between “Person 1” and their partner, thus in shared accommodation arrangements where Person 1 is not in the same-sex relationship, no indication is provided.
- It only captures relationships that appear to be between people who have the same sex marker, thus excluding same-gender couples in which a transgender or intersex partner's sex marker differs from their own lived gender in the relationship.

The ABS has previously indicated that collecting data on same-sex couples “may have some limitations, including reluctance to identify as being in a same-sex de facto marriage and lack of knowledge that same-sex relationships would be counted as such in the Census”.⁸⁶

Sex / Gender

There is no opportunity for people of diverse sex and/or gender identity to be recorded. Currently, Question 3 asks, “Is the person male or female?” and instructs participants to record one or the other option. This question may require people of diverse sex and/or gender identity to classify themselves in ways that do not reflect their own identities accurately. Crucially, this may lead to people of diverse sex and/or gender being misclassified or ‘misgendered’ (incorrectly gendered), not just excluded from the Census.

Sexual Orientation

Beyond the indicative same-sex couple data, there is no record of an individual's sexual orientation.



Proposed amendments to Census

Update Question 5: Remove reference to the term “de facto” and include descriptive text “(including same-sex couples)”.

De facto is a word not widely understood, thus introducing a barrier to accurate recording of responses. For those who do understand the term, confusion over the legal requirements of the term may ensue. De facto people are required to live together for various lengths of time depending on the relevant piece of legislation.

A better approach would be through the simple phrase, “Partner of Person 1”, rather than the current term “de facto partner of person 1” that appears in Question 5.

For decades now, same-sex partners have not legally been recognised as a in a same-sex relationship. Accordingly, they have become accustomed to not recording their relationship on official documents.

Question 5 “What is the person’s relationship to Person1/Person2?” currently includes descriptive information underneath it. A descriptive dot point such as “(de facto) partner of Person 1, includes same-sex couples” is likely to lead to a higher reporting rate of same-sex couples and ensure couples are aware their relationship may be declared.

Update Question 3: Provide an option of “other” under “Sex/Gender” category with descriptive text and allow the selection of multiple responses

Use of “other” boxes is currently permissible in a range of Census questions. Most contain explanatory answers indicating what other options may include.

To better understand the diversity of sex and gender, options other than “male” and “female” must be provided. We recognise that there is a technical distinction between sex and gender, as well as a technical distinction between official classification of a person’s sex and their actual biological characteristics. However, to many Australians, these concepts are intrinsically linked. Accordingly, we believe it appropriate that the question expand to include gender and introduce an option of “Other”, with an accompanying free form text field, descriptive explanation and the ability to select multiple options. Given the large numbers of trans/transgender and intersex people who identify simply as women, men, female, or male, it will be vital to permit the selection of both ‘male’ or ‘female’ and ‘other’ and for the ABS to clearly provide these instructions in their how to fill in descriptors for the question. We feel further discussion on the best approach is warranted: Although we appreciate the need for a small number of questions in the census, we remain concerned that a single sex/gender approach may not solicit meaningful data for the ABS.

Collection of sex or gender is problematic for trans/transgender and intersex Australians when it is determined by collectors. rather than indicated by individual respondents. Many trans/transgender and intersex people report having their sex and gender misclassified by others based on name, appearance, and other characteristics. Accurate and inclusive data on sex/gender should be based solely on an individual’s classifications about themselves and not on the perceptions of those collecting these data.

3 Which of the following best describes the way the person thinks of their sex/gender?

Mark as many boxes as apply for each person—
Examples of other genders include kathoey; kinnar or hijra; or genderqueer;

- Male
 - Female
 - Trans/transgender
 - Intersex
 - Other
- Other please specify: _____

The above is an example of a possible census question, but it will be essential to engage in both field testing and community consultation with intersex people, trans/transgender and other people of diverse genders to ensure an inclusive methodological solution is found.

Providing an explanation of other as including kathoey, kinnar or hijra and genderqueer will signpost the purpose of the other box. Indeed, by including a non-binary option, the ABS may find a decrease in non-responsive answers currently experienced.

