

Response to the Call for Inputs of the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity: data collection and management

Submitted by the United Nations Development Programme

I. Background

The United Nations Development Programme is the UN global development network present in more than 170 countries and territories worldwide. In accordance with its Strategic plan of 2018-2021¹, UNDP is guided by the pledge made by UN Member States in the 2030 Agenda to leave no one behind and to strive to reach those furthest behind first.² As a founding co-sponsor of the Joint UN Programme on HIV/AIDS (UNAIDS) and in accordance with its strategy of 2016-2021, UNDP's HIV, Health and Development Group supports countries' efforts to remove punitive laws, policies and practices and promote enabling laws and policies that improve HIV responses, including by improving the human right situation of key populations most at risk to HIV – for instance men who have sex with men and transgender people.³ UNDP is one of the UN entities to sign the Joint Statement on Ending Violence and Discrimination against Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) People⁴. 53 countries worldwide benefit from UNDP's "SOGI and Rights" and "Being LGBTI in..." regional initiatives. UNDP, together with key partners, is leading the development of an LGBTI Inclusion Index to measure development outcomes for LGBTI people in countries, universally and with respect to certain groups within a country in five strategic areas. These strategic areas have been determined after comprehensive consultations with all stakeholders, including LGBTI people and global LGBTI organizations with ECOSOC status. UNDP's organizational policies prohibit discrimination based on LGBT status and promote equality and inclusion.⁵

Note on intersex people: UNDP supports countries to promote the rights and inclusive development of lesbian, gay, bisexual, transgender and intersex people. In the responses below UNDP has provided answers regarding the situation of "LGBT people", as requested. Where explicitly mentioned UNDP has also provided references to human rights challenges experienced by intersex people. It is important to acknowledge that human rights challenges experienced by intersex people are at their core related to sex characteristics, even though intersex people - like everyone else - have sexual orientations and gender identities and can be straight, lesbian, gay or bisexual, and cis- or transgender.

¹ UNDP Strategic Plan 2018-2021, <http://undocs.org/DP/2017/38>

² UNDP, What does it mean to leave no one behind?, 2018 <https://www.undp.org/content/undp/en/home/librarypage/poverty-reduction/what-does-it-mean-to-leave-no-one-behind-.html>

³ UNAIDS Division of Labour, 2018 http://www.unaids.org/sites/default/files/media_asset/20180620_UNAIDS_PCB42_Report-progress-implementation-action-plan_EN.pdf

⁴ Joint UN Statement on Ending Violence and Discrimination against Lesbian, Gay, Bisexual, Transgender and Intersex People, 2015 <https://www.undp.org/content/undp/en/home/librarypage/hiv-aids/LGBTIjointstatement.html>

⁵ https://www.ohchr.org/Documents/Issues/Discrimination/LGBT/UN_LGBTI_Summary.pdf

II. Responses to the questions posed by the Independent Expert in the Call for Input

1. *What are the current efforts by States to increase their knowledge of the LGBT population? Specifically, are questions about sexual orientation and gender identity included in government surveys (e.g. the census, national health surveys, income and living condition surveys, or other surveys funded or mandated by the State), administrative records (e.g. birth certificates/birth registries, identity Cards, school records, professional licenses, social security and public benefit records, and other government documents)?*

The global experience in collecting data and other information related to sexual orientation and gender identity is quite varied. With more than 70 countries and territories still criminalizing consensual sexual acts among adults and numerous countries and territories applying punitive measures (criminal and others) against transgender people, disclosing data about one's sexual orientation and gender identity can be associated with substantial risks.⁶ Even in countries where such punitive measures do not exist, the absence of anti-discrimination laws, policies and practices could lead to people refusing to disclose information about their sexual orientation and gender identity or provide information that is not accurate. On the other hand, in countries where punitive measures have been abolished and anti-discrimination legislation, which includes sexual orientation and gender identity, is in place, collecting information about gender identity and sexual orientation may often be restricted by privacy laws and regulations. In some countries medical and health insurance records include questions on sexual orientation and gender identity, answers to which in some cases are optional. In the context of the global HIV response, the term “men who have sex with men” was coined. It focuses on sexual behaviour rather than orientation as many men who have sex with men do not identify as gay, or bisexual. This approach has led to some results in data collection but only when it comes to (cisgender) men and with the caveat that this data does not provide accurate information about sexual orientation. Similarly, data on trans people collected through HIV programmes focus almost exclusively on trans women because of their greater vulnerability to HIV.⁷ Data on lesbians and bisexual women and trans men is generally not collected through HIV programmes.

