White paper

Making the Count: Addressing data integrity gaps in Australian standards for collecting sex and gender information

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Dr Gávriel Ansara

Manager of Research & Policy

National LGBTI Health Alliance

www.lgbtihealth.org.au

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Introduction

Summary

The 2016 *Standard for Sex and Gender Variables* has yet to incorporate some key recommendations made to the Australian Bureau of Statistics (ABS) by the National LGBTI Health Alliance (the Alliance) and participating community organisations. After three years of direct engagement with the ABS, our Manager of Research & Policy, Dr. Gávi Ansara, explains the concept of data integrity and provides an overview of some key data integrity gaps in Australian standards for collecting sex and gender information. The paper identifies some evidence-based solutions that would address these data integrity gaps and meet the needs identified in our community consultations. A white paper is a brief report designed to inform readers about a complex issue. This white paper is intended as a continuation of Australia's ongoing conversation about how we can improve data collection and align more closely with evidence-based best practice.

We hope this white paper will stimulate the well-informed, evidence-based conversations that lead to effective policy change and improved health outcomes.

Background

Inclusion is a core value for members of the Alliance. Since 2012, the National LGBTI Health Alliance has continued to raise concerns with the ABS regarding the need to improve national data collection in a way that adequately counts people's sexuality, relationships, genders, and bodies. In February 2013, the Alliance published a discussion paper [PDF] on the need to collect LGBTI-inclusive data that could inform evidence-based policy and a submission [PDF] to the ABS review of the Sex Standard. Since 2013, the Alliance has also had multiple meetings and teleconferences with ABS staff regarding Census 2016, the Review of the Sex Standard, and the development of the new Gender Standard. In the years prior to these engagements, multiple Alliance members had advised the ABS of the need to improve data collection in the Census. Several organisational partners and universities also raised concerns regarding the LGBTI data indicators needed to ensure inclusive alcohol, tobacco, and other substance use data sets.

Recent Events

On Tuesday 2 February, the ABS released the 2016 Standard for Sex and Gender Variables. The 2016 Standard replaces the 1999 Sex Standard. The Standard sets national classification categories used by government and government-funded projects for the collection of sex and gender information. The new Standard is intended to ensure consistency with the Commonwealth Attorney-General's Department (AGD) *Australian Government Guidelines on the Recognition of Sex and Gender.* On behalf of the Alliance, I have served on the advisory group responsible for the review of the Guidelines, although some of the advisory group's recommendations to the AGD remain unaddressed.

In a recent media release, the Alliance congratulated the ABS for formally recognising people who do not identify as women or men and for some recognition that people's assigned sex categories do not necessarily reflect their gender identity. We also praised the ABS for ensuring that the Guidelines that accompany the Standard provide useful guidance on sensitive ways to ask all people to classify themselves instead of assuming their sex and

gender during face-to-face or telephone interviews. Despite some beneficial changes, the new Standard does not reflect some of the Alliance's key recommendations for inclusive data collection with intersex people and with people of trans and/or non-binary experience. We are committed to continuing our work with the ABS and our national consultations with people directly affected by this issue.

A note about privacy

Accurate data collection requires careful attention to respondents' needs and concerns. The issue of privacy is frequently raised in discussions about how to collect sex and gender information. Although asking about assigned sex at birth does require careful attention to privacy concerns, so do the questions about 'sex' that are routinely asked in national data collection today. When we address these privacy concerns, respondents will feel able to provide more accurate information about themselves. **Addressing respondent's privacy concerns will improve data integrity.**

What is 'data integrity'?

The term 'data integrity' refers to the comprehensiveness, accuracy, and consistency of data. Some key components of data integrity are:

- **Consistency across time** — data should be consistent between time intervals
- **Consistency across space** — data should be consistent across different regions, cultures, settings, and populations
- **Construct validity** — a measure of whether variables actually measure what data collectors claim to be measuring
- **Ecological validity** — a measure of whether collected data provide an accurate picture of the real world
- **Inter-rater reliability** — a measure of the extent to which different people would assign the same classifications to data

This is not an exhaustive list, but covers some of the statistical concepts most frequently invoked in discussions about how to collect sex and gender information. Throughout this

paper, I use the term data integrity to refer to one or more of these distinct meanings. In making this decision, I have balanced scientific precision with accessibility to readers from a variety of backgrounds. Each of these distinct component of data integrity is based on the principle that data are only as good the instruments and methods we use to collect them.