Additional Question: Seek information on Sexual Orientation, with descriptive text

Providing a question on sexual orientation would allow for the recording of some LGB people. While a more interesting indicator might be one of “sexual attraction”, we recognise that this would be of little value to most ABS stakeholders. However, the indicator of “sexual attraction” has been used in several population-based studies overseas,⁸⁷ such as the Swiss Multicentre Adolescent Survey, which uses the indicators attraction, based on the Minnesota Adolescent Health Survey.⁸⁸ The attraction indicator can capture behaviour and intention, which are both implicated in mental health and suicide risks, even where the individual does not identify as lesbian, gay or bisexual.

Another indicator used in overseas population based studies of health and mental health is sexual “behaviour,” including the “gender” of past and present sexual partners, which can capture a wider range of people who are at risk of specific health and mental problems, including suicide.⁸⁹

The more likely information sought by the users of ABS data will be on the issue of “Sexual Identity” which could be asked as follows:

Which of the following best describes the way the person thinks of their sexual orientation?

- Answering this question is *OPTIONAL*.
 - Your information is protected with confidentiality under Australia’s Privacy laws.
 - If you do not wish to answer, please mark the “I would rather not say” box
- Straight/Heterosexual (attracted to a different sex)
 - Gay/Lesbian/Homosexual (attracted to the same sex)
 - Bisexual (attracted to more than one sex)
 - Undecided; not sure; questioning
 - Other
- Other please specify: _____
- I would rather not say

It may be necessary, due to layout of Census design to move the bracketed explanation from the response answer to part of the descriptive text under the question. However, without an explanation of the meaning, there may be different levels of understanding of the labels used. Design, development and testing of a sexual identity question⁹⁰ recently in the US concluded that inclusion of the word “heterosexual” led to some response difficulties. Further the study recommended inclusion of the words “that is, not gay” at a lower positioning of the response surveys as heterosexual people did not identify with being heterosexual rather they dis-identified with being gay. It is noted that testing of such formats would be necessary in an Australian setting before being adopted in Australian standards.

It is also important to note that the term “best describes” and “thinks of their” have been deliberately used. It is important that the individual concerned has input into the answer of the question and that the question recognises that while not all respondents will fit neatly into a specified category, a “best describes” answer is a suitable outcome.

Consultation, testing, decisions: should be made involving dialogue with LGBTI community

The National LGBTI Health Alliance recognises changes to Census questions should only occur following rigorous testing across the representative sample of the population to ensure that the question is both understood and answered, and that data is as accurate as possible. We recommend the inclusion of explanatory descriptive text which will assist in maximising understanding. We also stress the need for the ABS to consult closely regarding best practices for ensuring LGBTI-inclusive methodology.

We stand ready to work with the ABS on the design of any field questions and to link the ABS with leading LGBTI researchers both in Australia and internationally to discuss the findings of the ABS investigation.

Monitoring – Research

Australia has an increasing need to monitor various aspects of the lives of its LGBTI citizens. One form of data that could be used for monitoring outcomes is national population and longitudinal studies. This section will discuss the need for LGBTI indicators to be included within research and the options available for this inclusion.

It is important however to note that while the collection of LGBTI indicators may seem as simple as including questions in research papers, the analysis of such data requires a sophisticated level of understanding about diverse sexual orientations, sex and gender people in order to obtain accurate results.

Where do we need to know about LGBTI people?

Indicators of LGBTI outcomes are required in almost all areas of research to inform public policy. In the area of human rights, the introduction of federal anti-discrimination laws on the basis of sexual orientation and gender identity,⁹⁷ along with the Government's stated desire to monitor human rights outcomes⁹² will increase the demand for data to be available.

In areas such as health and wellbeing, the inclusion of LGBTI people within public policy documents such as the National Male Health and National Women's Health policies will increasingly require quality data to inform the action plan stemming from these policies.

Where do we have existing data on LGBTI people?

There are questions on sexual identity contained in leading national research for mental health,⁹³ alcohol and other drugs,⁹⁴ mental and physical health of women,⁹⁵ and sexual health.⁹⁶ However, the former two surveys do not record indicators for sexual health for same-sex attracted individuals. For individuals of diverse sex and gender, and within a broad range of other health fields, data for LGBTI people are limited to a few studies that have focused on LGBTI populations⁹⁷⁻⁹⁹.

The sampling methods used in LGBTI-specific surveys are often through promotion of the survey through existing LGBTI networks (community press, websites, e-lists etc.). As such, these surveys do not provide a truly representative sample of same-sex attracted and sex/gender diverse Australians. Inclusion within mainstream, national, population-size studies is therefore necessary.

