A guide to LGBTIQ-inclusive data collection







The Canberra LGBTIQ Community Consortium is a partnership of four agencies brought together by the common goal of ensuring health, wellbeing, access, social inclusion and equity for Canberra's lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) communities.

The Consortium is led by the AIDS Action Council of the ACT in partnership with A Gender Agenda, Northside Community Service and Sexual Health and Family Planning ACT (SHFPACT).

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A note from the Consortium

November 2017

Dear Readers,

The Canberra LGBTIQ Community Consortium (hereafter referred to as the Consortium) is pleased to provide the ACT service sector with this resource. The Consortium is a partnership of four agencies, brought together by the common goal of ensuring health, wellbeing, access, social inclusion, and equity for Canberra's lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) communities.

Consultations with LGBTIQ communities undertaken by the Consortium revealed that data collection practices that are not inclusive are a significant barrier to services for LGBTIQ clients. Data collection tools, such as intake forms, are often the first means of communication between a client and the service provider, and as such, they can set the tone of the relationship. While inclusive services are not guaranteed by inclusive data collection, this resource is designed to support service providers in taking important steps towards advancing the LGBTIQ-inclusiveness of their services by ensuring their data collection practices are inclusive and respectful. Access to inclusive services is fundamental to achieving equity in health and wellbeing outcomes in our community. The language used when collecting information about sex, gender identity, and sexual orientation has significant implications for the accessibility and inclusiveness of services for LGBTIQ communities. It is important that service providers are equipped to determine when it is appropriate to collect information about sex, gender, and sexual orientation, and how to do so in a respectful and sensitive manner.

There are some systemic barriers to inclusive data collection that need to be addressed through government policy. However, service providers can contribute to significant change both within their own practices of data collection and service delivery, and by developing best-practice models that can be adopted more widely. We hope that this resource will support service providers to take positive steps towards increasing the inclusiveness and accessibility of services to LGBTIQ communities.

Yours faithfully,

AIDS Action Council A Gender Agenda Northside Community Service Sexual Health and Family Planning ACT

Glossary: Understanding LGBTIQ terminology

Too often gender and sex are used incorrectly or interchangeably. These terms relate to distinct categories, and it is essential that service providers have a clear understanding about what these terms mean to ensure they are collecting the right information.

Sex

Sex refers to a person's biological status. It is typically assigned at birth based on a person's external genitalia. However, there are a number of markers of sex, including hormones, gonads, and chromosomes.

Gender identity

The term gender identity is used throughout this resource to describe a person's self-identification of their gender. Gender identity may or may not correspond with a person's sex as assigned at birth. Additionally, each person's expression of gender identity is unique and may or may not conform to traditional notions of masculinity and femininity.

Non-binary

Non-binary gender identities are identities that cannot be described with reference to categories such as masculine/feminine. For example, people who are gender fluid, occupy more than one gender category, do not occupy a gender category, or occupy another type of gender category beyond the binary may (though will not necessarily) identify themselves as non-binary.

Sexual orientation

A person's sexual identity, behaviour, and attraction all contribute to determining their sexual orientation. Sexual identity refers to the way a person might label themselves, their behaviour refers to the kinds of sexual acts in which they engage, and their attraction refers to the kinds of people to whom they are sexually attracted.

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The Consortium uses LGBTIQ throughout this resource to refer to distinct and diverse individuals that identify as lesbian, gay, transgender, intersex, and/or queer. LGBTIQ people are not a homogenous group or community. Individuals in these communities have multiple, distinct, and sometimes overlapping demographics, resulting in unique histories and experiences.

Lesbian

The term lesbian is used throughout this resource to describe a person identifying as a woman who is romantically and/or sexually attracted to other women.

Gay

The term gay is used throughout this resource to describe a person identifying as a man who is romantically and/or sexually attracted to other men.

Bisexual

The term bisexual is used throughout this resource to describe a person of any gender who is romantically and/or sexually attracted to people of more than one gender.

Transgender

The term transgender is used throughout this resource to describe people whose gender identity does not align with the sex they were assigned at birth. Non-binary genders also fit under this umbrella term, as well as under the term gender diverse.

Intersex

The term intersex is used throughout this resource to describe people who are born with sex characteristics, including genitals, gonads and chromosome patterns, that do not fit typical binary notions of male and female bodies.