Birth certificates and birth registries are not suitable sources of data collection for sexual orientation and gender identity as these are not apparent at birth. Many countries include “sex” rather than “gender” in their identity cards, even though in recent years the number of countries that have introduced a “third gender” on the identify documents has increased.⁸

⁶ See ILGA, *State-sponsored homophobia*, 2017, https://ilga.org/downloads/2017/ILGA_State_Sponsored_Homophobia_2017_WEB.pdf. See also: Global Commission on HIV and the Law, *Rights Risk and Health*, 2018 Supplement, www.hivlawcommission.org

⁷ UNDP, *The Sustainable Development Goals: Sexual and Gender Minorities*, 2018, <https://www.undp.org/content/undp/en/home/librarypage/hiv-aids/sexual-and-gender-minorities.html>

⁸ It is reported by various sources that Austria, Australia, Canada, Denmark, Germany, India, The Netherlands, Nepal, New Zealand, Pakistan, Philippines, Thailand, United Kingdom, United States, and Uruguay provides some forms of recognition of non-binary gender. See: Open Society Foundations, *License to Be Yourself*, 2014 <https://www.opensocietyfoundations.org/sites/default/files/license-to-be-yourself-20140501.pdf>. It has to be noted that the situation of legal recognition of intersex people is more complex and confirmed global information is not

Surveys such as the one carried out the European Union Agency for Fundamental Rights (FRA) across all the European Union countries and some candidate countries and provide valuable information on the situation of LGBT people since 2008. Now FRA surveys also collect information about intersex people.⁹ Historically, the surveys have focused on discrimination, harassment and violence, experienced by LGBT people but now also collect data related to employment, education, healthcare.¹⁰ FRA surveys now follow the standards of the EU General Data Protection Regulation (GDPR) and anonymized data sets are stored on the UK Data Service servers.¹¹

The 2011 censuses in Nepal and Indian were the first in the world to include a third gender option. The introduction of this option produced useful data, even if data collection efforts were not always uniform and hampered by technical difficulties.¹²

In the United States, a “Census Equality Act” has been proposed to improve data collection by requiring the collection of information on sexual orientation and gender identity in the 2020 census and the American Community Survey, which act has not been passed yet.¹³ Non-state actors such as The Williams Institute and National Center for Transgender Equality have analysed census data for same-sex households and surveyed respectively LGBT people overall and trans people in particular.¹⁴

Canada is country that has carried out data collection on sexual orientation, same sex couples and families with the following focus: same-sex couples, same-sex parents, sexual orientation, health care, physical activity and stress.¹⁵

available. Malta provides recognition to intersex people through its *Gender Identity, Gender Expression and Sex Characteristics Act* (2015) but human rights institutions have reported that more countries provide recognition.

⁹ For instance, Croatia before it joined the EU, and the Republic of North Macedonia, currently a candidate country. The FRA methodology is also used in other countries in Eastern Europe. See: World Bank and ERA, *Life on the Margins: Survey Results of the Experiences of LGBTI People in Southeastern Europe*, 2018, <http://documents.worldbank.org/curated/en/123651538514203449/pdf/130420-REPLACEMENT-PUBLIC-FINAL-WEB-Life-on-the-Margins-Survey-Results-of-the-Experiences-of-LGBTI-People-in-Southeastern-Europe.pdf>

¹⁰ FRA surveys are organized according to the EU Charter Articles: Article 1 - Human dignity; Article 2 - Right to life; Article 14 - Right to education; Article 21 - Non-discrimination; Article 35 - Health care; Article 47 - Right to an effective remedy and to a fair trial. See EU LGBT survey - European Union lesbian, gay, bisexual and transgender survey - Results at a glance <https://fra.europa.eu/en/publication/2013/eu-lgbt-survey-european-union-lesbian-gay-bisexual-and-transgender-survey-results>