McNair, Gleitzman and Hillier¹⁰⁰ provide a wide discussion on why same-sex attracted women are not included in population-based health research. These principles apply equally to same-sex attracted men and are similar to the challenges faced by sex and gender diverse people.

McNair et al have also published on same-sex attracted and same-sex identified women's physical and mental health based on the Australian Longitudinal Women's Health Survey.¹⁰¹

As with all research it is important that appropriate analysis of the data collected occurs. In the example of health disparities between LGBTI and non LGBTI people, an appreciation for the well documented principle that health disparities of LGBTI people are caused by discrimination and prejudice is necessary. Without such context, it is possible an inaccurate conclusion may be drawn that the health differences are caused by some inherent attribute of being LGBTI.

Known LGBTI Data sources in Australia Mainstream Research

Contains	Research Title	Organisations	Year	Data published?
Sexual Identity	National Drug Strategy Household Survey http://www.aihw.gov.au/publication-detail/?id=32212254712	Australian Institute of Health and Welfare	2007 2010	Not Published Published
Sexual Identity	National Survey of Mental Health and Wellbeing http://www.abs.gov.au/ausstats/abs@.nsf/mf/4326.0	Australian Bureau of Statistics	1997 2007	Not included Published
Sexual Identity & Gender Identity	Victorian Public Health Survey http://www.health.vic.gov.au/healthstatus/survey/vphs.htm	Public Health Unit, Department of Health, Victorian Government	2001 2009	Unpublished, included since 2009
Sexual Identity	The SEEF Project: Understanding the impact of social, economic and geographic disadvantage on the health of Australians in mid to later life: What are the opportunities for prevention? (Sub-study to NSW's 45 and Up Longitudinal Study) http://qoo.gl/AN9BA	The Sax Institute	45UP SEEF	Not included Currently unpublished
Sexual Attraction Behaviour & Identity	Australian Study of Health and Relationships http://www.latrobe.edu.au/ashr/	Led by: Australian Research Centre in Sex, Health and Society in partnership with Central Sydney Area Health Service, National Centre in HIV Epidemiology and Clinical Research, University of NSW.	2002	Published
Same-sex Couples	The Household, Income and Labor Dynamics in Australia http://melbourneinstitute.com/hilda/ Unknown which year data was introduced	Melbourne Institute of Applied Economic and Social Research, Melbourne University	Since 2001	Unknown
Sexual Identity	The Australian Longitudinal Study of Women's Health Sexual Orientation only asked for: • Young Cohort, second wave (2000) ¹⁰¹ • Med Age Cohort, third wave (2001) ¹⁰² • Young Cohort, third wave (2003) ¹⁰³	University of Newcastle University of Queensland	YngW2 - 2000 MedW3 - 2001 YngW3 - 2003	Published Published Published
sexual attraction, behaviour and identity	Australia Longitudinal Study of Health and Relationships www.latrobe.edu.au/alshr	La Trobe University	2005-2009	Published
Same-sex couples	Family Characteristics Survey http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4442.0Main+Features12009-10?OpenDocument	Australian Bureau of Statistics	2009-10	Published

Please note that the below is a summary of data and a brief indication if the indicated LGBTI indicator data identified has in the "contains" column, has been published fully. None of the below publications include data on trans/transgender or intersex people.

Key LGBTI Specific Research

Data Contained	Research Title	Conducted by	Year	Data published?
Assigned Sex at Birth Gender Identity Sexual Identity	TranZnation: A report on the health and wellbeing of transgendered people in Australia and New Zealand http://qlhv.org.au/files/Tranznation_Report.pdf	ARCShS	2006	Published
Sexual Identity Sexual Behaviour Sexual Attraction Gender Identity	Sydney Women and Sexual Health Survey http://www.acon.org.au/get-involved/events/health-check-sydney-women-and-sexual-health-survey	ACON In partnership with UNSW and USYD	1996 onwards (Sydney) Perth since 2010	Published
Sexual Behaviour Sexual Identity	Gay Community Periodic Survey (Adelaide, Canberra, Melbourne, Perth, Queensland, Sydney) http://nchr.arts.unsw.edu.au/publications/	National Centre in HIV Social Research with the Kirby Institute and state AIDS Council and state Health Department	1996 but varies by state 2011	Published
Gender Identity Sexual Identity	Private Lives 2: The second national survey of the health and wellbeing of GLBT Australians http://www.qlhv.org.au/report/private-lives-2-report	ARCShS, GLHV, Beyond Blue, Movember Foundation	PL1 – 2006 PL2 - 2012	Published Published
Gender Identity Sexual Identity Sexual Behaviour Sexual Attraction	Writing themselves In 3: The third national study on the sexual health and wellbeing of same sex attracted and gender questioning young people. http://www.qlhv.org.au/report/writing-themselves-3-wti3-report	La Trobe University ARCShS	WTi1 – 1998 WTi2 – 2004 WTi3 – 2010	Published Published Published