Queer

The term queer is used throughout this resource as an umbrella term to describe intersex, transgender, and gender diverse people, as well as people of diverse sexual orientations, all of whom identify as part of the 'queer community'. It is often used as an umbrella term by people wishing to indicate that their sex, gender, and/ or sexuality cannot be understood within the boundaries of normative notions of sexuality and gender.

A note on terms

While we have provided definitions for some common terminology, this list is not exhaustive, and some people may prefer to use other terms to refer to their gender and sexuality. The above terms, while they capture more diversity than typical understandings of gender and sexuality, do not represent the full range of possibilities that exist when it comes to talking about the individual experiences that people have of gender, sex, and sexuality.

LGBTIQ-Inclusive Data collection

What does data collection mean?

Data collection refers to the collection of information. It is not limited to formalised processes for collecting data, such as forms and documents explicitly created to collect certain kinds of information. It also encompasses data collected from sources, including face-to-face communication, telephone conversations, online forms and communication, documents, and visual cues.

Data collection tools refer to anything used to collect data, both quantitative and qualitative. These include physical and online data collection tools, like checklists, questionnaires, forms, surveys, tests, exams, polls, administrative data gathering measures, and emails. Other data collection tools include verbal questioning, conversations, and interviews.

Why does data collection need to be inclusive?

Communicating respect and acceptance

When data collection practices are inclusive of people with diverse sex characteristics, gender identities, and sexual orientations, they communicate to LGBTIQ clients that they are welcome, accepted, and respected.

When data collection practices are not inclusive, they can marginalise and exclude LGBTIQ clients and act as one of the most significant barriers to accessing services. Furthermore, participating in discriminatory systems has a proven negative impact on the health of LGBTIQ community members.¹

Since 1 August 2013, the Sex Discrimination Act 1984 has provided federal protection from direct and indirect discrimination on the basis of sexual orientation, gender identity, and intersex status in a variety of areas of public life, including employment, education, and the provision of goods, services, and facilities (including healthcare).

Balancing interests: Gaining necessary information while respecting privacy

Ensuring data collection practices are inclusive and respectful is not always a straightforward process, as data collection is often informed by competing interests and requirements. For example, it can be difficult to collect data that meets both organisational data needs and the requirements of funding bodies in a way that

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adheres to Australia's privacy laws and best practice inclusive data collection. Furthermore, LGBTIQ communities have unique and justified concerns about privacy as a result of a history and continuing experiences of discrimination and stigma. As a result, service providers need to consider the privacy implications of the ways in which they collect data.

Seeing diversity: The importance of accurate demographic data

It is common for service providers to believe that their services are inclusive because they enforce a policy of treating all clients the same. This approach, however, overlooks the social and cultural determinants of health for LGBTIQ communities and the numerous barriers that LGBTIQ clients experience when accessing mainstream services. When data collection practices do not allow clients to accurately record their sex, gender identity, and sexual orientation, it can lead to LGBTIQ people being "invisible" to service providers. This blocks universal access to services and inhibits the effective targeting of services to LGBTIQ community member needs.² A recent study in Australia concluded that the idea that "treating everyone the same" is good practice is actually the biggest barrier to change within organisations.³

In order to both provide tailored services to LGBTIQ clients and assess the efficacy of such services, we need to collect accurate demographic information.⁴

Effective policies rely on accurate population data, which can come from a range of service-related sources, including statistics on service use and program evaluations. This data is used to inform funding decisions, the development of policies, programs, and services, as well as social, political, and legislative reforms that tackle discrimination at a structural level.⁵ When data collection tools are not inclusive of diverse sex characteristics, gender identities, and sexual orientations, these groups become invisible to policy makers. Service providers have a role to play in ensuring that population data is representative of the diversity in our communities.

Enabling effective service delivery

Inclusive data collection does not guarantee inclusive service delivery, but it can be an important step in the right direction. Inclusive data collection practices not only enable the delivery of more tailored services, but also create a space that fosters open communication about personal information that may be crucial to the provision of high-quality care.

LGBTIQ people experience an elevated risk of poor health and wellbeing outcomes compared to the general population.⁶ This is not because of their sex characteristics, gender identity, or sexual orientation, but due to the discrimination and marginalisation they experience.