Why is data integrity important?

Data integrity is necessary to ensure that collected data provide an accurate representation of the real world. Ultimately, data integrity is about making sure that no one falls through the cracks, so that we can achieve social cohesion. Social cohesion is a term that describes the process by which we can build shared Australian values and reduce disparities. When we build shared values and reduce disparities, we enable people to be contributing members of our society.

When we talk about whether collected data provide accurate representation of the real world, we need to remember that people of trans and/or non-binary experience and intersex people are part of that real world. We want to make sure that the ABS and other Australian data collectors are also aware of trans, non-binary, and intersex populations in all areas of Australia. The principle of data integrity is often used to justify exclusionary data collection practices. The assumption behind this claim is that existing data are accurate and consistent. A typical argument against changes to data collection practices may invoke the concept of consistency across time. Some data collectors may argue that consistent data—however flawed—are better than accurate data that cannot be aligned with previous data collection instruments and findings. Yet data that exclude marginalised populations cannot be regarded as having integrity.

Those who are comfortable with 'business as usual' may fear that change could interfere with the accuracy or consistency of previously collected data. This concern overlooks the serious problems with how data are currently collected. Making some necessary changes outlined in this white paper can increase data integrity by making sure that we collect more accurate information. This does not mean that data collected in the past were worthless, but that they

had limitations we can address. When we have more accurate information, adequate resources can be allocated to those whose needs have not been met in the past.

We can achieve scientific excellence by aligning our data collection practices with reality, not by ignoring it.

Data integrity gaps in Australian data collection standards

What are the data integrity gaps?

So what's problematic about the ABS 2016 Standard for Sex and Gender Variables? How can Australian data collectors address similar data integrity gaps? In this brief analysis, we will explain five key issues that we have been discussing with the ABS since 2013.

Non-binary people are not 'optional'

The 2016 Standard states that further breakdown of the third or 'Other' category is recommended *'when undertaking an in depth social study'* (sic). This advice promotes the belief that researchers do not always need to include people of *non-binary* experience (i.e., people who do not identify as either women or men). Elsewhere, the ABS appeared to endorse exclusionary data collection practices, despite the clear threat such practices present to data integrity. In an official ABS statement read at the Slipping Through the Cracks event for which I and others served as panelists, the ABS explained that people who wish to select 'Other' on Census 2016 should ring a number to obtain a secret password. When the ABS statement was read, multiple audience members groaned audibly. *'Ring a number and probably get misgendered? No thanks!'*

Several panelists and respondents expressed concern that very few non-binary people would choose this option. **The resultant underreporting of non-binary people could then be used to justify future exclusion.** In other words, people of non-binary experience are being told they need to spend more time and expend more effort than other people, if they wish to be counted by our government. There's a technical term for this requirement: **direct discrimination**.

The *Sex Discrimination Act 1984* (the SDA), which provides federal protection from both direct and indirect discrimination, was amended to include sexual orientation, relationship status, gender identity, and intersex status from 1 August 2013. This legislation explicitly includes people who do not identify their gender identity as either women or men. The legislation applies to employment, education, accommodation, goods and services, and the administration of federal laws, programs, and policies. Section 5B(2) of the Act states:

> For the purposes of this Act, a person (the **discriminator**) discriminates against another person (the **aggrieved person**) on the ground of the aggrieved person's gender identity if the discriminator imposes, or proposes to impose, a condition, requirement or practice that has, or is likely to have, the effect of disadvantaging persons who have the same gender identity as the aggrieved person.

The Act contains numerous exemptions. Unfortunately, Section 43A of the Act clarified that:

- The making of a request for information is not unlawful under Division 1 or 2 merely because the request does not allow for a person to identify as being neither male nor female.

- Nothing in Division 1 or 2 makes it unlawful to make or keep records in a way that does not provide for a person to be identified as being neither male nor female.

