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**Human Rights Council****Forty-first session**

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Agenda item 3

**Promotion and protection of all human rights, civil,  
political, economic, social and cultural rights,  
including the right to development****Data collection and management as a means to create  
heightened awareness of violence and discrimination based  
on sexual orientation and gender identity****Report of the Independent Expert on protection against violence and  
discrimination based on sexual orientation and gender identity\****Summary*

The present report is being submitted to the Human Rights Council pursuant to Council resolution 32/2.

In the report, the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, Victor Madrigal-Borloz, focuses on data collection and management as a means to create heightened awareness of violence and discrimination based on sexual orientation and gender identity, identifies risks associated with data collection, use and storage, and highlights key human rights safeguards in that regard.

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\* Agreement was reached to publish the present report after the standard publication date owing to circumstances beyond the submitter's control.



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## I. Introduction

1. The present report is the second submitted to the Human Rights Council by the Independent Expert on protection against violence and discrimination based on sexual orientation and gender identity, Victor Madrigal-Borloz, since he took up his functions under the mandate.
2. In his 2018 report to the Human Rights Council,<sup>1</sup> the Independent Expert expressed concern at the impact of stigmatization and negation on the global, regional and national base of evidence available to inform effective measures to address violence and discrimination. In particular, he underlined that in contexts of negation, data gathered would be unreliable, unsystematic and biased, and that all State measures to address violence and discrimination, be it public policy, access to justice, law reform or administrative actions, would be hindered by that fact.<sup>2</sup> In the present report, the Independent Expert consequently focuses on the role of data in the creation of a state of heightened awareness of the scourge of violence and discrimination based on sexual orientation and gender identity; the risks associated with data collection, use and storage; and key human rights safeguards in that regard.
3. The report is issued pursuant to Human Rights Council resolution 32/2, and reflects the work carried out from 1 May 2018 to 30 April 2019.

## II. Activities carried out from 1 May 2018 to 30 April 2019

4. In its resolution 32/2, the Human Rights Council included engagement in dialogue as one of the guiding principles for the mandate. The Independent Expert has actively engaged with a vast group of interlocutors, including States, United Nations agencies, funds and programmes, regional human rights mechanisms, national human rights institutions, civil society organizations, academic institutions, and leaders and members of faith-based communities. All of the dialogue takes as the point of departure a basic common ground: violence and discrimination on the basis of sexual orientation and gender identity are never justified and must be prevented and condemned.
5. The Independent Expert held several meetings with State representatives, regional groups and coalitions, and representatives of international and regional organizations. The meetings were held in Geneva, on 19 June 2018, 13 February 2019 and 25 April 2019; in Vancouver, Canada, from 5 to 7 August 2018; in New York, from 22 to 24 October 2018; and in Washington, D.C., from 5 to 8 March 2019.
6. Meetings and consultations with dozens of civil society organizations and individual experts were held virtually and in person in Gaborone, from 31 May to 3 June 2018; in Geneva, from 13 to 20 June 2018 and on 12 and 13 February 2019; in New York, from 22 to 24 October 2018; and in Wellington, from 17 to 21 March 2019. The meetings were focused on receiving input with regard to the issue of violence and discrimination as seen by stakeholders, with a particular emphasis on legal gender recognition and depathologization, data and sociocultural inclusion, as well as on the dissemination of the objectives and functions of the mandate.
7. The Independent Expert conducted two country visits: one to Georgia (25 September to 5 October 2018) and one to Mozambique (3 to 10 December 2018). He would like to express his thanks for the invitations he received and for the collaboration with respect to the visits. He is also grateful for the invitations extended to him by Iceland, Malta, Sri Lanka and Ukraine. Upon request of the custodial system of the Costa Rican judiciary he provided technical advice through digital consultations.

<sup>1</sup> A/HRC/38/43.

<sup>2</sup> *Ibid.*, para. 62.