The National LGBTI Health Alliance created the following seven principles of LGBTI-inclusive service delivery:

- 1 Recognition and affirmation of sexuality, sex, and gender diversity.
- Recognition of the negative impact of discrimination, stigma, homophobia, and heterosexism on a person's wellbeing.
- 3 Critical analysis of the assumption that all consumers or staff are heterosexual and not diverse in terms of sex or gender.
- 4 Recognition of LGBTI populations as high risk of suicide populations for organisational planning, outreach, and service delivery.
- 5 A client-centred approach that takes into account the broader social determinants that impact on the wellbeing of LGBTI persons.
- 6 A culturally competent and safe workforce that is knowledgeable and responsive to the lived experience of LGBTI persons.
- Safe and welcoming environments and services that are free from discrimination based on sexuality, sex, or gender diversity.⁷

Meeting goals and fulfilling obligations

Inclusive data collection practices are prudent for encouraging respect and recording diversity. They may also be essential to complying with laws and other contractual obligations to funding and reporting bodies, as well as obligations to do with quality of care (particularly for health organisations). They will also aid in meeting organisational goals that aim to provide services that meet the needs of individual clients or communities. Such a goal could depend on obtaining information about gender, biological characteristics, and sexual orientation. Tailoring and targeting services to specific groups and people depends on having relevant data. For health-based services, it is crucial to have accurate information on clients to dispense necessary care and advice.

Five steps to LGBTIQ-inclusive data collection



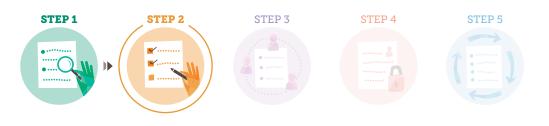


STEP 1 Review data collection practices

Do a stocktake of your organisational procedures and activities that may result in the collection, storage, or transmittal of personal information relating to sex, gender, and sexuality.

What information does your organisation collect? How is it collected? You may be surprised to find that much of the information you collect on sex and gender is gathered "just because"⁸ or even "by accident". You should be aware of the various ways in which your organisation collects personal information, and carefully consider the implications of these processes on the communities you service.

Start by identifying the instances in which you collect personal information, particularly information that relates to sex, gender identity, and sexual orientation. This may be relatively straightforward for organisational procedures that exist for the primary purpose of collecting information, such as recording new client information or collecting client feedback in a survey. However, it may be less obvious for activities that *incidentally* collect personal information, such as taking telephone messages, recording staff working hours for pay roll, or receiving personal information during email exchanges.



STEP 2 Check: Do you really need it?

Make an informed decision about what information is necessary for your service to collect.

Each service provider will need to make a decision about what information is necessary for its particular services. As a general rule, if you cannot identify how the information will enable your organisation to better meet the needs of LGBTIQ communities, you should not be collecting this information. Below are some examples of when it might be appropriate to collect this information:

- Organisations or programs that specifically target LGBTIQ communities may need to collect information on sex, gender identity, and sexual orientation to ensure they are reaching their target communities.
- Organisations on a journey towards inclusive service delivery may collect information on sex, gender identity, and sexual orientation to assess whether their services are accessible to LGBTIQ communities, and to test the effectiveness of their strategies for increasing the inclusion of these groups.
- Information on sex, gender identity, and sexual orientation may be medically
 necessary or necessary for the provision of care. In these cases, attention needs
 to be paid to the phrasing of questions to ensure that they capture necessary
 information and do not make assumptions about a person's sex, gender identity, or
 sexual orientation based on their biological characteristics.
- Some service providers will have a contractual requirement to report on the demographic information of clients. This commonly includes sex and/or gender, and can include sexual orientation for funding targeting LGBTIQ communities. Service funding agreements can appear to limit the ability to capture the diversity of sex characteristics and gender identities, but organisations may have scope to provide additional information about diversity in their client bases.



STEP 3 Collect data in a respectful and inclusive way

Once we have assessed what information is appropriate and necessary to collect, we need to ensure that our collection practices are inclusive. Firstly, this means being inclusive of diverse sex characteristics, gender identities, and sexual orientations. Secondly, it requires us to acknowledge and mitigate the discrimination and marginalisation of LGBTIQ communities.

Use inclusive language

It is important to use empowering, consistent, and inclusive terminology in all data collection tools, including intake forms, surveys, and feedback forms. It is common for forms to use gendered language, which can exclude LGBTIQ people. For example, when questions provide the options mother/father or husband/wife, they exclude people that do not fit into these categories. This can easily be corrected by using gender-neutral language, such as parent/guardian and partner. If you are collecting information on titles, such as Mr, Ms, Mrs, or Mx, do not assume that someone's title preference is linked to their gender identity.

