

DRAFT

Principles for the safe and ethical
collection of data about SOGIESC in
State efforts to monitor progress toward
the Sustainable Development Goals

Foreword

The United Nations Member States adopted the 2030 Agenda and the Sustainable Development Goals with the pledge to leave no one behind – and this certainly includes lesbian, gay, bisexual, transgender and intersex people. Generating, collecting, and using disaggregated data for LGBTI people is of critical importance for delivering on this pledge. At the same time, LGBTI people continue to be exposed to punitive approaches, stigma and discrimination and often cannot enjoy privacy and protection offered to the general populations.

In the process of developing 51 SDG-compatible indicators to collect data on LGBTI inclusion in five strategic areas, ultimately to serve for an LGBTI Inclusion Index, UNDP has been approached with the request to also ensure the privacy, safety and security of LGBTI people and their communities during data collection, storage and use. These principles have been developed to address this concern.

Generating data for the LGBTI Inclusion Index will require routine collection and analysis of data about the sexual orientation, gender identity and expression, and sex characteristics - including intersex status - of members of the population. These principles offer guidance to States engaged in this activity.

Additionally, these principles rely on multiple efforts among UN agencies and stakeholders to investigate the opportunities and risks related to such data collection in this and other contexts and aspire to be applicable also beyond the data

collection efforts for the LGBTI Inclusion Index. The opportunities and risks of data collection related to LGBTI people were the subject of a report by the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity entitled “Data collection and management as a means to create heightened awareness of violence and discrimination based on sexual orientation and gender identity.”¹ These principles rely on feedback and analysis resulting from investigative activities undertaken in preparation for the report.

On February 4, 2019, the Independent Expert issued a call for written submissions regarding the need for, and risks associated with, data collection. He “received around 90 [responses], including around 30 from Member States and many from civil society organizations, national human rights institutions, ombudspersons, academics and United Nations agencies, funds and programmes.”² In addition, he held a public consultation on February 13, 2019, and a cross-disciplinary expert consultation on February 14, 2019, both in Geneva. Over the next month, he held four regional video consultations in English, French and Spanish.

In addition, on July 19, 2019, the UN Development Programme convened an in-person meeting of stakeholders on the issue of privacy, safety, and security in collection, storage, and use of data of LGBTI people and other marginalized populations. Participants included representatives from permanent missions to the UN, LGBTI rights and inclusion activists, and experts from,

¹ IESOGIE.

² Id. at 4.

multilateral organizations, civil society, academia, and the private sector. This document was provided to civil society organizations to review before finalization.

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1. Purpose of the principles

This document sets out seven broad data protection and privacy principles related to the collection and use of personal data about SOGIESC³ (sexual orientation, gender identity and expression, and sex characteristics). Each of these interrelated principles describes a different approach to a common set of aims – including LGBTI (lesbian, gay, bisexual, transgender, and intersex) people in efforts to monitor the progress toward the Sustainable Development Goals, while at the same time

- protecting the privacy, safety, and human rights of LGBTI people,
- ensuring the accuracy and usefulness of data related to LGBTI people, and
- promoting trust and confidence in State institutions and statistical organizations.

These principles apply to State activities related to the collection and use of personal data about SOGIESC, as well as the activities of other entities acting on behalf of the State, including contractors, donors, and multilateral organizations.

The need for data

In adopting the 2030 Agenda for Sustainable Development, UN Member States have pledged to leave no one behind and create a “just, equitable, tolerant, open and socially inclusive world in which the needs of the most vulnerable are met.”⁴ As LGBTI people can be found in all societies,⁵ these goals cannot be met unless States make efforts to include them in development activities. Disaggregating data bsexual orientation, gender identity and sex characteristics can provide a deeper understanding of the progress of LGBTI toward goals, and can facilitate a comparison between the outcomes of LGBTI and non-LGBTI people.⁶ These principles provide guidance to all those involved in these endeavors, though these principles apply primarily to State based activities.

³ “SOGIESC” refers to general categorizations - all people have a sexual orientation, gender identity, gender expression, and sex characteristics. Sexual orientation can refer to a self-identity, to attraction to people of the same- and/or different-sex, or sexual behaviour with people of the same- and/ or different-sex. Gender identity refers to each person’s deeply felt internal and individual experience of gender. Gender expression refers to how people express femininity, masculinity, or characteristics associated with a nonbinary gender in their appearance, speech, or other behaviours. Sex characteristics refer to physiological aspects of an individual that relate to sex.

⁴ UNGA, p. 8.