In practical terms, the 43A exemption means that people who do not identify as either women or men can be denied equal treatment in any area of public life that involves data collection: opening a bank account, applying for rental accommodation, enrolling in a school or university course, going to a medical appointment, and completing a job application. Direct discrimination against non-binary people in data collection leads to indirect discrimination in employment,

education, accommodation, goods and services, and in the administration of federal laws, programs, and policies. In effect, **the information and record-keeping exemptions disadvantage non-binary people in precisely those ways that anti-discrimination legislation is designed to prevent.**

Fortunately, the Australian Government Guidelines on the Recognition of Sex and Gender (*the Guidelines*) published by the Commonwealth Attorney-General's Department (the AGD) recommend inclusive data collection with non-binary people. Although those of us who served on the advisory group for the revision of the *Guidelines* have published an open letter expressing concerns that the AGD did not address in the November 2015 updates, the *Guidelines* provide a much clearer mandate for the inclusion of non-binary people in data collection than the SDA. The Guidelines, which commenced in July 2013, recognise that people

> ... may not identify as exclusively male or female, and that this should be reflected in records held by the government...

As a statement on the AGD's website clarifies, all ABS data collection activities and standards are within the scope of the *Guidelines*:

> The guidelines apply to all Australian Government departments and agencies that maintain personal records (including employee records), and/or collect sex and/or gender information. The guidelines commenced on 1 July 2013, and were updated in November 2015. Australian Government departments and agencies are to progressively align their existing and future business practices with the guidelines by 1 July 2016.

As Australia's official statistical organisation, the ABS aspires to be a high quality, objective, and responsive national statistical service. **To achieve scientific excellence, the ABS and Australian data collectors will need to recognise that non-binary people exist rather than treating their existence as optional.** Despite the ABS claim to the contrary, the 2016 Standard is not consistent with the Guidelines. In order to align their existing and future practices with the *Guidelines*, the ABS will need to include people of non-binary experience in all of their policies and practices.

What does the evidence tell us about the existence of non-binary people?

The treatment of non-binary people as expendable stems from the misconception that they are extremely rare and thus not part of 'the general population'. Few Australian data collectors appear familiar with the research. So what does the research tell us? Let's look at some of the evidence:

- A nationally representative study of New Zealand/Aotearoa high school students asked "Do you think you are transgender? This is a girl who feels like she should have been a boy, or a boy who feels like he should have been a girl (e.g., Trans, Queen, Fa'faffine, Whakawahine, Tangata ira Tane, Genderqueer)?" Among respondents, 1.2% reported being transgender and 2.5% reported that they were unsure of their gender. In other words, 3.7%, or approximately 4 in 100 young people, reported having a trans and/or non-binary gender experience. That figure does not include young people who dropped out of school due to gender-related bullying or young people who did not feel safe answering the question in school. The misgendering language used in this question (i.e., the inaccurate description of a self-identified boy as 'a girl' and 'she' and of a self-identified girl as 'a boy' and as 'he') may also have underrepresented young people with a trans experience who understand themselves to be girls or boys already and those non-binary people who do not also consider themselves to be transgender. Among respondents who reported being transgender, 27.3% reported having 'wondered about being transgender' when they were under 8 years old and 17.9% had done so when they were 8-11 years old. In other words, 45.2% of high school students of trans experience reported having questioned their gender before the age of 12.

- Over one third of young respondents in Australia whose data were included in the From Blues to Rainbows Report classified their gender as non-binary. Among the respondents, 26% reported identifying as either genderqueer or genderfluid, 7% reported their gender as no gender or agender, 2% as bi-gender, and 1% as brotherboy (a First Australian gender). In addition to the 36% of respondents who identified with these non-binary options, the survey documented a range of additional non-binary responses. In other words, the use of multiple non-binary options led to a more accurate representation of Australian gender diversity.

- Additional studies support this finding that non-binary people are far more common than data collectors assume and that providing multiple non-binary response options will result in more comprehensive data, Among the young people who participated in the [Writing Themselves In 3 Report](), more than one in three young people did not identify as either girls/women or boys/men.

- People often talk about women and men as being the only 'traditional' genders. Yet [this map]() shows many cultures and societies around the world that have traditionally recognised more than two genders. For example, the Bugis society on Sulawesi, Indonesia has five traditional genders. Even this map is likely to be incomplete, as Australia was added only after I asked the PBS to add a flag recognising traditional gender diversity among First Australians. Many people from societies around the world with more than two traditional genders are living in Australia today. Giving everyone a 'fair go' in our multicultural Australian society requires non-discriminatory data collection.