8. On 24 May 2018, the Independent Expert was a keynote speaker at the IDENTITY Conference. He attended and presented a keynote speech at the fourth regional conference organized by Pan Africa ILGA [International Lesbian, Gay, Bisexual, Trans and Intersex Association], held in Gaborone from 31 May to 4 June 2018. On 18 June 2018, he gave a presentation in Geneva on the occasion of the trans advocacy week organized by the Asia Pacific Transgender Network, Global Action for Trans Equality (GATE), the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA), the Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights (RFSL) and Transgender Europe. On 29 June 2018, he took part in, and delivered a keynote presentation at, the high-level meeting organized by the Humanistic Institute for Development Cooperation (Hivos) on opportunities and challenges in the context of the rights of lesbian, gay, bisexual, transgender and intersex persons, held in San José. On 7 August 2018, he participated in a panel discussion during an event entitled “Leaving no one behind: Canada’s Role in Advancing LGBTQ2 Human Rights Globally”, held by the Vancouver branch of the Canadian International Council. On 27 October 2018 he delivered a keynote presentation at the annual conference of ILGA-Europe, held in Brussels. On 18 January 2019 he took part in a roundtable discussion on equality and non-discrimination focused on sexual orientation and gender identity, organized by the Commonwealth Secretariat in London. On 5 February 2019 he delivered a presentation at Harvard Law School in Massachusetts, United States of America. He was a panellist at the consultation on human rights in the HIV response, an event held in Geneva on 12 and 13 February 2019. He was a keynote speaker at the annual research symposium held by the National Consortium of Torture Treatment Programs in Washington, D.C., on 4 March 2019. He delivered a presentation at an event co-hosted by the Council of Global Equality, the Human Rights Campaign and the Better World Campaign on 7 March 2019. He participated in the ILGA-World Conference, held in New Zealand from 17 to 22 March, including through the delivery of a keynote speech on decriminalization of same-sex relations.

9. In keeping with the active outreach approach that he is setting as a standard for the mandate, the Independent Expert gave 12 in-depth interviews, joined or issued a total of eight press releases and maintained an active social media presence throughout the period. In order to ensure ongoing dialogue with States Members of the United Nations he joined or initiated a total of 23 communications, in which allegations of human rights violations in relation to sexual orientation and gender identity were raised or by which he sought to provide technical advice on legislation and policies.

10. For the preparation of the present report the Independent Expert sought views and encouraged input through various channels and from various stakeholders. On 4 February 2019, he issued a call for written submissions; he received around 90, 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. He held a public consultation, open to Member States, United Nations agencies, funds and programmes and all other interested stakeholders, in Geneva on 13 February 2019; the following day, he held, in partnership with the United Nations Development Programme (UNDP), a meeting of experts with the aim of creating a cross-disciplinary discussion. In order to ensure accessibility for stakeholders based outside Geneva, the mandate holder held online consultations in English, French and Spanish in different time zones on 27 and 28 February, and 5 and 6 March 2019. The mandate holder is impressed by the quality and quantity of inputs involved in the consultation undertaken for the report. Given the richness of the information received throughout the process, the submissions will be published on the official webpage of the mandate, with the exception of submissions for which the author specifically requested the input to be kept confidential.<sup>3</sup>

11. The Independent Expert is indebted to the vast group of entities, organizations and individuals who are committed to supporting his work and who have so significantly contributed to it.

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<sup>3</sup> See [www.ohchr.org/EN/Issues/SexualOrientationGender/Pages/ReportOnData.aspx](http://www.ohchr.org/EN/Issues/SexualOrientationGender/Pages/ReportOnData.aspx).

### III. Data related to sexual orientation and gender identity

#### A. The case for data collection and management

12. State and non-State stakeholders, as well as human rights mechanisms at the global, regional and national levels, have recognized that collection and proper management of relevant data is essential in order to adequately address violence and discrimination. However, as a result of barriers created by criminalization, pathologization, demonization and other institutional drivers for stigmatization, there are no accurate estimates regarding the world population affected by violence and discrimination based on sexual orientation and/or gender identity. Recently, the Independent Expert was shocked to hear from a high-level officer responsible for the formulation of public policy in a country with a population in the tens of millions that, in the officer's opinion, the country's population of lesbian, gay, bisexual, trans and gender-diverse persons "could not exceed 300 or so", and similar misconceptions are common all over the world. Given the evidence of violence and discrimination against these populations and communities, maintaining such a level of ignorance without seeking an appropriate evidence base, and applying such a personal preconception and prejudice to public policy are, in the opinion of the mandate holder, tantamount to criminal negligence.