⁵ Susan D. Cochran et al., *Proposed declassification of disease categories related to sexual orientation in the International Statistical Classification of Diseases and Related Health Problems (ICD-11)*, 92 Bull. World Health Organ. 672–679 (2014). World Medical Association, *WMA Statement on Natural Variations Of Human Sexuality* (2013).

⁶ Guidance by the UN Office of the High Commissioner for Human Rights states that data should be disaggregated by key characteristics identified in international human rights law, including sexual orientation and gender identity. OHCHR (2018), p. 7. See also UNGA, para. 48.

Concerns and risks

These principles are designed to address risks associated with the collection and use of data related to sexual orientation, gender identity and sex characteristics. Because LGBTI people face stigma and discrimination, information about SOGIESC can be used in ways that cause harm to LGBTI people. Data about SOGIESC is considered “sensitive,” because it concerns matters that are private, subjected to criminalization in over 70 countries, and stigmatized in all parts of the globe. Handling such data requires special attention to guard against inappropriate disclosure and misuse.⁷ The occurrence of such harm may also damage the credibility of State data collection effort and limit the participation of the public in those efforts. Stereotypes and misinformation about LGBTI people might be reinforced if research methods are rooted in biased understandings of LGBTI people. Lastly, data that misrepresents LGBTI populations may also contribute to human rights violations caused by a failure to recognize the identities of LGBTI people.⁸

Affirming existing standards of ethics and data protection

This document affirms, and is based on, longstanding principles of data protection and privacy enumerated in international declarations, treaty interpretations, and guidance issued by UN agencies and multilateral bodies (see section 3). These principles have withstood the test of time, reflecting the importance of their core values and the extent to which they have been incorporated into practices related to data collection and research.

In recent years, many states have sought to uphold these principles through the adoption of data protection laws. For example, the European Union General Data Protection Regulation (GDPR), Brazil’s Lei Geral de Proteção de Dados (LGPD), and the California Privacy Rights Act (CPRA) all restrict the processing of

sensitive personal data without the consent of the data subject. Data revealing a person’s sex life is considered sensitive under each of these laws. The GDPR and the CPRA also consider data revealing a person’s sexual orientation to be sensitive.⁹ All of these standards recognize the need to give such data special attention.

Though these data protection laws are recent arrivals to the data protection landscape, they amplify, rather than supplant, already existing norms regarding data privacy. Indeed, the GDPR and LGPD both include a list of exemptions to the rules restricting the processing of sensitive data. These exemptions apply when the data is collected in healthcare or research settings, for statistical purposes, to comply with legal obligations, or for achieving purposes in the public interest.¹⁰ The CPRA only applies to for-profit business and it permits the processing of sensitive data where such information is necessary to provide requested good and services.¹¹ Accordingly, though these laws may not directly impact State activities to collect SOGIESC data for the purposes of tracking progress toward development goals, they affirm the importance of data protection and privacy to people who are marginalized because of their SOGIESC.

⁷ CIOMS, Guideline 15; DoH, para. 19 and 20; DoT, para. 17; IOM, pp. 14, 60, 72, 75, 77, and 78; OHCHR, pp. 13 and 17; UNDG, Principle 4.

⁸ OHCHR (2018), p.11.

⁹ GDPR, art. 9(1); LGPD, art. 5; arts. 11, 12; CPRA, Sec. 10.

¹⁰ GDPR, art. 9(2), LGPD, arts. 11, 12.

¹¹ CPRA, Sec. 5.