Identified research for inclusion

As a general principle, LGBTI indicators should be included in all research. It would be impossible to list all the specific areas in which LGBTI data is required. While in many scenarios regarding health it will be necessary to ask about sex/gender, it should always be considered prior to any survey etc. whether it is necessary to request sex/gender at all.

LGBTI data collection and reporting measures should address both distinctions and overlaps across the LGBTI spectrum. Effective data collection and reporting measures will acknowledge that LGBTI people may also be members of culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) populations; may not necessarily consider their LGBTI experience or history to be their identity; may or may not identify publicly within the LGBTI spectrum; and may or may not be actively involved in an LGBTI community.

The National LGBTI Health Alliance believes that through discussion, design, testing and funding all challenges surrounding the introduction of LGBTI indicators are able to be resolved. Further as discussed in this paper, the need for LGBTI data to better inform public policy and service allocation necessitates the inclusion of LGBTI data.

While respecting the individual choices of research teams about the data to be collected, the Alliance believes that more leadership from key government agencies on the issue of LGBTI data is necessary.

This leadership could be through a range of mechanisms including:

- **Development of an Australian guideline for LGBTI indicators.** Such a document may outline standardised questions, discussion of methodological challenges, sampling approaches, statistical validity and reporting guidelines. Development should occur following a genuine for consultation with a range of LGBTI stakeholders in the development of this guideline and must also provide guidance/ training on the sensitivity of collecting such information.
- **Inclusion of LGBTI data within research funding** priorities and guidelines to incentivise the collection of LGBTI data
- **Annual reporting of LGBTI data** available noting the contact details of the relevant researcher and a summary of data (where available for publication) to highlight the LGBTI data across research fields and encourage discussion within research circles.

Key population health surveys that are sought for immediate consideration to include better LGBTI data are:

- Australian Health Survey (AHS)¹⁰⁵
- Australian Survey of Disability, Ageing and Carers (SDAC)¹⁰⁶
- Household Expenditure Survey¹⁰⁷
- Household Income and Labour Dynamics in Australia Survey (HILDA)¹⁰⁸
- General Social Survey¹⁰⁹

Monitoring - other data sets

Monitoring outcomes, particularly health outcomes, may also be possible by introducing LGBTI data in data sets that are nationally aggregated, from instances of police reports of violence relating to sexual orientation, sex and/or gender identity; recording sexual orientation in clinical settings; and through the introduction of government mandated requirements to collect in national minimum data sets.

The issues discussed regarding privacy, confidentiality and understanding the purpose/use of the data being collected are of particular relevance. Additionally however, as some data sets may be collected by a third party (Police, Doctor, Nurse, Allied Health Professional etc.) training around asking questions in data sets is particularly important.

Australia's health data collected is largely based on one of three data dictionaries, all of which should be updated to better reflect LGBTI demographics:

- National Health Data Dictionary Version 15 (NHDD)
- National Community Services Data Dictionary Version 6 (NCSDD)
- National Housing Assistance Data Dictionary (NHADD)

Requirements for Minimum Data Set reporting are various, but none contain the requirement for sexual orientation to be included. Surprisingly, not even the instances of sexually transmitted infections and blood borne viruses identify sexual orientation.¹¹⁰

The Australian Institute of Health and Welfare discusses the standardised terminologies used under the Australian Family of Health and Related Classifications and principles used for inclusion under these classifications.¹¹¹

Identified data sets for possible LGBTI inclusion

However, there are a number of potential sources where LGBTI identifiers could be either included or aggregated from existing sources.

Clinical Management System of Service Providers including General Practitioners

General Practitioners are the starting point of accessing health care for most LGBTI people. Most of Australia's leading GP clinical management systems have fields for the collection of sexual orientation information,¹¹² but diverse sex and/or gender identity is not believed to be recorded. While the introduction of a "gender identity" field may be possible, the introduction of diverse "sex" categories are likely to present challenges due to the binary nature of minimum data sets and other data transmission information such as Medicare data.