¹¹ UK Data Service, *European Union Lesbian, Gay, Bisexual and Transgender Survey*, 2012: Special Licence Access, <https://beta.ukdataservice.ac.uk/datacatalogue/studies/study?id=7956>

¹² Kyle G. Knight, Andrew R. Flores, Sheila J. Nezhad; *Surveying Nepal's Third Gender: Development, Implementation, and Analysis*. *TSQ* 1 February 2015; 2 (1): 101–122. doi: <https://doi.org/10.1215/23289252-2848904>

¹³ See: Senate Bill 3314 <https://www.congress.gov/bill/115th-congress/senate-bill/3314/text>

¹⁴ See: Williams Institute USA LGBT Statistics, <https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/?topic=LGBT#density>, See also: US Trans Survey <http://www.ustranssurvey.org/about/>

¹⁵ Statistics Canada, *Same-sex couples and sexual orientation... by the numbers*, https://www.statcan.gc.ca/eng/dai/smr08/2015/smr08_203_2015

The UNDP-led LGBTI Inclusion Index aims to measure the extent to which access to opportunities as well as development outcomes for LGBTI people exist in each country, universally and with respect to certain groups within a country. The Index considers multiple and intersecting types of stigma and discrimination. The five strategic areas of LGBTI inclusion in the Index - economic well-being, political and civic participation, personal security and violence, health, and education - have been determined after extensive consultation with LGBTI people, government and multilateral representatives, academics, and relevant private sector stakeholders. While several LGBT/SOGI indices focus on issues such as legal environment, public opinion or military policies, none are as comprehensive as the UNDP-led LGBTI Inclusion Index. The proposed 51 Index indicators, launched together with the World Bank, are compatible with the SDG global indicator framework, and oriented towards sustainable, uniform, and disaggregated data collection. The Index aims to inform policies, programmes and investments for strengthening LGBTI rights and inclusion.¹⁶

2. *What kinds of data can be collected by government to understand the nature and extent of violence (e.g. through statistics on LGBT-phobic hate crimes and hate speech), discrimination, and disparities in health, education, labour, civic participation, and other important areas?*

The LGBTI Inclusion Index envisions data collection in all the above-mentioned areas considering violence but also going beyond and exploring discrimination and disparities. In the specific context of personal security and violence a proposed set of 11 indicators is proposed (See Annex I), which focus on bodily, physical and psychological integrity, hate crimes and incitement to violence, SOGIESC-related violence, asylum based on SOGIESC, and access to justice for LGBTI people. Like the SDG indicators, the proposed Index indicators are organized in three feasibility tiers:

- Tier 1: Data already exist in a form that can be immediately used.
- Tier 2: Data already exist in some sense (such as, a law or policy either exists or not), but resources would be necessary to collect the data.
- Tier 3: Data do not exist in a significant number of countries, and it will take time and resources to create it.

The engagement of governments, provided that all human rights and personal and data safety and security concerns are addressed, is especially important in Tiers 2 and 3, where mobilization of resources (financial, technical and human) is needed to collect the data.

3. *What safeguards are in place, and what safeguards are needed, to protect the human rights of individuals providing personal data as well as individuals collecting such data? This question includes the following:*

- a. *Safeguards to protect the privacy of individuals who provide data about their sexual orientation/gender identity, and the confidentiality of the data provided by these individuals.*
- b. *Broader statutory rules or administrative policies to insure transparency and accountability of government institutions such as statistical bodies.*

¹⁶ UNDP and the World Bank, A Set of Proposed Indicators for the LGBTI Inclusion Index, 2017 (Annex I).

The question about safeguards is relevant to both the general question on safeguards for data collection, storage, and use, which is becoming increasingly important, as well as to the specific question about data collection on lesbian, gay, bi, and trans people. Privacy standards and practices differ globally, from the lack of data collection protection safeguards in general to very strict levels of protection such as the EU GDPR, and up to human subject research standards in the medical field, which are already impacting data collection globally. Similarly, in countries that do not protect against discrimination based on sexual orientation and gender identity typically there are no, or there are low, safeguards to protect the privacy of individuals in the context of data about their sexual orientation and gender identity.