2. The Principles

The Principles for the safe and ethical collection of data regarding SOGIESC

1. Privacy.

2. Do no harm.

3. Community Participation.

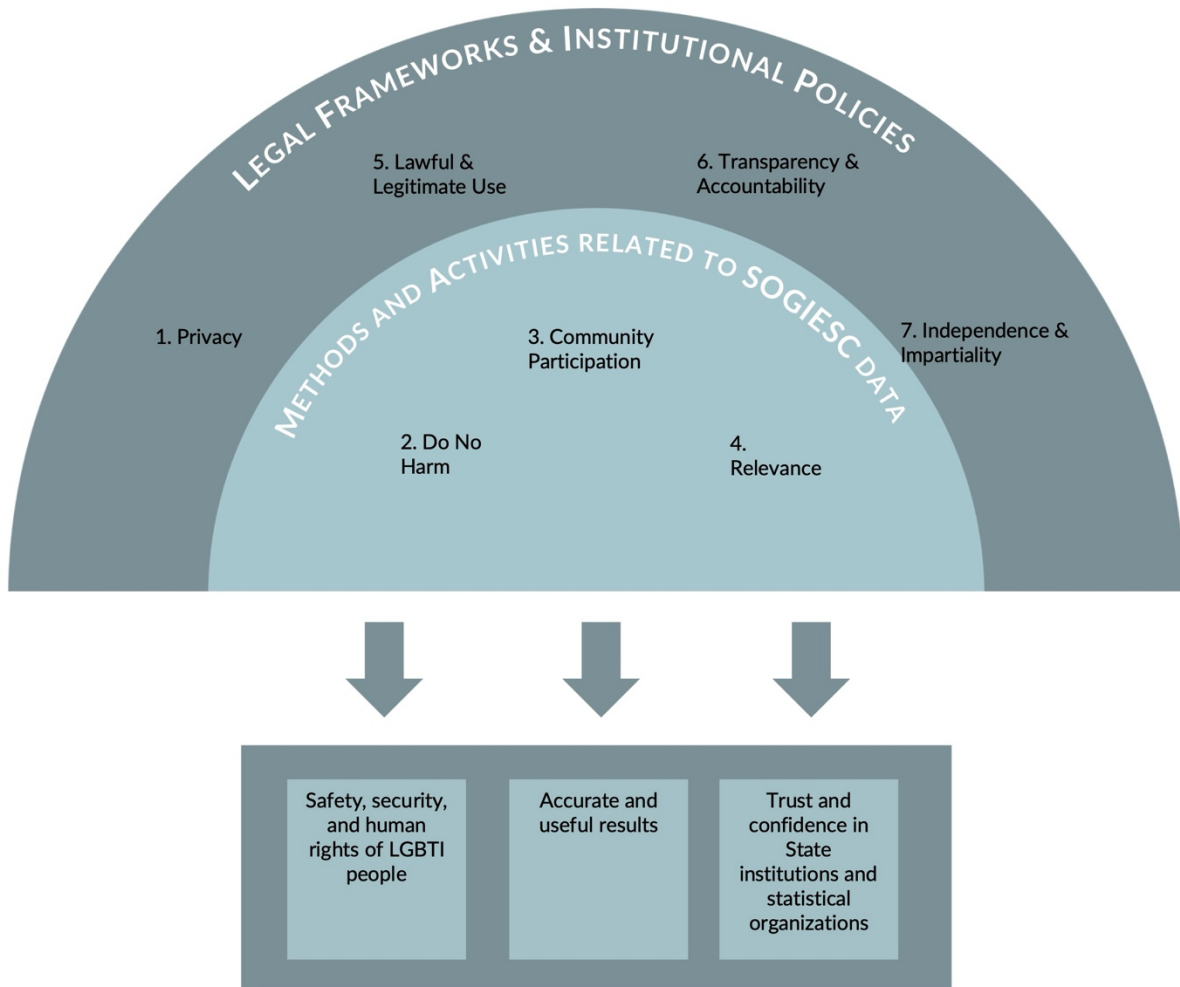
4. Relevance.

5. Lawful and Legitimate.

6. Transparency and Accountability

7. Independent and Impartiality

Each of the principles describes a different approach to a common set of aims.



Principle 1.

Privacy

Because LGBTI people face varying levels of stigma in most countries, disclosure about their SOGIESC can cause harm even in legal and social environments that are relatively supportive of LGBTI people. Accordingly, the privacy of LGBTI individuals, including the confidentiality and security of their personal data, is a central concern. Violations a data subject's privacy can be based on different impulses such as carelessness, improper behavior, malicious intent, or personal profit.

The UN Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity reports that stakeholders have expressed concern that data about an individual's SOGIESC could be used "as the basis for surveillance, harassment, entrapment, arrest and persecution by government officials,"¹² particularly in hostile settings. In any case, such violations can bring harm to LGBTI people, and substantially damage the reputation and credibility of the entities involved in collecting and using such data.

Protecting the privacy and confidentiality of individuals and personal data concerning them is

a well-established ethical principle for researchers, statistics practitioners, and statistical organizations.¹³ Current international standards call for States to establish a legal framework which regulates the gathering and holding of personal information and respects the right of individuals to control their own personal information, including how it is used. Many of the other principles described in this document are part of such a legal framework, providing additional mechanisms for individuals to control their personal information.

International human rights law specifies that the right to privacy extends to the right to privacy of one's identity, confidentiality of one's personal data, and the right to limit the use of the data to purposes that are lawful or that have been consented to.¹⁴ Accordingly, States must take measures to ensure that individuals understand how, and for what purpose, data about them will be used, to protect the privacy of individuals and their data, and to only use data in ways that have been consented to or are lawful and legitimate

¹² IESOGI, p. 8.