13. The principle of due diligence, which requires States to protect those at particular risk of violence and discrimination and to take measures to understand and eliminate cultural stigmatization and other social causes of violence and discrimination, is also part of the basis of the State's responsibility when the State knows, or has reasonable grounds to believe, that abuses are being perpetrated. 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.<sup>4</sup> This includes data relating to demographic, economic, social and cultural characteristics, literacy rates, unemployment rates, voting patterns, the number of reported cases of violence and other indicators. States also need data of this nature for their reports to international human rights bodies pursuant to their obligations. Monitoring includes looking at data gathered by administrative agencies and through statistical surveys, the census, perception and opinion surveys and expert judgements.<sup>5</sup>

14. The following are examples of the manner in which data can shed light on the root causes of violence and discrimination based on sexual orientation and gender identity:

- Data from a 2010 survey in one country in the Americas showed that bisexual women who responded to the survey had suffered a significantly higher lifetime prevalence of violence when compared to lesbian and heterosexual women who responded. It was reported that, among the respondents, 61.1 per cent of bisexual women had, at least one time in their lives, been victims of rape, physical violence and/or stalking by an intimate partner, compared to 43.8 per cent of lesbians and 35 per cent of heterosexual women;<sup>6</sup>
- A systematic review of quantitative studies from multiple countries provided evidence of a "high prevalence of physical and sexual violence motivated by perception of sexual orientation and gender identity experienced by sexual and gender minorities, particularly among transgender people";<sup>7</sup>

<sup>4</sup> See Office of the United Nations High Commissioner for Human Rights (OHCHR), *A Human Rights-Based Approach to Data* (2018).

<sup>5</sup> See OHCHR, *Human Rights Indicators: A Guide to Measurement and Implementation* (2012).

<sup>6</sup> Inter-American Commission on Human Rights, *Violence against Lesbian, Gay, Bisexual, Trans and Intersex Persons in the Americas* (2015). See also Movement Advancement Project, *Invisible Majority: The Disparities Facing Bisexual People and How to Remedy Them* (2016).

<sup>7</sup> Karel Blondeel and others, "Violence motivated by perception of sexual orientation and gender identity: a systematic review", *Bulletin of the World Health Organization*, vol. 96, No. 1 (January 2018), p. 34. Available at <https://doi.org/10.2471/BLT.17.197251>.

- The results of the first multicountry survey carried out in this area by the European Union Agency for Fundamental Rights revealed significant perceptions of discrimination as reported by the lesbian, gay, bisexual, trans and gender-diverse respondents, and led to the recognition of a need to develop equal treatment policies for such persons in the European Union;<sup>8</sup>
- Data from large-scale population surveys have established causal links between poor health outcomes and the experience of stigmatization of and prejudice against lesbian, gay, bisexual, trans and gender-diverse persons.<sup>9</sup> They facilitate a comparison between that population and the general population with regard to rates of depression, cancer and HIV/AIDS. The collection of such data is deemed critically important in bettering the understanding of the life experiences of the members of the lesbian, gay, bisexual, trans and gender-diverse population to improve their mental and physical health and their well-being.<sup>10</sup>
- Data establishing intersectionality reflects the dynamic process of the lived experience of an individual; for instance, such data is able to show that race multiplies the effect of discrimination against trans and gender-diverse people;<sup>11</sup>
- The extent to which young lesbian, gay, bisexual, trans and gender-diverse persons face homelessness became evident when a 2012 survey of 354 homeless support agencies in one country suggested that 40 per cent of homeless young persons identified as part of this group, with family rejection the leading cause of homelessness among them;<sup>12</sup>
- A recent review of data in Organization for Economic Cooperation and Development (OECD) countries shows that homosexuals are only half as likely to be invited to a job interview as their heterosexual counterparts.<sup>13</sup>

15. Submissions to the mandate holder revealed a broad range of themes in relation to which data is indispensable or useful, among them: health access and outcomes, patterns of violence, levels of school bullying and education outcomes, domestic violence, hate crime, femicide and other killings, labour participation, workplace discrimination, access to housing, inclusion in civic spaces, and political leadership. Many other areas still lack data and remain unexplored, for example, the concerns of ageing lesbian, gay, bisexual, trans or gender-diverse people and intersections with disability, racism and xenophobia, even though there are pressing needs to be addressed. Submissions also revealed a lack of understanding of faith-based tolerance and inclusiveness of lesbian, gay, bisexual, trans and gender-diverse individuals in different contexts around the world, as data has not been collected in this area.<sup>14</sup>

<sup>8</sup> See [https://fra.europa.eu/sites/default/files/fra-eu-lgbt-survey-main-results\\_tk3113640enc\\_1.pdf](https://fra.europa.eu/sites/default/files/fra-eu-lgbt-survey-main-results_tk3113640enc_1.pdf).