The National LGBTI Health Alliance's Inclusive Language Guide provides a useful summary of the importance of inclusive language. Language is inclusive when we use words in ways that demonstrate our respect for how people describe their own genders, bodies, and relationships. It is important to show this respect even when we are describing people who are not present. Researchers have found that how we are described by others has an enormous impact on our health and wellbeing, as well as on how likely we are to seek health care when necessary. Inclusive language improves the health of our families and communities.⁹



Be accommodating

Many Australians take identity documents and processes for granted. Those who wish to change their sex and/or gender on official documents and records, however, face significant challenges. State and Territory laws govern the classification of sex markers on birth certificates, Australia's principal proof of identity document. In the ACT, this is the *Births, Deaths and Marriages Registration Act 1997* (ACT)ⁱ.

When collecting information on sex and gender, it is therefore important to be aware that:

- The identifier on an identity document may not be reflective of the person's sex or gender identity, and as such, should not be asked about or relied upon unless there is a persuasive reason to require information about someone's "legal" sex;
- A person may have differences between their identification documents if they are in the process of changing, or are choosing not to change, their legal records; and
- Your clients or stakeholders may have had challenges managing the current legal requirements for changing sex on identity documents, and as such, the issue should be approached with empathy and respect.

Use inclusive processes

It is important to use accurate and inclusive language, but it is also important to ensure that the way we are communicating is inclusive.

Face-to-face: Avoid assuming information about a person's sex, gender identity, and sexual orientation from their appearance, voice, or dress. Staff should be briefed as to the importance of using inclusive and accurate language. A good strategy is to check with clients about their preferred pronouns, but be wary of doing this in public or open spaces because this can compromise privacy and safety.

Phone: Avoid assuming information about a person's sex, gender, or sexual orientation from their voice. Privacy is an important consideration in all forms of communication, including over the phone. As such, steps should be taken to ensure the privacy of information given by phone. Phone conversations can provide scope for clients to verbally discuss and disclose (or choose not to disclose) their gender, sex, and sexual orientation in ways that a form may not.

Email: Avoid assuming information about sex, gender, and sexual orientation from indirect information, such as names and email addresses. Ensure that emails are addressed using the correct name and preferred pronoun. If collecting personal information by email, take steps to ensure the privacy and security of the information collected, and the inclusivity of the language used to collect it.

Online forms: To collect data in an inclusive way on online platforms means being aware of the limitations of online forms, designing them with sensitivity, and paying attention to steps needed to secure information disclosed online. Some fields in online



forms can often be phrased with insufficient options for people of diverse and non-binary genders, sexes, and sexualities to self-identify themselves as they would prefer. Providing free-text fields in some places and designing online forms so that they are inclusive can help to mitigate these issues. Also consider allowing users to choose a username in order to protect privacy and identity when disclosing personal information.

Collecting data anonymously or pseudonymously: Wherever possible, service providers should provide clients with the option to provide personal information anonymously or under a pseudonym. While this may not be possible on intake forms, it can provide protection for clients completing evaluation surveys and feedback forms. Indeed, research demonstrates that people are more willing to answer surveys when the information they provide is kept anonymous.¹⁰ This is particularly so for those who identify as transgender.¹¹

Anonymity or pseudonymity?

Anonymity and pseudonymity are distinct concepts. Anonymity means that a person may deal with your organisation without providing any personal information or identifiers. To provide anonymity, your organisation should not be able to identify the person at the time of collecting the information or afterwards.

Pseudonymity means that a person can deal with your organisation by using a name, term, or descriptor that is different to their usual name. For example, a person may employ a username when filling out an online form.

You should ensure that, as far as practicable, your clients and stakeholders have the opportunity to deal anonymously or by pseudonym, and that they are aware of these options. You might implement this advice by:

- having a prominent note on your website stating that an individual may use the contact forms without providing personal information;
- including a message on your answering machine or automated telephone messaging service that callers are not required to provide personal information;
- including a prominent note on your forms or documents that personal identification boxes are not mandatory; or
- informing people at the beginning of a telephone conversation that they may interact anonymously.