¹³ CIOMS, Guidelines 4, 11, 12; DoH, para. 24; DoT, pars. 9, 10; FPoOS, Principle 6; HRC16, para 10; ICRC, Preamble, art. 8; IOM, Principle 6; OECD, Pt. 1; OHCHR, p. 16 ; PGISA, para. 6.; UNDG, p. 2; UNDRG, p. 6; UNESCO, art. 9.

¹⁴ The International Covenant on Civil and Political Rights, art. 17, provides that "[t]he gathering and holding of personal information on computers, data banks and other devices, whether by public authorities or private individuals or bodies, must be regulated by law. Effective measures have to be taken by States to ensure that information concerning a person's private life does not reach the hands of persons who are not authorized by law to receive, process and use it, and

is never used for purposes incompatible with the Covenant. In order to have the most effective protection of his private life, every individual should have the right to ascertain in an intelligible form, whether, and if so, what personal data is stored in automatic data files, and for what purposes. Every individual should also be able to ascertain which public authorities or private individuals or bodies control or may control their files. If such files contain incorrect personal data or have been collected or processed contrary to the provisions of the law, every individual should have the right to request rectification or elimination" Human Rights Committee, General Comment 16, ICCPR/C/21/Add. 6, para. 10.

Principle 2.

Do No Harm

As noted by the UN Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, LGBTI people are particularly vulnerable in countries with laws that criminalize gender non-conformity and consensual same-sex relations between adults, laws that prohibit public discussion of homosexuality or gender non-conformity such as so-called anti-propaganda laws, cybersecurity laws, and child protection laws. Even in legal environments where LGBTI people enjoy formal legal protections, the collection and use of data by certain State agencies would still raise concerns because those agencies continue to violate the human rights of LGBTI people. For example, stakeholders from some States have expressed a higher degree of trust for staff in health clinics to collect data as compared to data collection by police and security officers in those same States.¹⁵ Not only could misuse of personal data lead to harm for LGBTI people, it would also damage the public's trust and confidence in State data-related activities, and possibly subject State employees and agencies to claims of professional and legal wrongdoing.

The principle of do no harm requires those involved in data collection and research activities to balance the benefits of such activities against the risks and burdens on LGBTI people and communities, and to take measures to minimize those risks and/or discontinue such activities if

the risks are too great.¹⁶ The principle requires such assessment to be ongoing and to apply to all aspects of research and data collection, analysis, storage and dissemination.

In countries where LGBTI people face high levels of marginalization, social hostility or punitive legal environments, the risk of harm may be too high to proceed. The IE proposed that, in such environments, "a presumption must exist that data is gathered for purposes that are contrary to international human rights."¹⁷ On the other hand, such a presumption is rebutted by the fact that in some countries with hostile environments, LGBTI communities have nevertheless survived and even thrived. Thus, the existence of legal and social hostility should not rule out research and data collection.

In these cases, the local LGBTI community may be in the best position to understand risks and assess whether data collection and research efforts should proceed. Both the Office of the UN High Commissioner for Human Rights and the UN Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity advise that "[d]ecisions concerning data collection on particularly vulnerable or marginalized groups,"¹⁸ including "assessment of threats and risks to the safety, resources and rights,"¹⁹ should be made in close partnership with LGBTI communities.

¹⁵ Statements from participants at meetings referenced in fn. 5 of IESOGI.

¹⁶ DoH, paras. 17 and 18; CIOMS Guidelines 1, 4, and 15; OHCHR, pp. 11-12; UNDG, Principle 3 and 4; UNDRG, p. 6; UNESCO, art. 4;

¹⁷ IESOGI, p. 8.

¹⁸ OHCHR (2018), p. 9.

¹⁹ IESOGI, p. 15.

Accordingly, before launching new data collection initiatives, States should ensure the local LGBTI community

- a. understands the purposes and design of the research and data collection efforts,
- b. has considered the extent to which the laws and practices in the country protect the privacy of identity of data subjects, confidentiality of data, possible lawful uses of the data, whether public agencies that handle data are sufficiently transparent, accountable, independent and impartial with regard to data,
- c. has adequate and opportunity, resources and technical knowledge to deliberate about the advisability of the research, and
- d. is able to participate in questions of whether and how to implement data and research activities.

The benefits, risks and burdens of each proposed data collection initiative must be considered separately.

Principle 3.

Community Participation

Participation of relevant groups in State data-related activities is a core principle of a human rights based approach to data.²⁰ Not only does it respect the right of individuals to participate in public affairs, it is also instrumental to the realization of the aims of other principles in this document. Engagement with LGBTI communities can help ensure that the methods used in data related activities are grounded in an authentic understand of LGBTI people (see Principle 6. Determine Relevance), assess risks and benefits of data collection initiatives (see Principle 2. Do no Harm), and help garner public support for data collection activities (See Principle 5. Transparency and Accountability).