The starting point for practically acquiring information into minimum data sets will be reliant upon the ability of industry systems to cater for the information to be included. However it is also important that training and appropriate processes (including confidentiality) are put in place by the service providers and communicated to service users before this information is collected.

McNair,¹¹³ Bowers et al,¹¹⁴ the Gay and Lesbian Medical Association (US),¹¹⁵ Well proud¹¹⁶ and the Fenway Institute^{117 118} discuss in detail how and why GPs should ask information on sexual orientation and gender identity. Diverse sexual orientation, sex and gender people have specific health risks and higher rates of specific health problems, including mental health and suicide risks, compared to the general population. Many people do not disclose their diverse sexual orientation, gender or sex to their GP's, which can lead to poor health outcomes.

Further training of GPs about sensitively broaching the topic of sexual orientation and diverse sex/gender would be required to ensure appropriate approaches were used to solicit open, honest answers.

The recently introduced role of medical locals provides a unique opportunity to better understand local health needs of LGBTI populations. Robust and appropriate collection of LGBTI indicators by Medicare locals may ensure the appropriate local services are in place to meet LGBTI population needs.

E-Health

It may be possible, in the future, for an individual to elect to include their sexual orientation, diverse sex and/or gender identity within their *personally controlled e-health record*¹¹⁹. If included in future releases of E-Health information, patients will maintain control over which medical practitioners may access their information. Patients may also opt-in to their e-health record being included as part of research.

Through the future enhancement of e-health to include options for LGBTI identifiers that consumers can choose to include or not, a rich source of LGBTI information may become available over time for future research. However, more importantly, the inclusion of LGBTI

identifiers in a personal e-health record will allow a patient to easily share or not share this information with medical professionals, on a case-by-case basis. However during the final 2014 requirements for the electronic health record, the American Centre for Medicare and Medicaid Services declined to include sexual orientation and gender identity data elements within the electronic health record as it did not meet the objective of meaningful use at this stage.¹²⁰ Further work on the benefits and methods of including these data sets is being undertaken by the US Institute of Medicine and the US National Research Council.¹²¹

Intersex Births

Statistics around births in Australia are collected by the ABS based on information from the Registrars of Deaths, Births and Marriages in each state. Currently state BDM's do not maintain records on the number of intersex births. This may be due to the overwriting of sex indicators from intersex/indeterminate to male or female after 90 days. BDM data collection should collect and record these data.

Mortality Datasets

Statistics around deaths in Australia are collated by the ABS based on information from the Registrars of Deaths, Births and Marriages in each state. As part of this state based registration process, the cause of death information is provided either by a Medical Practitioner (Medical Certificate of Cause of Death) or as a result of a coronial inquest, based upon coroner report data.¹²² ABS also receives information from the National Coroners Information System.¹²³ ABS then codes causes of death by health classification using International Classification of Diseases 10th revision (ICD-10).¹²⁴ There are other options for collecting some data on suicides related to same sex status. In Denmark, suicide data is matched to registered relationship status, so suicides of people currently or previously in same-sex registered relationships can be compared to those in heterosexual registered relationships.¹²⁵

Statistics on mortality for other health risks on top of suicide are also needed for LGBTI people. A study in the Netherlands found that transsexual people had a far higher mortality rate than the general population.¹²⁶ An American population based study found significantly higher mortality rates for men who had sex with men than the general population.¹²⁷ Data on mortality rates for intersex people has not been collected in population based studies, but several studies have shown an increased risk of suicide and suicide attempts for intersex people.¹²⁸

Of particular interest to LGBTI mental health specialists is the data created identifying suicides in Australia. This data can be generated in a range of ways via the coroners system. One of the main sources of information around a suicide comes from the state police department.

Obtaining information from a source other than the victim presents ethical questions around the victim's right to privacy. It is crucial therefore that any questions continue to be framed around identified "associated issues" with sexuality, not focused on "sexual identity". These issues could include questioning sexual attraction, same-sex



experience/behaviour or bullying and other issues with being perceived to be LGBTI (e.g. not masculine/feminine enough). It is also important to note that while maintaining the victim's right to privacy, there is a strong public policy benefit of learning more about causes (and thus hopefully prevention) of suicides in Australia. As further research into the mental health of diverse sex and/or gender identity emerges, consideration may also need to be given towards inclusion of these identifiers in a similar "associated issues" approach.

