

Data collection and management:

An essential component in creating awareness and providing effective measures to address violence and discrimination based on SOGI



Data is crucial to creating visibility and building an evidence base of human rights abuses and potential responses to them. Currently, there are serious gaps in available data to capture the lived realities of lesbian, gay, bisexual, trans and gender-diverse (LGBT) persons. Some States deny the existence of violence and discrimination against LGBT folks, or even the presence of LGBT persons in their jurisdiction. Where prejudice or criminalization exist, rates of non- or under-reporting of violence and discrimination tend to be higher.

Having accurate data would provide evidence of the extent of the challenges faced by the LGBT population, and indicate the policy and legislative needs in that regard. Data should be the basis for policy-makers and advocates to create more effective State measures for socio-economic inclusion, access to health and education, inclusion in the civic and political sphere, anti-discriminatory measures, prevention of abuses, and access to justice. Ultimately, it would likewise contribute to dispelling myths and stereotypes that feed stigma and discrimination.

States must act with due diligence to protect those at particular risk of violence and discrimination. Taking measures to understand and eliminate cultural stigmatization and the root causes of such human rights violations becomes a necessary step to fulfil that duty. Disaggregation of data allowing a comparison of population groups therefore forms part of the human rights obligations of States and has become an element of the human rights-based approach to data.

In multiple contexts, civil society organizations are left to fill the voids created by State inaction. This work is of exceptional value, but it does not relieve the State of its duty to obtain accurate information or to build environments conducive to obtaining it. Non-State agents might even be preferred by victims for issues of safety, but there are limitations to their work, such as funding vicissitudes, non-guarantee of continuity, and lack of integration with public information systems.



Risks and challenges associated with data collection and management

Information about an individual's sexuality and gender continues to be highly stigmatizing. That is why collecting data about sexual orientation and gender identity raises concerns about privacy, identity, self-determination, and security. Stigma exacerbates risks because it might create a motivation to hack, steal or otherwise unlawfully access the data. It also multiplies the damaging impact of disclosure of information due to negligence or mistakes. There is an urgent need for discussions on cybersecurity and to build the capacity of stakeholders, including civil society, to address and mitigate cybersecurity risks.

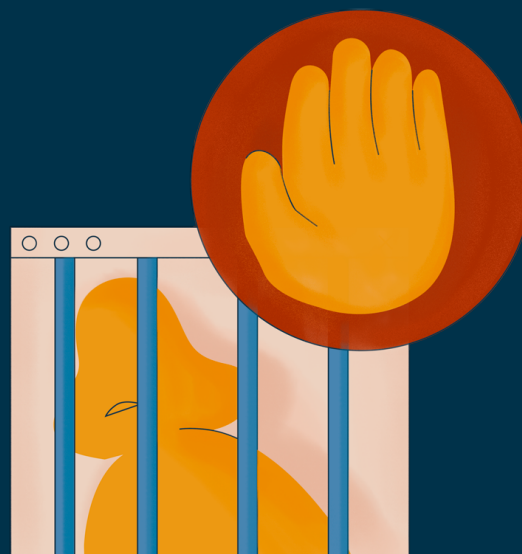
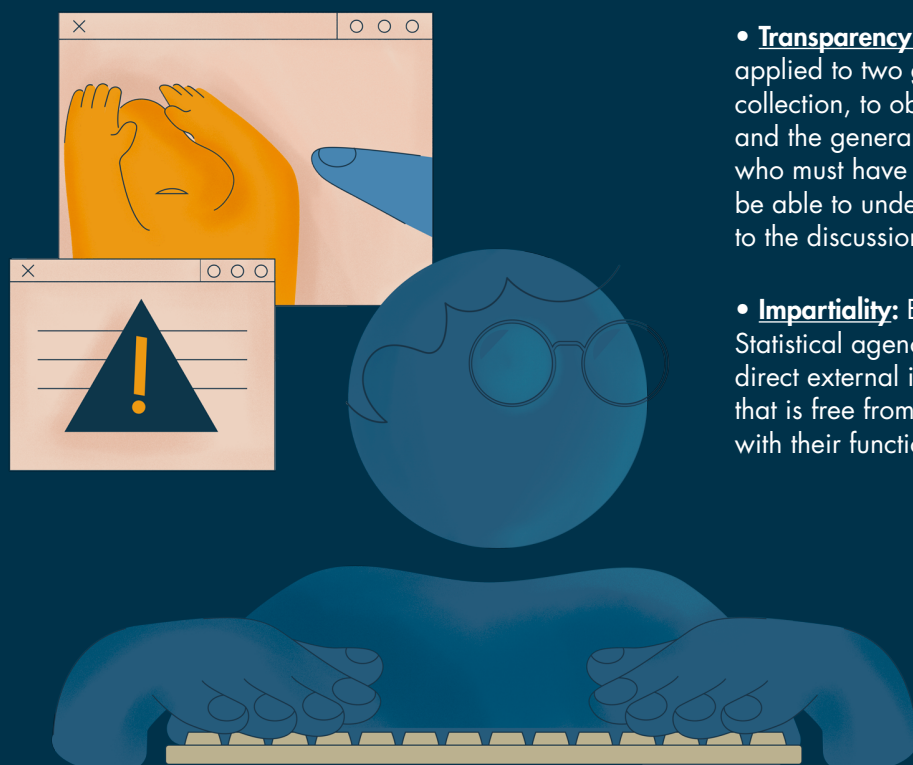
In countries where same-sex sexual conduct is criminalized, where laws and policies are used to discriminate against or persecute LGBT persons, or where stigma and prejudice are rampant, victims will be much less likely to report abuses. This is due to fear of prosecution, stigma, reprisals or victimization, unwillingness to be "outed", or lack of trust. In some contexts, collected data has been reportedly used for surveillance, harassment, arrest and persecution by government officials.