Design inclusive questions

The following provides some example questions to help guide organisations in the construction of questions to gather information about sex, gender identity, and sexual orientation when it has been determined appropriate and necessary to do so. It should be stressed, however, that as the needs of organisations, the reasons for collecting data, and the context in which data is collected will vary, these example questions may need to be tailored to the specific needs of each organisation and use. These questions build on the Consortium's experience working with LGBTIQ communities and evidence-based good practice. Every effort has been made to be inclusive and respectful of the diversity of sex characteristics, gender identities, and sexual orientations. Furthermore, in recognition that there is no consensus on terminology, we promote the inclusion of space for people to express their identities in their own ways.

Being asked to provide personal information about your sex, gender, and sexual orientation can feel invasive, and it can trigger concerns about privacy and discrimination. A short note that acknowledges the sensitivity of this information, explains how the data will be used and stored, and assures confidentiality, can go a long way to assuage any concerns and create trust.¹²

Collecting information on gender and/or sex

When collecting information on gender and sex, it is important to create space for people's experiences that do not fit neatly into sex and gender binaries, such as people of diverse and non-binary genders, intersex people and transgender people.

The Australian Government Guidelines on the Recognition of Sex and Gender, which apply to all Australian Government departments and agencies, state that it is the approach of the Australian Government to collect and use information on gender rather than sex. The Guidelines also state that when gender (and sex, in the event that this information is required) is collected and recorded, individuals should be given the option to select *M (male), F (female) or X (Indeterminate/Intersex/Unspecified)*.^{1,ii} This is also the approach taken by the ACT Government for recording sex on ACT birth certificates.

i This was the policy at the time of writing, however it is understood that the government is exploring the possibility of changing the descriptor of X to 'non-binary'. The Consortium unequivocally supports this move.

ii Australian Government (November 2015), Australian Government Guidelines on the Recognition of Sex and Gender, https://www.ag.gov.au/Publications/Documents/AustralianGovernmentGuidelinesontheRecognitionofSexandGender/ AustralianGovernmentGuidelinesontheRecognitionofSexandGender.pdf





The Consortium welcomes the inclusion of a third category for recording gender and sex, however, we join the Sex and Gender Advisory Groupⁱⁱⁱ in advocating for the use of 'non-binary' rather than 'X (Indeterminate/Intersex/Unspecified)', as this better reflects the preferences of the populations most affected by this issue. Where possible, we also advocate for the inclusion of an 'other' box with free text, to provide the option for people to self-identify.

Collecting information on gender

In most circumstances, it will be more useful and appropriate to collect data on gender than on sex.

Q EXAMPLE QUESTION			
How do you describe your gender identity? (Select all that apply)			
Woman			
Man			
Non-binary			
Other (please specify)			
I do not wish to disclose			

Collecting information on sex

In some circumstances, organisations may need to collect information about a person's sex. In the ACT, a person's ACT Birth Certificate or interstate recognition certificate indicates their sex for legal purposes. Service providers will have to determine if it is necessary to collect this information about clients. However, if you are collecting information about sex, you should also collect information on gender identity. This will demonstrate that your organisation is aware that a person's gender identity cannot be assumed from their sex.

Remember: a person's identification documents may not reflect their sex, or it may be listed differently on different documents if they are choosing not to change their legal records or are in the process of changing them.

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iii The Sex and Gender Advisory Group, which was convened by the Commonwealth Attorney-General's Department to guide the Department on the Review of the Australian Government Guidelines on the Recognition of Sex and Gender has expressed unanimous concern about the use of X Indeterminate/Intersex/Unspecified). For more information, see http://lgbtihealth.org.au/wp-content/uploads/2015/10/FOR-DISTRIBUTION-AGD-Sex-and-Gender-Guidelines-Review-Advisory-Group-Endorsement-Letter.pdf

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Collecting information on physical sex and body characteristics for medical reasons

When data on a person's physical attributes and characteristics needs to be collected for medical reasons, it is important that this is done in a way that does not infer sex or gender from those characteristics. This is not only about showing respect and being inclusive, it also prevents individuals from being misclassified, which can result in inappropriate medical care and advice. Instead, questions should be constructed with the aim of only gathering information relevant to specific medical and biological interests.

Collecting information on transgender identities

Many, though not all, transgender people identify as male or female rather than transgender. Some people may identify as both male or female and transgender. Therefore, if it is appropriate and necessary to collect information about transgender experience, this should be done in a separate question.