- Aboriginal and/or Torres Strait Islander [sistergirls]()' traditional gender roles have been excluded from Commonwealth Government data collection, as has recognition of [brotherboys](). This erasure of the oldest and first Australians contributes to further marginalisation. Although sistergirls (traditionally known as yimpininni in the Tiwi Islands) have been estimated by community members to be 5% or more of Aboriginal and/or Torres Strait Islander populations, their exclusion from national data collection means their needs are not considered in decisions about funding and resource allocation. As a result, many [sistergirls have been forced to leave their families and communities due to lack of services](). We cannot expect to 'close the gap' and address existing health disparities until ABS data collection provides equal recognition for First Australians.

Some data collectors and researchers may believe that recognising cross-cultural gender diversity and people who do not identify as women or men reduces data integrity. In fact, we inhibit scientific excellence by excluding people of non-binary experience from general population data collection. Unfortunately, the misconception that people of non-binary

experience are exceedingly rare and outside of normal human experience can have far-reaching consequences. As a result of exclusionary data practices, we do not know how large this population may be. National data are used to determine government funding priorities, resource allocation, and national policy. For this reason, **all data should be collected inclusively.**

Recognising non-binary people: isn't it too complicated to put into practice?

There are simple statistical solutions to ensure recognition people of non-binary experience and avoid discriminatory data collection. **Where there is a statistical will to be inclusive, there is a statistical way.** The Alliance routinely provides advice to researchers, government, and the non-profit sector. There are multiple better options for accurate data collection than overlooking naturally occurring gender diversity or lumping all people of non-binary experience together as an undifferentiated 'other'.

Although some people may consider it 'too complicated' to improve on existing data collection practices, research excellence demands such changes. The Center of Excellence for Transgender Health (CoE) is a University of California San Francisco collaboration between the Pacific AIDS Education and Training Center (PAETC), and an internationally recognised leader in HIV prevention research, and the Center for AIDS Prevention Studies (CAPS). In their Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care, and Services, the CoE explains the rationale for changes to the collection of sex and gender data:

> It is imperative to improve and enhance our surveillance and data collection methods to better capture and understand complexities among diverse people. There are demographics and characteristics that over time have been broadened to be more inclusive and better reflect the diversity of the population in the United States, such as race and ethnicity. To collapse our many races and ethnicities into 2 or 4 categories would provide an extremely skewed information base (e.g., how would you identify someone who is Puerto Rican if you only had two choices: African-American or white), and what about people who identity as multiracial or multiethnic?

As noted by the CoE, population change over time makes it difficult to achieve consistency with past findings without sacrificing scientific excellence. To ensure data integrity and maintain public trust in ABS statistics, the ABS must collect inclusive and accurate data on non-binary people. In Australia, **we have been talking about the inclusion of non-binary people as if it threatens data integrity, when including non-binary people is one of the best ways to safeguard data integrity.**

Recommendation: We recommend that the ABS and Australian data collectors should comply with the requirement in the aforementioned AGD Guidelines to include people of non-binary experience in all data collection standards and practices. There is an urgent need for the ABS and other data collectors to review their existing policies and practices to ensure non-discriminatory data collection, including in Census 2016.

Assigned 'sex' categories are not actual physical characteristics:

The ABS have claimed that 'sex' data can be necessary in health and medical research contexts. This claim appears to stem from the misconception that assigned 'sex' categories provide accurate information about people's physical characteristics and biomedical needs. The 'female' and 'male' markers on government records refer to *assumed* rather than *actual* physical characteristics. In Australia, most 'sex' category assignments are based solely on external genital appearance at birth, not on comprehensive physical evaluations. Although the words 'female' and 'male' are often substituted for and conflated in in everyday speech with gender identity terms such as 'woman' and 'man', gender is distinct from assigned 'sex'. As the Alliance explained in previous feedback to the ABS, **treating administrative 'sex' categories as if they were measures of actual physical characteristics can actually hinder medical research and clinical care.**

Here are some examples of how treating assigned 'sex' categories as if they were actual physical characteristics can threaten data integrity.