Meaningful participation requires time, skills and resources from all those involved. Due to the scarcity of resources, LGBTI communities may not have the capacity to fully engage with State actors without diverting resources away from current priorities. Many LGBTI organizations experience “consultation fatigue” when they seek to satisfy requests that are not accompanied by adequate resources for preparation, participation and follow-up. Additional resources can improve the impact of participation efforts.

Global standards of research ethics, statistical practice, and human rights all recognize that communities have a role to play in decisions that will impact them.²¹ State efforts to undertake research or collect data about LGBTI people, including all phases of design, data collection, analysis, dissemination and maintenance of data, should include participation of the LGBTI community. Participation should be structured to include individuals and groups of the specific identities relevant to the data collection activities. States should ensure that LGBTI communities and civil society have sufficient capacity, security, and technical training to fully participate in State efforts to undertake research or collect data about LGBTI people. Approaches to participation are context specific, and States are encouraged to consider a broad range of methods to engage stakeholders.

²⁰ OHCHR, p. 3. The right to participate in public affairs, including the right of minorities to participate in governance issues which impact them, is explicitly recognized in human rights treaties. The International Covenant on Civil and Political Rights, art. 25. This is supplemented by more general rights to participation in treaties including the International Covenant on Economic, Social and Cultural Rights, arts. 13.1, 15.1; Convention on the Elimination of All Forms of Discrimination Against Women, art. 7; the Convention on the Rights of the Child, art. 12; the

Convention on the Rights of Persons with Disabilities, art 29; as well as in Declarations, including the Universal Declaration of Human Rights, art. 21; the Declaration on the Right to Development, arts. 1.1, 2, 8.2; the Declaration on the Rights of Indigenous Peoples, arts. 5, 18, 19, 41; and the Millennium Declaration, para. 25.

²¹ See id. regarding human rights standards. Also see FPoOS, Principle 1 (discussion on interaction with users); CIOMS, Guideline 7; DoH, art. 13; DoT, art. 20; OHCHR, p. 2; UNESCO, art. 18.2.

Principle 4.

Relevance

In order for data about LGBTI people to be relevant and useful, it should reflect the realities of the LGBTI populations. Sexual orientation, gender identity and expression, and sex characteristics are multi-dimensional concepts relating to identity, behavior, cognitive perceptions, and physiology. Empirical research has established that each of these dimensions may operate independently. That is, if an individual exhibits a particular sexual orientation or gender identity according to one dimension, they may not exhibit the same sexual orientation or gender identity according to a different dimension. When looking at health outcomes, for example, the most relevant dimensions might be those that are physiological or behavioral. When looking at employment outcomes, dimensions of identity might be more relevant.

Additionally, terms and concepts associated with LGBTI populations in one country may not be applicable to the LGBTI population in another country. In fact, the terms and concepts of lesbian, gay, bisexual, transgender, and intersex, may themselves lack relevance in cultures where local populations employ different terms and concepts. Local LGBTI communities can help

States determine the relevance of the terms and concepts used in data-related activities.

Identity is an important dimension of SOGIESC. Identity is self-determined, and the respect and protection of personal identity is central to human dignity and human rights.²² Data that does not authentically reflect local LGBTI communities, and State policies based on such research, may constitute a misrecognition of identities. Often, such misrecognition can compound stereotypes already in place²³ and result in a violation of the right of LGBTI people to recognition and self-determination.²⁴

To be relevant and useful, the measures, terms, definitions, and classifications of sexual orientation, gender, and intersex status should reflect the attributes and characteristics of the LGBTI population. In particular, categories of identity employed by States should be drawn from those set by the members of the population. Parameters of the population cannot be externally imposed. States are encouraged to develop their approach in collaboration with LGBTI communities

²² UNDRG, Principle 9.

²³ The Convention on the Elimination of All Forms of Discrimination against Women, art. 5; The Convention on the Right of Person with Disabilities, art.8(1)(b); and the Convention on the Elimination of Racial Discrimination (Committee on the Elimination of Racial Discrimination, General Recommendation 30, Discrimination against Non-citizens, Sixty-fourth session, 2004, U.N. Doc. CERD/C/64/Misc.11/rev.3, 2004, para. 12) all express obligations concerning harmful and wrongful stereotyping.

²⁴ The right to recognition is recognized in the Universal Declaration of Human Rights (art. 6) and the International Covenant of Civil and Political Rights (art.16). OHCHR guidance states that personal identity characteristics (particularly those that may be sensitive, such as religion, sexual orientation, gender identity or ethnicity) should be assigned through self-identification, and not through imputation or proxy." OHCHR (2018), p. 12.