Inclusion of a specific question on sexual orientation and gender identity within the police report is vital to obtaining suicide-related data on LGBTI/questioning people. Training on how to approach the question sensitively will ensure appropriate collection can occur. Failure to include a specific question to prompt Police to collect the data will continue to result in underreporting of the issue.

Police Databases

Criminal reports captured within the various state police reporting systems require a "finger search" within the body of the report for key words such as "same-sex" or "LGBTI" to identify any statistics relating to the LGBTI community. Different states have different processes on how to record anti-LGBTI crimes and police are generally not trained on using specific words to allow for consistent data collection. This leads to a significant under-reporting of LGBTI-related crime.

Additionally, when transgender and intersex people are categorised, they are often mislabelled as being 'gay' by the criminal justice system and the media, further marginalising these populations groups¹²⁹.

Mental Health Data Sets

The Bettering the Evaluation and Care of Health (BEACH) database uses classifications from the International Classification of Primary Care, 2nd edition (ICPC-2), along with the psychological chapter of ICPC-2 for treatment and referrals (ICPC-2 PLUS).¹³⁰

BEACH contains the following relevant LGBTI diagnostic codes:

P09 - Concern about sexual preference

P45009 - Advice/education; sexuality

P58005 - Counselling; sexual; psychological

The National Hospital Morbidity Database 'mental health related hospital' data contains both patient admissions and ambulatory-equivalent information. It uses codes based on ICD-10-AM

National Hospital Morbidity Database¹³¹ uses codes:

F52 - Sexual dysfunction, not caused by organic disorder or disease

F64 - Gender identity disorders

F65 - Disorders of sexual preference

F66 - Psychological and behavioural disorders associated with sexual development and orientation

The NHMD does not contain demographic information around sexual orientation, diverse sex and/or gender identity.¹³² Accordingly, information currently within the database could only inform instances of case presentations relating to the above codes.

As is discussed through the Alliance's MindOUT! Project,¹³³ there is a greater need for research and data in terms of LGBTI mental health outcomes. LGBTI people have a significantly higher risk of depression, suicidality and suicide than the general population and research suggests that LGBTI-related discrimination, stigma and trauma are key factors in these health issues.¹³⁴ Unfortunately, there is little national level data collected on these needs. Subpopulations of LGBTI people have specific risk factors. For example, trans/transgender people have specific health needs and concerns such as those reported in the *Scottish Trans Mental Health Study 2012*, a comprehensive national study of trans people's health needs and experiences that was largest survey of its kind in Europe, and LGBTI people who are immigrants or refugees may also have specific health needs such as those reported in the *Sanctuary, Safety, and Solidarity* report on LGBT asylum seekers in Scotland.¹³⁵ Enhancing the above data sources to identify demographic information will enhance the mental health outcomes of LGBTI people.

Minimum Data Sets

National Minimum Data Sets are created by agreement between the state and Commonwealth governments.¹³⁶ As such, the Alliance recognises the challenges and length of time it may take to secure national agreement for the inclusion of LGBTI people within minimum data sets. However, the Alliance also believes that this process of scoping, discussion and engagement should commence sooner, rather than later. To assist in facilitating focused discussions, some key data sets are listed below for consideration to include LGBTI people:

- Home and Community Care MDS¹³⁷
- Aged Care Assessment Program MDS¹³⁸
- Alcohol and other Drug Treatment Services NDMS¹³⁹
- Admitted patient mental health care NMDS¹⁴⁰
- Community mental health care NMDS¹⁴¹
- Residential mental health care NMDS¹⁴²
- Supported Accommodation Assistance Program (SAAP) Client data collection MDS (homelessness)¹⁴³

The international LGBTI experience

There is significant progress internationally towards including LGBTI people within national surveys across a wide range of topics. Most comparable countries to Australia recognise same-sex couples in their national Census, but recognise the inherent challenges in receiving accurate data given both the structure of Census relationship questions (only referring to the relationship of the first respondent and requiring couples to live together) in addition to sensitivities around disclosure of sexual identity.

The 2008 Statistics New Zealand discussion paper¹⁴⁴ on Sexual Orientation, discusses many international examples. The paper acknowledges the emerging importance of collecting sexual orientation data along with the difficulties of respondents answering questions where concepts have been poorly defined or understood.