On forms and questionnaires

The administrative labels of 'female' and 'male' have limited utility. For example, the ABS seems to assume that a respondent who selects 'female' has XX chromosomes, a uterus, a vagina, stereotypically female hormone production, and the capability to become pregnant unless otherwise specified. Yet this 'F' category tells us very little that is medically useful. Recent medical research has documented that 'sex' chromosomes are not the sole determinants of whether someone develops as 'female' or 'male' (the scientific process called sex *differentiation*). 'Sex' is not as simple as XX and XY. We know that people are born with 47,XXY; 47,XYY; 48,XXXX; 48,XXXY; 48,XXYY; 48,XYYY; and other genetic variations.

Human physical diversity transcends popular stereotypes. Even without considering people of trans and/or non-binary experience and people born with intersex characteristics, not all 'females' have a uterus. Some have a 'typically male' height. Some are muscular and athletic. Some do not menstruate or have reproductive capability. Well-informed medical researchers and clinicians are aware of this diversity.

Now let's consider the case of a man born with a stereotypically 'female' body who was assigned as 'female' at birth. Since having various surgical interventions to affirm his gender, this man now has a stereotypically male chest, no ovaries or potential to become pregnant, a typically 'male' hormonal profile, and a typically 'male' distribution of hair, fat, and muscle. He also has a typically 'male' face and voice, hormonally enhanced erectile tissue that he considers his penis (without direct surgical enhancement to give him a 'typically male' penis), and a uterus. He is likely to consider himself as 'male', and scientifically should be treated as 'male' in some areas of medical data collection. However, he may still have a uterus, so he might not be stereotypically 'male' in some physical aspects. On a survey that merely asks people to use an administrative sex category (M, F, etc.), someone with this exact same physical profile might select M, F, or another category. Neither response may be particularly useful or informative. Thinking back to the definition of data integrity introduced at the beginning of this paper, we might then question whether relying on this man's assigned 'sex' category gives us an accurate representation of the real world.

In medical research

Medical studies have found that men of trans experience have higher rates of polycystic ovary syndrome (PCOS) (e.g., Baba et al., 2007), which is a risk factor for numerous severe medical conditions. Yet general studies of PCOS categorically exclude all 'males'. In practice, this has led to the inability of trans men to access clinical trials, resources, and research participation opportunities. Now imagine if instead of relying on assigned 'sex' categories, PCOS researchers invited all people with ovaries to participate and coded respondents' own labels for their genders. The research could include a larger sample and provide more useful results that increased data integrity—that is, the results would provide a more accurate or *ecologically valid* representation of the real world.

In hospital-based clinical settings

The ABS have claimed that a 'sex' variable is useful in clinical settings, when detailed information about people's bodies is needed. So does knowing someone's assigned 'sex' category actually ensure data integrity in medical contexts? Not according to some hospitals. Let's look at one case example from a top Canadian hospital.

Mount Sinai Hospital is an internationally recognised, 442-bed acute care academic health sciences centre affiliated with the University of Toronto and part of Sinai Health System in Canada. Mount Sinai Hospital specialises in women's and infants' health, chronic disease management, specialised cancer care, emergency medicine, and geriatrics. Mount Sinai was awarded Exemplary Status from Accreditation Canada and is the first Canadian hospital to receive Magnet® status for nursing excellence and patient care.

As one of the top hospitals in Canada, Mount Sinai provides an international model for best practice in data integrity. Mount Sinai's Gender Identity Policy is to record people's own gender classifications on all hospital records. Instead of relying on assigned 'sex' categories, Mount Sinai will only 'request and disclose a patient's birth-sex, genital status and/or reproductive organs physiology only when directly related to their care'. In other words, the hospital

recognises that a person's assigned 'sex' category does not provide medical data about their genitals, their reproductive anatomy or physiology, or their other biomedical characteristics. This policy applies not only to all activities involving Mount Sinai's computer and communications systems, but also 'to all activities which take place at the hospital, as well as to hospital-related activities which occur elsewhere, including but not limited to business undertakings, teaching or training programs, research initiatives, community projects, partnership activities, social functions, fundraising events'. When a hospital as distinguished as Mount Sinai Hospital can receive international recognition for excellence in healthcare, inclusive and accurate data collection is clearly possible to achieve and not 'too hard' or 'impractical'. Administrative convenience is not scientific excellence.

Scientific excellence means collecting detailed biological information rather than relying on administrative 'sex' categories. This misuse of assigned 'sex' categories can contribute to misclassification and exclusion from important areas of health research. For example, *The Los Angeles County Transgender Population Estimates 2012* Report estimated that approximately 50% of people of trans experience had been misclassified in Los Angeles County HIV/AIDS surveillance data prior to 2002. Misclassification and exclusion reduce data integrity.