Principle 5.

Lawful and Legitimate Use

Data used to monitor the progress toward development goals comes from many sources. One source is surveys and interviews conducted on behalf of statistical organizations for the purpose of producing statistical data. Another source is data collected from and about individuals and households by government agencies in the course of their operations. Such administrative data offers a rich opportunity to assess variables of an entire population involved in a particular program. Each of these data sources raises concerns about the potential for misuse of data.

International principles oblige States to only use personal data for lawful and legitimate uses.²⁵ Individuals have the right to limit the use of data to lawful purposes and/or the use consented to when the data was provided. Individual data collected by statistical agencies for statistical compilation are to be strictly confidential and used exclusively for statistical purposes. If State records contain personal data that is incorrect or has been collected, processed or stored contrary to the provisions of the law, individuals should have the right to have the record rectified or, if rectification is not permitted for legal, historical,

or archival reasons, have the record annotated. Data should not be used in a way that violates human rights, or in any other way are likely to cause unjustified or adverse effects on any individuals or groups of individuals. As a general preference, data considered sensitive, including data related to sexual orientation, gender identity and sex characteristics, should be collected and used only with the express consent of the individual concerned.²⁶

²⁵ FPoOS, Principle 2, 4, 6; ICRC, art 1, IOPM, art. 1 and 2; OECD, Revised Guidelines 7, 10, 11, p 14-15; UNDG Principle 1 and 2;

²⁶ The General Data Protection Regulation, art. 9(1), sets out the general principle that the “processing of personal data revealing... a natural person’s sex life or sexual orientation shall be prohibited.” EU Regulation 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (EU General Data Protection

Regulation), [2016] OJ L119/1, art. 9(1). However, this prohibition is accompanied by “an exhaustive list of exceptions...” including to exercise legal claims, achieve purposes in the public interest, scientific or historical research purposes or statistical purposes, for public interest reason in the area of public health, for substantial public interest reasons, and where the subject consents or has already made such data public. European Union Agency for Fundamental Rights, Handbook on European data protection law, 2018 edition, p. 160.

Principle 6.

Transparency & Accountability

When the methods and procedures to produce data are fully disclosed, members of the public are able to assess its quality and work to improve it. Additionally, openness on the part of those collecting data facilitates trust and cooperation of individuals whose data is sought as well as relevant communities. In places where data collection about SOGIESC is new, transparency is particularly important given the lack of a track record on these issues.

The importance of transparency is recognized in global standards relating to research ethics, statistical practice and human rights.²⁷ It is based on an understanding that transparency improves the quality of scientific inquiry, helps fulfill the right of research subjects and communities to engage in research activities that impact them, and reinforces trust in data related activities. States should ensure open, quick and transparent access to information on what data relating to sexual orientation and gender identity is maintained, how it is used, and how to correct, amend, annotate it. This principle includes the obligation to inform individuals being asked for such data about the purpose of data collection efforts and how, and by whom, the data will be used and stored.

²⁷ PGISP, Principle 3; ICRC, art. 2, 7-13, 15; IOM, art. 7; OHCHR, p. 14, 18; OECD Revised Principles 12-15; PGISA, para. 4; UNDRG, Principle 4, p22; UNDG, Principle 8; UNESCO, art. 18.1; FPoOS, Principle 3; DoT, art. 20; See also the The International Covenant on Civil and Political

Rights specifies the right to see, receive, and impart information. (art. 19)²⁷ The right to [petition, expression]. And the International Convention on the Rights of People with Disabilities, art. 31 (requiring accessible dissemination of statistical data.)

Principle 7.

Independence & Impartiality

LGBTI people have a legitimate concern that any entity holding personal data related to SOGIESC will fall under pressure to use that data for purposes that may violate the human rights of LGBTI people. Statistical agencies must be free from indirect or direct external influence that interferes with a science-based approach to data. Additionally, agencies producing official statistics are expected to treat LGBTI people and communities fairly and non-discriminatorily, granting them equal access to data and accompanying scientific documentation and being at liberty to comment publicly when data is interpreted in ways that are clearly contrary to scientific conclusions.

The principle of Independence and Impartiality helps ensure that statistical agencies are not subject to external influence, and that they will treat everyone equally.²⁸ Independence is achieved through, among other things, a legal framework that establishes a sufficiently high hierarchical standing of the statistical agency and its head official, insulates budget decisions and hiring and firing of staff, and protects the ability of the agency to communicate publicly on issues related to statistical data.