Aside from Nepal's recent inclusion of a "third gender" in part of their national Census, there has been no international discussion identified about the inclusion of trans/transgender or intersex people within Census. The US Department of Minority Health has committed to the inclusion of gender identity within population health studies and is currently consulting and testing on question designs. A considerable number of state health and population surveys include sexual orientation and gender identity indicators within them.

Nepal

In 2011 the Nepal Census recognised an additional category of "third gender" as part of its Census collection of Household Listings.¹⁴⁵ Sadly, the more comprehensive Schedule¹⁴⁶ to the Census, which is a sample survey of every 8th residence, continues to identify citizens as male or female.¹⁴⁷

India

The Census of India 2011 Household Schedule¹⁴⁸ permits for individual respondents to elect a sex indicator other than male or female. Data from the responses have not yet been made available by the Census Commissioner.

United Kingdom

In 2006 the Office of National Statistics in the UK commenced investigation of including sexual orientation in the 2011 Census.^{149 150} Like Australia, the UK seeks to include sexual orientation in the Census to measure the impact of the suite of UK Equalities legislation. To date, the UK has not included sexual orientation within their Census, but following a "Sexual Identity" project, the UK has begun to include sexual orientation information in a range of national surveys. This work built on the two previous papers by the Scottish Government in 2003.^{151 152} In 2009, the Office of National Statistics published a Trans Data Position Paper on the collection of sex and gender information on the Census. This document contained a guideline with three separate questions and discussed the limited statistical value of a single question approach.

UK Office for National Statistics – Useful documents

Trans Data Position Paper (May 2009)

www.ons.gov.uk/ons/guide-method/measuring-equality/equality/equality-data-review/trans-data-position-paper.pdf

Sexual Identity Project (2006-2009)

www.ons.gov.uk/ons/guide-method/measuring-equality/equality/sexual-identity-project/index.html

Discussion of Census Assessment to User Feedback regarding proposal to include sexual orientation in 2011 Census. (March 2006)

www.ons.gov.uk/ons/about-ons/consultations/closed-consultations/2006/2011-Census---responses/sexual-orientation.pdf

Developing survey questions on sexual identity: Rationale and design of sexual identity questioning on the Integrated Household Survey (IHS) (December 2008)

www.ons.gov.uk/ons/guide-method/measuring-equality/equality/sexual-identity-project/question-testing-and-implementation/rationale-and-design-of-sexual-identity-questioning-on-the-integrated-household-survey--ihs-.pdf

Developing survey questions on sexual identity: Cognitive/in-depth interviews (July 2009)

www.ons.gov.uk/ons/guide-method/measuring-equality/equality/sexual-identity-project/question-testing-and-implementation/developing-survey-questions-on-sexual-identity--cognitive-in-depth-interviews.pdf

Developing survey questions on sexual identity: Exploratory focus groups report

(August 2008)

www.ons.gov.uk/ons/guide-method/measuring-equality/equality/sexual-identity-project/sexual-identity-focus-group-report.pdf

Equality and Human Rights Commission

Policy Report: Beyond tolerance: Making sexual orientation a public matter (October 2009)

www.equalityhumanrights.com/uploaded_files/research/beyond_tolerance.pdf

New Zealand

Despite commencing consultation on including Sexual Orientation as part of the 2011 New Zealand Census, a broad decision was taken in 2008, mid-way through the project, that no new information would be contained in the 2011 Census. It is anticipated that the issue will be reconsidered as part of planning for the 2016 Census.

The New Zealand census of 2006 does include information on same-sex couples.¹⁵³

Statistics NZ – useful documents

Sexual orientation data in probability surveys: Improving data quality and estimating core population measures from existing New Zealand survey data (February 2010)

<http://statisphere.govt.nz/further-resources-and-info/official-statistics-research/series/2010/page2.aspx>

Sexual Orientation Focus Group Research Outcomes (2006)

http://www.stats.govt.nz/browse_for_stats/people_and_communities/marriages-civil-unions-and-divorces/sexual-orientation-focus-group-research.aspx

Canada

Statistics Canada considered the issue of sexual orientation as part of the 2006 Census. It cited results of its testing:

*The focus groups demonstrated that the survey context is important because it provided an explanation as to why the question was being asked and how the data could be used. For example, participants were most willing to answer questions within the context of a health survey or a discrimination and human rights survey. Most participants did not approve of including a sexual orientation question on the Census.*¹⁵⁴

Canada has included questions¹⁵⁵ about sexual identity within its Canadian Community Health Survey¹⁵⁶ since 2003 along with its General Social Survey on Victimization since 2004¹⁵⁷ and includes same sex couples in its Census.¹⁵⁸ The British Columbia Adolescent Health Survey¹⁵⁹ has collected sexual orientation data since 1992.