In the context of the UN system, the UN High Level Committee on Management (HLCM) at the Chief Executives Board for Coordination (UN CEB) adopted, in October 2018 “Principles on Personal Data Protection and Privacy”.¹⁷ The Principles establish a framework for the processing of personal data by UN organizations, or on their behalf, and aim to:

- harmonize personal data protection standards across the UN System
- facilitate accountability in data processing
- ensure respect for the human rights and fundamental freedoms of individuals, in particular the right to privacy.

The Principles apply to personal data in any form and processed in any manner. The Principles can also be applied for the processing of non-personal data, when a sensitive context may expose individuals or groups to risk.

The UN Statistical Commission has endorsed “Fundamental Principles of Official Statistics and Declaration of Good Practices in Technical Cooperation in Statistics” and provides many guidance documents and resources on transparency and accountability in data collection and statistics. Similarly, such documents are provided by the UNDP Human Development Report Office.¹⁸ UN Global Pulse, an initiative of the United Nations Secretary-General on big data works on ensuring that big data is harnessed safely and responsibly, with specific focus on digital data.¹⁹

UNAIDS has facilitated the development of guidance for collecting data that can expose people living with HIV, or key populations most at risk of HIV, to risk.²⁰

In general, safeguards need to ensure that the data collected cannot be used to trace individuals or small groups of people – especially when linked to location data. For researchers and other data collectors, it is important that they can execute their work without interference from the outside, be it by those who mean harm to them or the people they study, or by those who wish to influence the outcomes of their work.

¹⁷ HLCM, Principles on Personal Data Protection and Privacy <https://www.unsceb.org/privacy-principles>

¹⁸ See Principles Governing International Statistical Activities https://unstats.un.org/unsd/methods/statorg/principles_stat_activities/principles_stat_activities.asp . See also: UN Human Development Reports <http://hdr.undp.org/en/global-reports>

¹⁹ UN Global Pulse <https://www.unglobalpulse.org/projects>

²⁰ UNAIDS, Guidance for constructing regional indicators to measure progress towards zero discrimination for Latin American and Caribbean countries: http://www.unaids.org/sites/default/files/media_asset/gam-lac-progress-zero-discrimination_en.pdf. See also: The People Living with HIV Stigma Index. <http://www.stigmaindex.org/>

4. *What are the risks associated with the collection and management of data on sexual orientation and gender identity and initiatives to overcome those?*

The risks associated with the collection, storage and use of data related to sexual orientation and gender identity are substantial, particularly in the context of punitive legal, policy and political environments. This data can be used and have been used to identify and target individuals and their families. They have been used to access sources to identify and persecute other individuals as well. Lastly, data related to sexual orientation and gender identity can be used to inform policies that are harmful to the human rights of LGBT people, for instance by limiting access to knowledge, limiting space of civil society, adopting discriminatory policies and practices.²¹

5. *Are there circumstances where data collection is ill-advised, such as in countries that criminalize same-sex behaviour or where particular government agencies have demonstrated a cause for concern regarding their treatment of issues related to sexual orientation and gender identity?*

Yes, there are. When legal systems criminalize, or otherwise punish, consensual sexual relations between adults of the same sex, or non-cisgender gender expression, collecting data on sexual orientation and gender identity is extremely risky and must be carried out with abundant caution if at all. Experience in data collection about certain key populations – men who have sex with men and transgender people in countries with challenging legal environments can contribute to mitigating the risk. Data collection in such cases is carried out by non-state actors, often with the engagement of community representatives. UNDP, as a principal recipient of Global Fund grants, including in challenging operating environments, supports and strives to ensure the confidentiality of data collection efforts.