²⁸ FPoOS, Principle 2; OHCHR, pp. 17 - 18; PGISP, Principle 2, Principle 4; UNDRG, Principle 7.

3. Resources

A. Definitions

SOGIESC and terms referring to characteristics	LGBTI and terms referring to populations
<p>SOGIESC Abbreviation for sexual orientation (SO), gender identity and expression (GIE), and sex characteristics (SC).</p> <p>SOGIESC refers to a category of personal characteristics. Everyone has a sexual orientation, a gender identity and expressions, and sex characteristics.</p>	<p>LGBTI Abbreviation for lesbian, gay, bisexual, transgender and intersex.</p> <p>LGBTI refers to a population. When LGBTI is used to refer generally to an indeterminate group of people, LGBTI refers to those people who are considered lesbian, gay, bisexual, transgender, and/or intersex. In addition, different cultures use different terms to describe people who have same-sex relationships or whose gender identity and expression does not fit a male-female model (such as hijra, meti, lala, skesana, motsoalle, mithli, kuchu, kawein, travesty, muxé, fa'afafine, fakaleiti, hamjensgara and two-spirit). It is not possible to include all these terms in a single abbreviation. Thus, the term LGBTI also refers to these groups even though they themselves may not use the term LGBTI to refer to themselves. When discussing a specific local population, it is preferable to use the terms used by that population.</p>

SEXUAL ORIENTATION (SO)

Sexual orientation can refer to a self-identity, to attraction to people of the same and/or different sex, or sexual behavior with people of the same and/ or different sex. Everyone has a sexual orientation.

LESBIAN

Women who are attracted to women

GAY

Individuals who attracted to people of the same sex as themselves.

BISEXUAL

Individuals who may be attracted to people of the same or different sex

GENDER IDENTITY AND EXPRESSION (GIE)

Gender identity reflects a deeply felt and experienced sense of one's own gender. Gender expression is the way in which we express our gender through actions and appearance. Gender expression is a person's presentation of gender, masculinity and femininity, through appearance, dress, mannerisms, names, and other behavioral patterns.

TRANSGENDER

Transgender is an umbrella term used to describe people whose current gender identity and expression differs in some way from social expectations associated with their gender assigned at birth. This includes transsexual people, cross-dressers (sometimes referred to as "transvestites"), people who identify as third gender, and others whose appearance and characteristics are seen as gender atypical. Transgender people can have any sexual orientation or intersex status

SEX CHARACTERISTICS (SC)

Sex characteristics are each person's physical features relating to sex, including genitalia and other sexual and reproductive anatomy, chromosomes, hormones, and secondary physical features emerging from puberty.

INTERSEX

Intersex people are born with sex characteristics which do not fit the typical definitions of male or female. These characteristics may be apparent at birth or emerge later in life, often at puberty. Intersex people can have any sexual orientation and gender identity and expression.

B. Abbreviations

The following abbreviations are used throughout this document:

CIOMS	Council for International Organizations of Medical Sciences and the World Health Organization, International Ethical Guidelines for Health-related Research Involving Humans (2016)
CPRA	California Privacy Rights Act of 2020 (CPRA), amending California Consumer Privacy Act of 2018 (CCPA); Cal. Civ. Code §1798.100 et seq. (effective Jan. 1, 2020)
DoH	World Medical Association, Declaration of Helsinki: Ethical Principles For Medical Research Involving Human Subjects, October, 2013.
DoT	World Medical Association, Declaration Of Taipei On Ethical Considerations Regarding Health Databases And Biobanks, 2016
FPoOS	United Nations General Assembly, Fundamental Principles of Official Statistics, Janyave 29, 2014 (A/RES/68/261)
GDPR	Regulation 2016/679 of the European Parliament and of the Council of Apr. 27, 2016 on the Protection of Natural Persons with Regard to the Processing of Personal Data and on the Free Movement of Such Data, and Repealing Directive 95/46/EC (General Data Protection Regulation), art. 4, 2016 O.J. (L 119) 33 (EU)
HRC16	Human Rights Committee, General Comment 16, ICCPR/C/21/Add.
IESOGI	United Nations General Assembly, Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, May 14, 2019. A/HRC/41/45
ICRC	International Committee of the Red Cross, ICRC Rules On Personal Data Protection (2015)
IOM	International Organization for Migration, IOM Data Protection Manual. Geneva, Switzerland: IOM (2010)
LGPA	Lei Geral de Proteção de Dados (translated as “General Data Privacy Law” in English) Lei No. 13.709, de 14 de Agosto de 2018, DIÁRIO OFICIAL DA UNIÃO [D.O.U.] de 15.8.2018 (Braz.)
OECD	Organisation for Economic Co-operation and Development, (OECD Privacy Framework (2013)
OHCHR (2018)	Office of the United Nations High Commissioner for Human Rights (OHCHR), <i>A Human Rights- Based Approach to Data</i> (2018)
OHCHR (2015)	United Nations High Commissioner for Human Rights (2015). Policy on the Protection of Personal Data of Persons of Concern to UNHCR. May. Geneva, Switzerland: UNHCR.