United States

The US Census Bureau did not collect Census information about LGBTI individuals in the 2010 Census. It has however recognised same-sex couples (both married spouse and unmarried partner^{160 161 162} and has continued to enhance a wide range of national research data to include LGBTI indicators.^{163 164 165} A good website for current sources of same-sex attracted data in

the US is http://www.gaydata.org/ds001_Index.html

In July 2011, the Office for Minority Health, US Department of Health and Human Services announced that it would begin to integrate sexual orientation and gender identity questions into population health surveys.¹⁶⁶ As part of the plan to “Improve data collection for the LGBT Community” it has engaged in an 18-24 month project to develop and evaluate questions on sexual orientation and gender identity.¹⁶⁷

A number of population based studies in the United States include questions on same sex attraction, behaviour or identity:

- National Health and Nutrition Examination Survey III¹⁶⁸ collects information on sexual orientation.
- National Survey of Family Growth (NSFG)¹⁶⁹
 - collects information on sexual orientation or same sex behavior.¹⁷⁰
- The National Co-Morbidity Survey
- National Household Survey on Drug Abuse
- National Health and Nutrition Examination Survey III
- The Youth Risk Behavior Surveillance System (YRBSS)¹⁷¹
- National Longitudinal Study of Adolescent Health¹⁷²
- MIDUS, Mid life in the United States, A National Longitudinal Study¹⁷³
- National Survey on Family Growth¹⁷⁴
- the National Household Survey on Drug Abuse¹⁷⁵
- the National Latino and Asian American Survey¹⁷⁶
- the National Epidemiological Survey of Alcohol and Related Conditions¹⁷⁷.

There are a three significant papers outlining inclusion of LGBTI indicators from the US:

- Badgett, MVL (November 2009), Best Practices for Asking Questions about Sexual Orientation on Surveys, The Williams Institute, University of California, California, USA (<http://williamsinstitute.law.ucla.edu/research/Census-lgbt-demographics-studies/best-practices-for-asking-questions-about-sexual-orientation-on-surveys/>) .

- The GenIUSS Group (February 2013), ‘Gender-related Measures Overview’, The Williams Institute, University of California, USA (<http://williamsinstitute.law.ucla.edu/research/transgender-issues/geniuss-group-overview-feb-2013/>)

- Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities (March 2011) The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding, Institute of Medicine, National Academy of Sciences, Washington DC, USA (www.iom.edu/lgbthealth)

- Centres for Disease Control and Prevention CDC Health Disparities and Inequalities Report — United States (January 2011) Morbidity and Mortality Weekly Report (<http://www.cdc.gov/mmwr/pdf/other/su6001.pdf>)

Denmark

Census includes currently or formally in a same-sex registered partnership, and death certificates record suicide and same-sex registered partnerships.¹⁷⁸

Sweden

National Public Health Survey - Includes transgender, heterosexual with some homosexual elements, bisexual, homosexual with some heterosexual elements.¹⁷⁹

Switzerland

The Swiss Multicentre Adolescent Survey on Health.¹⁸⁰

Ireland

Census collects information on same sex couples.¹⁸¹



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⁶ See section 4 of the Anti-Discrimination Amendment Bill 2012 (Tas) available at http://www.parliament.tas.gov.au/bills/pdf/45_of_2012.pdf

⁷ Various legislation, most comprehensive summary available at, including links to specific legislation http://en.wikipedia.org/wiki/Recognition_of_same-sex_unions_in_Australia#State_registries_in_Australia

⁸ Various legislation, most comprehensive summary available at, including links to specific legislation http://en.wikipedia.org/wiki/LGBT_adoption_and_parenting_in_Australia

⁹ Australian Human Rights Commission (2009) Sex Files: the legal recognition of sex in documents and government records. Concluding paper of the sex and gender diversity project, Sydney, Australia (http://www.humanrights.gov.au/genderdiversity/SFR_2009_Web.pdf)

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