Q EXAMPLE QUESTION
EXAMPLE GOESTION
Do you have a transgender history, experience, or identity?
Yes
No
I do not wish to disclose

Including an option for people that do not wish to disclose their transgender or intersex status or their sexual orientation can communicate to clients that you understand the sensitivity of the information you are requesting.





Collecting information on intersex status

If it is necessary to collect information about intersex experience, it is important to separate the question from questions on gender identity and sexual orientation. Intersex people are born with sex characteristics (including genitals, gonads, and chromosome patterns) that do not fit typical binary notions of male and female bodies. Specifying the definition of intersex in the question will help to clarify for readers what the question is asking.

Q EXAMPLE QUESTION
Do you wish to disclose intersex status? (Intersex is used here as a collective term for people born with atypical physical
sex characteristics, including chromosomes, gonads, genitals, or hormones.)
Yes
No
I do not wish to disclose

Collecting information on sexual orientation

If it is necessary to collect information about sexual orientation, you should provide people with as much flexibility as possible, such as by allowing them to select all options that apply and describing their sexuality in their own ways. Also, be aware that it is not possible to assume the specifics of a person's sexual history or practices from data about sexual orientation alone. In many cases, if it is necessary to collect data on sexual practices, it will not be necessary to ask about sexual orientation. It may instead be necessary to collect data about sexual contact or conduct. In such cases, questions should be tailored appropriately for the specific context in which the question is being asked, in order to secure only that information necessary for the provision of a specific service. You should also consider providing a free-text field instead of a predetermined list to allow clients to share information as they see fit.



Q EXAMPLE QUESTION
How do you describe your sexual orientation? (Select all that apply)
Lesbian
Gay
Bisexual
Queer
Heterosexual
Other (please specify)
I do not wish to disclose

Collecting contact information

Collecting contact information, including details of new clients and emergency contacts, is a common and necessary activity for many organisations.

Names can be a complicated area for many people, and they are notably so for many people belonging to gender diverse communities. A range of circumstances exist in which a person's preferred name may not match their name on some forms of documentation. The changing of names to reflect marital status or to indicate a preferred nickname are two common scenarios, so this is not an issue unique to gender diverse people. Because many names in our culture are gendered, a transgender person's legal name may not reflect their gender identity and preferred name. Even after choosing a new, differently gendered name, the process of legally changing one's name takes time and money. Further, minors may not be able to change their names without permission.





Create a space for people to use a preferred first name

Ensure that you clearly communicate which name will be used for communications (including mail), and provide clear options for people to nominate names for different purposes. For example, a person who is not openly transgender may have a preferred name that they use with friends but that their family members are unaware of. Receiving mail to the incorrect name can be challenging and potentially life threatening.

Organisations should seek advice on whether they need to obtain a legal first name. If this information is not needed, just include a space for the preferred first name. By doing so, you will avoid making clients uncomfortable about disclosing this information.

	— Q EXAMPLE QUESTION —	
Legal Name		
Preferred Name		*
* All correspondence	will use will use this name unless you request otherwise.	

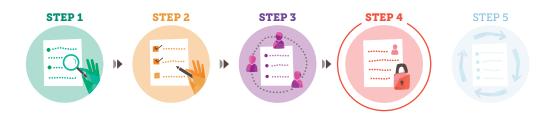
Titles

Many people inside and outside LGBTIQ communities do not feel comfortable with titles. It is therefore important to give people the choice to avoid using a title altogether. Also think about if this is information that you need to collect, because more often than not, it isn't needed at all.

Pronouns

Some pronouns imply gender, such as when we describe someone as 'she' or 'he'. Giving the option for a client to select their pronoun demonstrates that you respect their right to choose how they are described. Including a question on gender identity as opposed to one that only asks for legal sex can be a helpful indication. In online forms or written documents, this can mean including a space for clients to indicate the pronoun they use. By phone or email, this could include asking all clients which pronoun they use rather than making assumptions about the potentially gendered nature of a voice or name. In face-to-face communications, briefing staff to refer to documentation that indicates a client's pronoun can help to avoid the necessity of asking in public spaces, though asking clients their pronouns respectfully in a private space can be a good option for obtaining this information face-to-face.