In cases where there are no punitive laws, but anti-discrimination legislation is not in place, or does not include sexual orientation and gender identity, data collection is also associated with risks, there are no legal guarantees that collected data cannot be used to harm individuals and communities. Countries where privacy laws and data privacy frameworks are not sufficiently developed are often also countries where private actors collect data, including on sexual orientation and gender identity for the purpose of offering this data on the market. In addition, there is the case of inadequate enforcement of data confidentiality measures, which has led to many leaks of confidential data in cyberspace. A recent example is the case when data of the HIV status of 14,200 people in Singapore was leaked by an individual.²²

²¹ Wolfgang Benedek, OSCE Rapporteur's Report under the Moscow Mechanism on alleged Human Rights Violations and Impunity in the Chechen Republic of the Russian Federation, OSCE, 2018. <https://www.osce.org/odihr/407402?download=true> See also: Global Commission on HIV and the Law, 2018 Supplement, at 21-22.

²² See: Statement of the Ministry of Health of Singapore. <https://www.moh.gov.sg/news-highlights/details/unauthorised-possession-and-disclosure-of-information-from-hiv-registry>. See also: CNN HIV

The Global Commission on HIV and the Law in its 2018 supplement provided the recommendations that “[g]overnments must prohibit the non-consensual use by law enforcement or private entities of digitally-collected or stored private information, especially data related to sexual and reproductive health. Such data must not be used for discriminatory purposes or for commercial surveillance, profiling or targeting, except as provided by law, with the informed consent of the subjects and in circumstances consistent with universal human rights.”²³

It is important that data is anonymised as early as possible in the data collection effort and includes the design of data collection, the contact between interviewees and data collectors, data storage, data analysis. Anonymisation in the age of big data is getting increasingly challenging as individual answers to multiple data collectors – from scientific research to social networks - can add up to increasingly accurate individual data profiles. These profiles can be used to trace surveys back to individuals or a small enough number of people.

6. *When States engage in data gathering activity, to what extent is civil society able to meaningfully participate in the design and implementation of these programs? This question includes the following:*
 - a. *Do states have policies that guide the process of civil society participation national statistical programs and other State efforts to increase knowledge about LGBT populations?*
 - b. *Does civil society have the capacity, in terms of expertise and technical knowledge, to meaningfully participate in State efforts to gather data?*
 - c. *What constitutes meaningful participation in this area?*

The International Center for Not-for-Profit Law (INCL) has reported that, overall, countries should improve their capability to partner with civil society. Often national legal frameworks are not sufficiently well-developed to ensure meaningful participation of civil society. In many cases for profit entities enjoy more beneficial tax regimes than civil society organizations or are eligible to participate in tenders or to perform licensed services, access to which is restricted for civil society. This is the reason why engagement of civil society often informal and not sustainable. UNDP has been partnering in promoting the engagement of civil society in HIV responses, including through “social contracting” with government resources to provide HIV services that reach the most marginalized, including men who have sex with men and trans people. The independent Global Commission on HIV and the Law has identified the meaningful engagement of civil society as a priority and the shrinking civic space as a reason for concern – as civil society not only voices communities’ needs but also provides essential support services that can reach even the most marginalized people and communities.²⁴

status of over 14,000 people leaked online, Singapore authorities say <https://www.cnn.com/2019/01/28/health/hiv-status-data-leak-singapore-intl/index.html>

²³ Global Commission on HIV and the Law, 2018 Supplement, at 8.

²⁴ See ICNL, Closing Civic Space : Impact on Development and Humanitarian CSOs, 2016, <http://www.icnl.org/research/trends/Global%20Trends%20Vol.%207%20Iss.%203%20Challenges%20to%20Development%20Organizations%20final.pdf?pdf=trends7-3> . See also: Global Commission on HIV and the Law, 2018 Supplement, at 21-22. See also: UNDP, GFATM, OSF, A global consultation on social contracting: working toward sustainable responses to HIV, TB, and malaria through government financing of programmes implemented by civil society, 2017.

The capacity of civil society to participate in data collection varies significantly between and within countries and regions. Organizations such as ILGA World, ILGA Europe, the US-based National Center for Transgender Equality, OutRight Action International and other LGBTIQ organization have demonstrated leadership in data collection and analysis and their data is used by parliaments, UN bodies, academia, the media. At the same time smaller civil society organizations and grassroots groups do not have the capacity to meaningfully participate in data collection. An unfortunate phenomenon is the case of “data harvesting” by academic institutions and research organizations, predominantly from the Global North that benefit from the access of grassroots activist to information and data and collect this data against small remuneration, or for free, without this effort ever benefiting grassroots organizations and the communities they serve. A meaningful participation in data collection for LGBT communities and civil society also entails the opportunity to have a say in what data is collected, to benefit from the data collection effort, and to have information and control over how and by whom this data is used. The UNDP-World Bank research paper “Investing in a Research Revolution for LGBTI Inclusion” identifies the following priorities for investing to ensure meaningful and inclusive participation in LGBTI research.