Recommendation: We recommend that the ABS and Australian data collectors stop treating assigned 'sex' categories as actual physical characteristics. In cases where physical information is needed, we recommend the collection of specific information about people's relevant anatomical or physiological characteristics.

Misgendering reduces data integrity

Misgendering is a term to describe gender-associated language and behaviour that disregard someone's own understanding of their gender and body. In 2012, Dr Peter Hegarty and I co-authored the first empirical study of misgendering. This research documented misgendering as a form of cisgenderism, the system of thinking and action (ideology) that invalidates people's

own understanding of their genders and bodies. My peer-reviewed article on improving research methodology and my previous work with Dr Peter Hegarty identified recommendations for reducing cisgenderism in data collection and research.

Cahill and Makadon (2013) have also explained how accurate and inclusive data collection of gender data in clinical settings and electronic health records can be essential to reducing health disparities. Cahill and Makadon noted the 'overwhelming community support' by 145 leading health and community organisations for the routine collection of gender identity data in clinical settings. However, inclusion without accuracy is likely to reduce data integrity. For example, medical research often misgenders women of trans experience by misclassifying them as men who have sex with men (MSM). Similarly, gay and bisexual men of trans experience are typically misgendered as women (Bauer, Redman, & Bradley, 2012).

The ABS 2016 Standard contains a statement that 'a biological male may feel it may be dangerous to disclose their sex when they express and dress as a female'. This description lacks *ecological validity*—that is, it does not reflect an accurate understanding of the diverse ways in which many people of trans experience categorise and understand themselves in everyday life. In order to achieve data integrity, we need *ecologically valid* data collection practices. The person whom the ABS Standard described is a woman and may also classify her sex as female, whether or not she has altered her body through hormones or surgical intervention. She 'expresses' herself as a woman, so it is likely that she would prefer to be described using appropriately gendered language. Referring to her as 'their' and 'they' instead of as 'her' and 'she' here creates unnecessary ambiguity and fails to respect her gender as a woman. This kind of misgendering in a national standard is unfortunate and does not reflect international best practice.

What is international best practice?

Let's look at an example from the field of medical research on HIV/AIDS. In the CoE's Recommendations for Inclusive Data Collection of Trans People in HIV Prevention, Care, and Services, they note that:

currently many federal, state, and local agencies inaccurately collect data about individuals' sex and gender. Most often, only one question is asked: **What is your sex?** or **What is your gender?**, and only 2 or 4 options are provided requesting only one choice: **Male** or **Female**, or **Male**, **Female, Male-to-Female (MTF)**, or **Female-to-Male (FTM)**.

As mentioned previously, accuracy is one of the key components of data integrity. The ABS 2016 Sex and Gender Standard has the same data integrity issue described above. As the CoE explained,

Today, this method is too simplistic and binary to accurately and effectively collect critical information to assess HIV incidence and prevalence, identify emerging trends, allocate resources, improve health care services, and address service gaps among populations of individuals.

In other words, the 2016 Standard needs to be changed in order to achieve data integrity.

Recommendation: We advise the ABS and Australian data collectors to avoid misgendering by revising their standards and practices. We recommend revising the 2016 Standard to remove misgendering as in the example above. We advise the ABS and Australian data collectors to provide multiple questions and multiple response choices for the collection of data about assigned 'sex' and current gender identity.

Intersex people are not a 'third sex':

Intersex is an umbrella term to describe people born with one or more of over forty distinct physical, biochemical, and/or genetic characteristics that are not considered stereotypically 'female' or 'male' according to modern medical norms. Intersex status is a protected category in the SDA. The 2016 Standard refers multiple times to intersex as one option in the 'third category of sex', thus promoting the use of 'intersex' as a third sex category. Indeed, the aforementioned ABS statement even uses the phrase 'third sex'.

Most people who meet the definition of Intersex Status in the SDA do not wish to be considered a 'third sex' and do not want intersex to be confused as being their gender. However, many intersex people do wish to be recognised and acknowledged in national data collection. The conflation of sex and gender in data collection often forces intersex respondents either to accept invisibility or to select responses that do not accurately capture their sex or gender. In terms of *gender*, many intersex people identify as women or men. A careful approach is needed to ensure that intersex people can be included without being treated as a 'third sex' or erroneously assumed to have a 'third gender'.