<sup>9</sup> See David M. Frost and Ilan H. Meyer, "Internalized homophobia and relationship quality among lesbians, gay men, and bisexuals", *Journal of Counselling Psychology*, vol. 56, No. 1 (2009); Ilan H. Meyer, "Prejudice, social stress, and mental health in lesbian, gay and bisexual populations: conceptual issues and research evidence", *Psychological Bulletin*, vol. 129, No. 5 (2003); J.E. Pachankis, "The psychological implications of concealing a stigma: a cognitive-affective-behavioral model", *Psychological Bulletin*, vol. 133, No. 2 (2007).

<sup>10</sup> Submission from the American Psychological Association.

<sup>11</sup> See Jaime M. Grant and others, *Injustice at Every Turn* (National Gay and Lesbian Task Force and the National Center for Transgender Equality, 2011). Available at [https://static1.squarespace.com/static/566c7f0c2399a3bdabb57553/t/566cbf2c57eb8de92a5392e6/1449967404768/ntds\\_full.pdf](https://static1.squarespace.com/static/566c7f0c2399a3bdabb57553/t/566cbf2c57eb8de92a5392e6/1449967404768/ntds_full.pdf).

<sup>12</sup> See L.E. Durso and G.J. Gates, *Serving Our Youth: Findings from a National Survey of Service Providers Working with Lesbian, Gay, Bisexual, and Transgender Youth Who are Homeless or at Risk of Becoming Homeless* (Los Angeles, The Williams Institute with True Colors Fund and The Palette Fund, 2012). Available at <http://williamsinstitute.law.ucla.edu/wp-content/uploads/Durso-Gates-LGBT-Homeless-Youth-Survey-July-2012.pdf>.

<sup>13</sup> See Marie-Anne Valfort, "LGBTI in OECD countries: a review", OECD Social, Employment and Migration Working Papers No. 198. Available at <https://doi.org/10.1787/d5d49711-en>.

<sup>14</sup> Submission from the Global Interfaith Network.

## B. Risks associated with data collection and management

16. Denominations or identities related to sexual orientation and gender can be highly stigmatized characteristics, triggering multiple forms of violence and discrimination.<sup>15</sup> The extent to which information about a person's identity is available to the outside world, including the State, may be the result of disclosures responding to State efforts to collect information. This includes means that can yield that information indirectly, such as through information about household composition, usage of other names or aliases, and medical and relationship histories.

17. Human rights considerations demand careful management of the design and implementation of the processes for the collection and management of all personal information. In the areas of sexual orientation and gender identity the risks are exacerbated owing to the associated stigmatization in certain social contexts, which might create a motivation to hack or steal the data<sup>16</sup> or otherwise unlawfully access it.<sup>17</sup> Stigmatization also multiplies the damaging impact of disclosure of information due to negligence or mistakes.<sup>18</sup> Information about sexual orientation and gender identity may be released through data sharing, particularly when administrative data is shared between agencies in the course of programme administration, or if the data collection methods themselves are not conducted in a safe space or are conducted in a manner indicating that the data collection effort targets lesbian, gay, bisexual, trans and gender-diverse persons.<sup>19</sup>

18. As confirmed by experts at the meeting held by the Independent Expert in collaboration with UNDP in Geneva in February 2019 and at the UNDP-World Bank consultations, held in 2017, on indicators for the proposed lesbian, gay, bisexual, transgender and intersex inclusion index, 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.<sup>20</sup>

19. States and other stakeholders must respect the overriding principle to do no harm in every action conducive to human rights implementation. The mandate holder has determined that three factors interact in creating a risk of potential violence and discrimination based on sexual orientation and gender identity: criminalization, stigmatization and negation.<sup>21</sup> All are relevant when considering issues of data collection.

20. Lack of data about lesbian, gay, bisexual, trans and gender-diverse persons renders the community invisible to policymakers and government duty bearers,<sup>22</sup> 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.<sup>23</sup> Negation further enables violence and discrimination against persons in this group to go unchallenged, fuelling a vicious circle that leaves no one unaffected. Even where States collect data, negation can result in data that is unreliable, unsystematic and biased; all State measures to address violence and discrimination, be they public policy, access to justice, law reform or administrative actions, will be therefore hindered by this fact.<sup>24</sup>

21. In these and other contexts, lesbian, gay, bisexual, trans and gender-diverse persons are subjected to violence and discrimination because of stigmatization. Several stakeholders noted in their submissions that public exposure of an individual's sexual orientation and/or

<sup>15</sup> See A/HRC/38/43.