PGISA	United Nations Statistics Division, <i>Principles Governing International Statistical Activities</i> (2013)
UNDG	United Nations Development Group, <i>Data Privacy, Ethics and Protection: Guidance Note On Big Data For Achievement Of The 2030 Agenda</i> (2017)
UNDRG	United Nations Data Revolution Group (2014). <i>A World that Counts: Mobilising the data revolution for sustainable development. The UN Secretary-General's Independent Expert Advisory Group on a Data Revolution for Sustainable Development.</i> November.
UNESCO	United Nations Education Scientific And Cultural Organization., <i>The Universal Declaration On Bioethics And Human Rights</i> (2005),
UNGA	United Nations General Assembly, <i>Resolution 70/1: Transforming our world: the 2030 Agenda for Sustainable Development, A/RES/70/1, 21 October 2015</i>

C. References

Bell, Mark, *Analysis and comparative review of equality data collection practices in the European Union: Data collection in relation to LGBTI People*, European Commission (2017)

Bhugra, Dinesh et al. *WPA Position Statement on Gender Identity and Same-Sex Orientation, Attraction and Behaviours*. *World psychiatry: official journal of the World Psychiatric Association (WPA)* vol. 15,3 (2016): 299-300.

California Privacy Rights Act of 2020 (CPRA), amending California Consumer Privacy Act of 2018 (CCPA); Cal. Civ. Code §1798.100 et seq. (effective Jan. 1, 2020)

Council for International Organizations of Medical Sciences and the World Health Organization, *International Ethical Guidelines for Health-related Research Involving Humans* (2016)

Human Rights Committee, *General Comment 16, ICCPR/C/21/Add.*

International Committee of the Red Cross, *ICRC Rules On Personal Data Protection* (2015)

International Organization for Migration, *IOM Data Protection Manual*. Geneva, Switzerland: IOM (2010)

Lei Geral de Proteção de Dados (translated as “General Data Privacy Law” in English) Lei No. 13.709, de 14 de Agosto de 2018, *Diário oficial da União [D.O.U.]* de 15.8.2018 (Braz.)

Office of the United Nations High Commissioner for Human Rights (OHCHR), *A Human Rights- Based Approach to Data* (2018)

Organization for Economic Co-operation and Development, *(OECD Privacy Framework* (2013)

Regulation 2016/679 of the European Parliament and of the Council of Apr. 27, 2016 on the Protection of Natural Persons with Regard to the Processing of Personal Data and on the Free Movement of Such Data, and Repealing Directive 95/46/EC (General Data Protection Regulation), art. 4, 2016 O.J. (L 119) 33 (EU)

UN Expert Group on Statistical Classifications, Best Practice Guidelines for Developing International Statistical Classifications, (2010)

United Nations Data Revolution Group (2014). A World that Counts: Mobilising the data revolution for sustainable development. The UN Secretary-General's Independent Expert Advisory Group on a Data Revolution for Sustainable Development. November.

United Nations Development Group, Data Privacy, Ethics and Protection: Guidance Note On Big Data For Achievement Of The 2030 Agenda (2017)

United Nations Education Scientific And Cultural Organization., The Universal Declaration On Bioethics And Human Rights (2005),

United Nations General Assembly, Fundamental Principles of Official Statistics, January 29, 2014 (A/RES/68/261)

United Nations General Assembly, Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, Data collection and management as a means to create heightened awareness of violence and discrimination based on sexual orientation and gender identity, May 14, 2019. A/HRC/41/45

United Nations General Assembly,, Report of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, May 11, 2018, A/HRC/38/43, <https://undocs.org/A/HRC/38/43>

United Nations High Commissioner for Human Rights (2015). Policy on the Protection of Personal Data of Persons of Concern to UNHCR. May. Geneva, Switzerland: UNHCR.

United Nations Statistics Division, *Principles Governing International Statistical Activities* (2013)

World Medical Association, Declaration of Helsinki: Ethical Principles For Medical Research Involving Human Subjects, October, 2013.

World Medical Association, Declaration Of Taipei On Ethical Considerations Regarding Health Databases And Biobanks, 2016