Although the ABS reported that the current Standard was the product of community consultation, the Alliance and our intersex member organisations recommended unanimously that the ABS should discontinue the Sex Standard altogether. We have repeatedly cautioned the ABS against the use of intersex as a third sex category. The use of the third sex category promotes misclassification of intersex people who consider their sex to be female or male.

Recommendation: We continue to caution the ABS and Australian data collectors against the misclassification of intersex people as members of a 'third sex' category. Instead, we recommend that data collectors provide a separate question that allows respondents to note their intersex characteristics in a separate item where relevant.

How you ask is as important as what you ask

For some researchers, 'inclusion' is a mysterious buzzword that can be difficult to translate into practice. As discussed earlier in this paper, merely adding a question or response choice in data collection does not in itself achieve inclusion. Some of the many issues to consider when implementing strategies for inclusion are order effects, priming, and ecological validity.

Order Effects

Order effects are differences in participant responses that result from the order in which questions or answer choices are presented. When people are asked about their gender prior to being given the option to disclose being born intersex or having a trans and/or non-binary gender experience, they may select an inaccurate choice based on what they think data collectors want (an effect called _social desirability bias_).

Recommendation: We recommend that Australian data collectors use separate questions that allow people the option to note that they are intersex and to select their assigned sex at birth, prior to asking people about their current gender identity (including people who report themselves to have no gender or multiple genders). A statement explaining how the information will be used and how respondents' privacy needs will be addressed should appear immediately prior to any of these questions.

Priming

Priming refers to activation of unconscious memory functions, typically associations or representations, prior to carrying out an action. When respondents to a survey are 'primed' by particular language or associations, then this priming can affect their responses. Some forms of priming can lead to inaccurate results that threaten data integrity.

How can priming affect the use of sex and gender variables in national statistics?

The UK Office for National Statistics (ONS) is the UK equivalent of Australia's ABS. In 2009, the ONS Trans Data Position Paper noted that people are more likely to respond affirmatively to questions that use language with which they are comfortable and less likely to respond accurately to survey questionnaires that misgender them. We previously informed the ABS that all of our relevant member organisations disliked 'other', 'intergender' and 'indeterminate gender' and described these labels as stigmatising, vague, or inaccurate. This means that respondents to whom these concepts apply might be less likely to select these options. Think

back to the concept of *construct validity* discussed earlier in this paper. Priming effects may affect construct validity by causing participants to respond based on their reactions to the labels used rather than their actual gender identity. **Thus the current approach to using the 'Other' third category is likely to reduce data integrity.**

Recommendation: We recommend the use of multiple binary (woman/man) and non-binary options when collecting gender information. We advise against the use of 'Other' when collecting gender data and instead recommend less stigmatising language such as 'Another gender'.

Ecological Validity

Let's return to the concept of ecological validity discussed earlier in this paper. Recall that ecological validity is about making sure that data reflect the real world. So what do we know about that 'real world'? We know that many people of trans experience are offended by surveys that expect all trans people to select 'other' or 'trans' as their gender instead of woman or man. As explained in this article, people of non-binary experience do not necessarily consider themselves to be 'trans', so the assumption that 'trans' can always be used as an inclusive umbrella term is not supported by available evidence. We know that most trans people do not consider themselves to be a third sex. We know that intersex people may identify their gender as women or men. We know that questions that combine sex and gender typically exclude non-binary people and misclassify intersex people. We also know that some of our constituents live part of their lives as women and part of their lives as men. We know that some people consider fluidity itself to be the defining feature of their gender identity. For these constituents, it would be inaccurate for them to select only one gender choice. Due to these kinds of concerns, **the international best practice standard is to use more than one question about sex and gender.**

The ONS (2009) report notes that

> The Press for Change website **strongly advises against grouping transgender with gender or sexual orientation questions.** As most transsexual people do not consider themselves to be a third sex and being trans has nothing to do with who you are

attracted to. They therefore advise treating trans as a separate entity and using one of the following approaches **specifying that the question completion is optional...**

Both the ONS in the UK and the CoE in the US recommend asking **more than one question,** with one question asking for a person's current gender identity and a separate question asking about their assigned sex at birth. This approach has greater ecological validity than asking a single question. Both the ONS and the CoE have recognised that a single question approach that groups questions about trans experience with other sex and gender questions can lead to inaccurate data. In contrast, the CoE notes that using more than one question has produced 'increased accuracy in sex and gender information about patients and clients' in federally funded health and medical research over the past decade.