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STEP 4 Privacy matters: Create privacy mechanisms to protect personal information

As explored earlier in this resource, privacy is a central concern for LGBTIQ people, who often fear persecution if they disclose their gender identity, sex, or sexual orientation, or if such information is made public. In light of this, managing and protecting data on LGBTIQ people should be of paramount importance to organisations and service providers.

Organisations contracted by the ACT or Commonwealth Government may have legal obligations under ACT and/or Commonwealth privacy legislation. At the Commonwealth level, The Privacy Act 1988 (Privacy Act) regulates the handling of personal information about individuals. Australian Government agencies, contracted service providers, all health service providers in the private sector, and all businesses and not-for-profit organisations with an annual turnover of more than \$3 million have responsibilities under the Privacy Act. The Act includes thirteen Australian Privacy Principles (APPs), which set out standards, rights, and obligations for the handling, holding, use, accessing, and correction of personal information (including sensitive information).¹⁵

Check out the Australian Privacy Principles Guidelines for detailed guidance on how to interpret the principles: https://www.oaic.gov.au/images/documents/privacy/applyingprivacy-law/app-guidelines/APP-guidelines-combined-set-v1.pdf



In the ACT, the Information Privacy Act 2014 (ACT) regulates how personal information is handled by ACT public sector agencies and contracted service providers. This Act includes a set of Territory Privacy Principles (TPPs), which cover the collection, use, storage, and disclosure of personal information, as well as an individual's access to and correction of that information.¹⁶ The TPPs are similar to the Australian Privacy Principles (APPs) discussed above.

Service providers delivering health services may also have responsibilities under the Health Records (Privacy and Access) Act 1997 (ACT), which regulates the handling of health information by both public and private sector health service providers in the ACT.¹⁷

It is the responsibility of each organisation to ensure they understand and adhere to their legal obligations under Territory and Commonwealth privacy legislation. Even if the legal obligations do not apply, maintaining best practice approaches to privacy adds considerable value to establishing inclusiveness. Service providers can demonstrate that they understand the privacy concerns of their services' users by ensuring that all personal information is respected and protected with robust privacy mechanisms. This could include the following:

Providing the option to remain anonymous

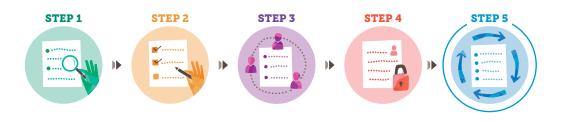
As detailed above in the section regarding data collection methods, providing clients with the option to remain anonymous or communicate under a pseudonym is one way of respecting their right to privacy.

Ensure the setting is private and confidential

You should consider the privacy afforded by the setting in which information is collected. Do not have conversations about personal information in public areas, and consider where a person will complete a questionnaire or survey. For example, asking someone to record information about sex or gender at a reception desk can compound marginalisation and negatively impact the integrity of the information being collected.

De-identify published information

If you are collecting information that will be published, it should be de-identified where practicable. You should be aware that sometimes you might identify individuals even when you are publishing data about your own organisation, if for example, the information reports on a small cohort of people. It is also important to remember that LGBTIQ communities are often small and/or tight knit, meaning it can be easy to identify someone unintentionally.



STEP 5 Build sustainable inclusive practices

The steps in this resource represent one small, though meaningful, part in your journey to creating an organisation that is truly inclusive. Your changes to forms, guidelines, and processes, and your efforts to enable anonymity, are not a "quick fix" solution, but they are a good way to both begin to make people feel more included and to improve data integrity. It is prudent to be cautious about giving people the impression that your organisation is welcoming and knowledgeable about LGBTIQ people if it is not. Sustainable inclusive practices need to be underpinned by policies, procedures, and systems. The complexity of these systems, and the relevance of the following suggestions, will depend on the size and complexity of your organisation. There are a number of options available to assist you in this work. Some useful resources are listed at the end of the section, and Consortium partners are available to provide training and support to organisations on their journeys towards inclusiveness (see below).

Workforce planning and training

Everyone who works in your organisation should be equipped with the basic tools required to treat LGBTIQ people with respect. You should ensure that your staff and stakeholders understand LGBTIQ inclusive practices. In particular, any staff members who engage with members of the public on a regular basis should be trained in terminology, definitions, and sensitivities associated with intersex, transgender, and gender diverse communities. Inclusive practice and privacy awareness should be part of regular staff training programs, as well as induction programs. You should ensure this training is available to short-term staff, service providers, and contractors.