- Invest in the development of capacity and partnerships between governments, LGBTI civil society groups, academics, multilateral institutions, and other stakeholders to create an infrastructure for LGBTI research and data collection.
- Invest in establishment and operationalization of the UNDP LGBTI Inclusion Index (contributing to the national capacity building outlined in Recommendation 1 for government, civil society, and academia) to undertake the targeted research required for each of the identified priority dimensions of the LGBTI Inclusion Index: health, economic well-being, personal security and violence, education, and political and civic participation.
- Invest in existing, new, or future research priorities identified by LGBTI civil society groups, whether related to local, national, regional, or global issues.²⁵

7. *Does the lack of a global classification scheme carry risks that data will not be useful for international comparisons or will not accurately reflect the identities and lived realities of local populations?*

We must acknowledge that “LGBT” is a term developed in the global North; many people and communities worldwide do not necessarily identify as “lesbian”, “gay”, “bisexual”, “transgender”. If international comparisons take into account the diverse realities of local population, ensure that “LGBT” concepts are adequately explained in the contexts of local lived experiences and then collected data is fairly and transparently interpreted for the needs of international research, data distortion can be mitigated. The creation of a global classification scheme may have a limited applicability also because notions of sexual orientation, gender identities and expressions evolve over time. Lived experiences of people around the world are diverse in many areas of life, not only in terms of sexual orientation and gender identity. Still, it is possible to collect data to carry out international comparisons. Responsible data collection and statistical methods for data harmonization and verification can be very helpful to ensure that no one is left behind in global data collection efforts.

²⁵ UNDP and the World Bank, Investing in a Research Revolution for LGBTI Inclusion, 2016.

III. Conclusions

- There are pressing global challenges related to the safety and security of collection, storage, and use of data related to sexual orientation and gender identity. This data can be used to identify L, G, B, T people and also to inform policies and practices that harm LGBT people.
- The general discourse on data safety and security and cybersecurity is relevant to data about sexual orientation and gender identity. There is even greater sensitivity and risk associated with data about sexual orientation and gender identity – due to punitive legal environments, or the lack of sufficient protection against stigma, discrimination, and violence.
- The experience and lessons learnt from data on HIV status or on key populations is relevant to the LGBT data discourse and should be used.
- The UN system is developing standards on data collection, storage, and use. The European Union is regulating data protection and privacy for all individuals in the EU and the European Economic Area. Good practices on data collection also exist in various Member States. These standards and good practices can be applicable to data related to sexual orientation and gender identity. However, there are no commonly accepted global human rights standards for data related to sexual orientation and gender identity. These standards should be developed and applied – first as self-enforced standards and later as mandatory international standards.
- As confirmed by the international expert meeting on SOGI data safety (Geneva, 2018) and the UNDP-World Bank consultation on the LGBTI Inclusion Index indicators (Washington DC, 2017) there is an urgent need to carry out discussions on cybersecurity and to capacitate stakeholders, including civil society, to address and mitigate cybersecurity risks.
- Data collection must engage LGBT people, their communities and organizations in a meaningful way – in determining what data is collected, how it is collected, stored and used and how these efforts benefit LGBT people, their communities and civil society. The “nothing about us without us” principle must apply.
- The diversity of people and communities and the limitations that “LGBTI” and “SOGI” terms entail must be acknowledged and data collection efforts must consider the identities and lived realities of people worldwide. From this perspective, and considering that identities evolve, a global classification scheme of sexual orientations and gender identities may have limited applicability. If such a scheme is to be developed its development and regular updates must be participatory and inclusive. It must be revised on an ongoing basis, as cultures and definitions of identities evolve.

IV. Annex I

UNDP and the World Bank, A Set of Proposed Indicators for the LGBTI Inclusion Index, 2017