Which questions should we ask to capture 'sex and gender' information?

Although best practice standards continue to improve, recent evidence offers some preliminary answers for how to ask people about their 'sex and gender' and document their responses in electronic health records. For example, one study conducted a trial of the internationally recommended two-step gender identity and assigned sex with patients at four health centres affiliated with the Community Health Applied Research Network (CHARN), which is funded by the US Health Resources Services Administration (Cahill et al., 2014). Cahill et al. trialled the use of two gender questions in patient data collection. The first question asked 'What is your current gender identity? (Check all that apply)'. Participants were able to select multiple responses, to record their non-binary identity, to select the 'additional gender category', or to decline to answer. Participants who selected the 'additional gender category' and those who declined to answer were given space to explain why they chose this response. This two-step gender identity and assigned sex approach evaluated by Cahill et al. has been adopted by the World Professional Association for Transgender Health (WPATH) (Deutsch et al., 2013) and by the influential Centres for Disease Control and Prevention (CDC) in their electronic surveillance and reporting systems.

The ABS and Australian data collectors have claimed that respondents might not understand non-binary gender options or might find questions about gender identity and assigned 'sex' category confusing. In contrast, Cahill et al. (2014)'s study found that most respondents

understood and were willing to answer all of the questions in the two-step gender identity and assigned sex at birth approach. Moreover, most respondents of trans experience felt that the gender identity question was designed in a way that allowed them to document their gender identity accurately. Among all respondents, 90% reported that they would not change the gender identity questions, and 88% of people who did **not** have a trans and/or non-binary experience agreed that they would answer the gender identity question when completing registration forms at their health centre. As the researchers concluded,

> We believe that this study demonstrates that a consensus exists regarding the importance of sexual orientation and gender identity information for the provision of optimal clinical care, and that **the measures developed in this study could function as standard measures that could be employed in real-world health care settings.** The [sexual orientation and gender identity] questions tested in these four settings could, if widely used, […] provide important information on patients that can help us better understand health disparities…

Recommendation: We recommend that the ABS change the 2016 Standard to align with the international best practice standard of two-step questions about current gender identity and assigned sex at birth. We recommend permitting multiple response options. We recommend the inclusion of non-binary gender options without having to ring a number, ask for a special password, or take any actions not equally required of women and men. In other words, we call on the ABS and Australian data collectors to end discriminatory data collection practices.

Conclusion

Dear Reader:

It is time for the ABS and Australian data collectors to act on the problems that the Alliance and our constituents have identified in this white paper. It is time for the ABS and Australian data collectors to implement our evidence-based solutions for achieving data integrity. These solutions focus on five key points:

- Non-binary people are not 'optional'
- Assigned 'sex' categories are not actual physical characteristics
- Misgendering reduces data integrity
- Intersex people are not a 'third sex'
- How you ask is as important as what you ask

Inclusive and appropriate data collection promotes data integrity. As illustrated by the examples in this paper, data integrity can increase social cohesion and improve health outcomes. As a national leader in the promotion of inclusive data collection, the Alliance looks forward to ongoing collaboration with the ABS and Australian data collectors. We also look forward to continuing to represent and consult with our members who are directly affected by current data integrity gaps in Australian standards for collecting sex and gender information.

Data integrity is not about administrative convenience; it is about scientific excellence. We have much work to do to achieve scientific excellence in Australian collection of sex and gender information. **We invite you to partner with us in this effort by adopting the recommendations in this white paper and by sharing this document widely.**

Stay tuned for the findings and recommendations in our forthcoming *Rainbow Research Report*, Australia's first national survey of research ethics, standards, and data collection practices relevant to sexuality, relationships, trans and/or non-binary experiences, and intersex characteristics.

Thank you for helping us to promote scientific excellence in Australia.

Dr. Gávi Ansara
Manager of Research & Policy
National LGBTI Health Alliance
www.lgbtihealth.org.au
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