Organisational policies and procedures

For larger organisations, you should consider developing policies to assist staff in managing relationships between the organisation and members of our LGBTIQ communities. Think about developing organisational policies and procedures, or codes of conduct, including references to relevant resources and materials. Where organisations work in partnership with other organisations or departments, seek to work with these partners to ensure consistency in policy and approach, and to encourage adoption of best practice within your workplace communities. Additionally, you should develop and implement a clear privacy policy, and ensure that privacy notices are up to date and consistent with your policy. Finally, you should implement risk management processes that allow you to identify, assess,





and manage privacy risks, including approaches to information on sex and gender. For organisations storing personal data, you should implement risk management processes that allow you to identify, assess, and manage privacy risks across your business, including personal information security risks.

Complaint handling processes

You should establish processes for receiving and responding to enquiries and complaints. Both the Australian Human Rights Commission and the ACT Human Rights Commission are able to investigate and conciliate complaints of discrimination, harassment, and bullying based on a person's gender identity and intersex status. You can find additional resources in the Office for the Australian Information Commissioner's (OAIC's) Guide for handling privacy complaints. Links to this guide and other useful resources are provided in Annex A.

Keep up to date on your obligations

You should keep up to date on the relevant legislative, regulatory, and policy requirements relating to the collection of sex and/or gender information, and amend these as required to ensure compliance. Establishing and maintaining best practice service delivery is the best insurance policy in this regard.

Systematically review your procedures and make room for feedback

You should systematically examine the effectiveness and appropriateness of your practices and procedures. You should monitor and review your processes, document your compliance with your privacy obligations and commitments to best practice, and keep records of reviews and complaints. Create channels for you, your staff, and your customers or stakeholders to provide feedback on your processes. Working with and sharing procedures and models for practices with other service providers can also be beneficial as we work towards a culture in which inclusiveness is the norm. This can enable organisations to not only take pride in their compliance with laws and standards, but also in providing an example of best-practice outcomes.

Useful resources

Championing Inclusion: A guide to creating LGBTI inclusive organisations, National LGBTI Health Alliance, available at http://lgbtihealth.org.au/ resources/championing-inclusion/

Employers' Guide to Intersex Inclusion, Pride in Diversity and Organisation Intersex International, available at https://oii.org.au/employer/

Factsheet: Developing an LGBTI-Inclusive Practice Policy, National LGBTI Health Alliance, available athttp://lgbtihealth.org.au/resources/factsheet-developing-lgbti-inclusive-practice-policy/

Inclusive Language Guide: Respecting people of intersex, trans and gender diverse experience, National LGBTI Health Alliance, available at http://lgbtihealth.org.au/resources/inclusive-language-guide/

LGBTI Cultural Competency Framework: Including LGBTI people in mental health and suicide prevention organisations, National LGBTI Health Alliance, available at http://lgbtihealth.org.au/resources/championing-inclusion/

Making Your Service Intersex Friendly, Organisation Intersex International, available at https://oii.org.au/services/

Silver Rainbow: LGBTIQ-Inclusive Ageing & Aged Care, National LGBTI Health Alliance, available at http://lgbtihealth.org.au/wp-content/ uploads/2016/07/Silver-Rainbow-FACT-SHEET-2.pdf

Navigating diversity: Information for transgender, intersex and gender diverse communities and service providers, A Gender Agenda, available at http://genderrights.org.au/sites/default/files/u9/AGA%20 InfoPack%202014.pdf

Private Lives 2: The second national survey of the health and wellbeing of GLBT Australians, Leonard, W., Pitts, M., Mitchell, A., Lyons, A., Smith, A., Patel, S., Couch, M. and Barrett, A., available at http://www.glhv.org.au/files/ PrivateLives2Report.pdf

Guide to developing an APP privacy policy, Office of the Australian Information Commissioner, available at https://www.oaic.gov.au/agenciesand-organisations/guides/guide-to-developing-an-app-privacy-policy

Privacy Compliance Manual, Not for Profit Law, available at http://www.nfplaw.org.au/privacy

Endnotes

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- Balarajan, M., Gray, M., & Mitchell, M. (2011), 'Monitoring equality: Developing a gender identity question' in *Equality and Human Rights Commission Research Report, 75.* Manchester Equality and Human Rights Commission, https://www.equalityhumanrights.com/en/publication-download/research-report-75-monitoring-equality-developinggender-identity-question
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