Even in progressive environments, the worry of regression may lead to non- or under-reporting. In addition, there is currently no globally-accepted definition, or international classification scheme, to facilitate internationally comparable data between subpopulations according to sexual orientation and gender identity.

Ultimately, lack of data about LGBT persons renders the community invisible to policymakers and government duty bearers, and will reinforce patterns of negation and the adoption of irrational State policies. In a context of negation, perpetrators feel motivated and enabled to suppress or punish diversity. So even where States collect data, negation can result in information that is unreliable, unsystematic and biased.

Guiding principles for data collection and management

- **Do no harm:** The decision to initiate and continue data-related activities, especially in hostile legal frameworks, should be based on an assessment of threats and risks to the safety, resources and rights of those involved in the activity and of the larger LGBT community.
- **Self-determination:** The ability to determine one's own identity, including with regard to sexual orientation and gender, is central to the right to equal recognition before the law. Personal identity characteristics should not be assigned through imputation or proxy.
- **Privacy and confidentiality:** The right to privacy establishes a personal sphere within which an individual may determine whether and how personal information is disclosed. An important aspect is the process of consent, whereby someone can limit the use of personal data to certain purposes.



- **Lawful use:** This principle limits the use of data to those purposes provided for by law and limits access to data to those individuals whose involvement is necessary to accomplish those purposes. Conversely, using data to enable criminal prosecution of same-sex relations is contrary to international human rights law and, by definition, a violation of the principle of lawful use.
- **Participation:** Ensuring the participation of affected communities maximizes the impact of data collected. They are more likely to identify the best indicators for assessing their own quality of life, as they speak from the perspective of lived experiences.
- **Transparency and accountability:** This principle is applied to two groups: the subjects of data collection, to obtain their full and informed consent; and the general public, including policy-makers, who must have access to all relevant information to be able to understand the data and its significance to the discussion.
- **Impartiality:** Essential for the credibility of data. Statistical agencies must be free from indirect or direct external influence and operate in a manner that is free from conflicts of interest and consistent with their functions and duties.

Conclusions and Recommendations

The IE SOGI finds that information about the lived realities of LGBT people around the world is, at best, incomplete and fragmented, but in most countries, it is simply non-existent. His findings show that barriers created by criminalization, pathologization, demonization and stigmatization hinder accurate estimates regarding the world population affected by violence and discrimination based on sexual orientation and/or gender identity. This means that in most contexts, policymakers are working in the dark, left only with personal preconceptions and prejudices to guide their decisions.

Data on demographic, economic, social and cultural characteristics, literacy rates, unemployment rates, voting patterns, the number of reported cases of violence and other indicators are essential to the efforts of States to comply with their obligations and to the evaluation of progress towards major development objectives, such as the Sustainable Development Goals.

The IE SOGI notes that States have the duty to understand how sexual orientation and/or gender identity impact someone's exposure of vulnerability to violence and discrimination. Data should be disaggregated by populations, considering aspects related to sexuality and gender identity, but also other factors, such as race, ethnicity, religion or belief, health status, age, class, caste and migration or economic status.

He recommends that States design and implement comprehensive data collection procedures to assess the type, prevalence, trends and patterns of violence and discrimination against LGBT persons. When doing so, States need always respect the overriding 'do no harm' principle and follow a human rights-based approach to prevent the misuse of collected data.



[Read the full report on Data Collection and Management \(2019\) in all official UN languages here.](#)



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