<sup>16</sup> Submissions from the Right Here Right Now consortium; The Fenway Institute; AR Arcon, activist from the Philippines.

<sup>17</sup> Submission from the Office of the United Nations High Commissioner for Refugees (UNHCR).

<sup>18</sup> Submissions from Ireland, Sweden and the Human Rights Commission of New Zealand.

<sup>19</sup> Submission from UNHCR.

<sup>20</sup> Submission from UNDP.

<sup>21</sup> A/HRC/38/43, paras. 50–65.

<sup>22</sup> Submission from the Commission on Human Rights of the Philippines.

<sup>23</sup> A/HRC/38/43, para. 62.

<sup>24</sup> *Ibid.*

gender identity could result in social exclusion.<sup>25</sup> There have been several reports of such persons being harassed on social media in Azerbaijan,<sup>26</sup> the Russian Federation<sup>27</sup> and Sri Lanka.<sup>28</sup>

22. By definition, full State diligence to prevent, prosecute and punish violence and discrimination based on sexual orientation and gender identity and expression is impossible in environments in which the State criminalizes certain forms of sexual orientation and gender identity and expression. In those environments, fully effective data collection, that is, data collection that serves the purpose of addressing violence and discrimination, is also impossible. Indeed, in contexts such as those a presumption must exist that data is gathered for purposes that are contrary to international human rights law, a working theory supported by multiple accounts received by the mandate holder of data being used in such contexts as the basis for surveillance, harassment, entrapment, arrest and persecution by government officials. For example, it has been reported that certain dating applications or pictures with the watermark of those applications have been used by authorities in Egypt, the Islamic Republic of Iran, and Lebanon to prosecute or blackmail gay men.<sup>29</sup> In addition, several stakeholders expressed concern that within criminalized environments, or in States with insufficient legal protection,<sup>30</sup> anti-propaganda laws,<sup>31</sup> cybersecurity laws,<sup>32</sup> child protection laws,<sup>33</sup> or foreign revenue laws<sup>34</sup> might be used to persecute persons on the basis of sexual orientation or gender identity. Some expressed concern that the practice of publishing private or identifying information about an individual with malicious intent – doxing – might be used as an oppressive tactic by State officials or by others with the acquiescence of the State.<sup>35</sup> This practice can lead to harassment, attacks, threats of violence, job loss or disqualification from military service.

23. Some stakeholders concurred with the above-mentioned concerns,<sup>36</sup> while varying levels of concern were expressed, with some stakeholders suggesting that the existence of a criminalization law prevents any safe, trustworthy data collection from taking place,<sup>37</sup> and others suggesting that data collection be undertaken only if risks can be managed.<sup>38</sup> The misuse of data further endangers programming aimed at, for example, increasing access to health services: in Indonesia, for example, data concerning sexual orientation collected as

<sup>25</sup> Submissions from AR Arcon, activist from the Philippines; Sarajevo Open Centre.

<sup>26</sup> CCPR/C/AZE/CO/4, para. 8.

<sup>27</sup> Joint civil society organization submission to the Special Rapporteur on the right to privacy (2018); resubmitted to the Independent Expert.

<sup>28</sup> E/C.12/LKA/CO/5, para. 17.

<sup>29</sup> Article 19, “Apps, arrests and abuse in Egypt, Lebanon and Iran” (2018). Available at [www.article19.org/wp-content/uploads/2018/02/LGBTQ-Apps-Arrest-and-Abuse-report\\_22.2.18.pdf](http://www.article19.org/wp-content/uploads/2018/02/LGBTQ-Apps-Arrest-and-Abuse-report_22.2.18.pdf). See also submissions from Da se zna! and the Eastern European Coalition for LGBT+ Equality; joint civil society organization submission on privacy (2018).

<sup>30</sup> Submission from TODXS Núcleo.

<sup>31</sup> Submission from the Eastern European Coalition for LGBT+ Equality.

<sup>32</sup> Oral comment made during the consultations in Gaborone, with particular reference to Uganda.

<sup>33</sup> Submission from the ASEAN SOGIE Caucus.

<sup>34</sup> Submission from the Right Here Right Now consortium. With regard to the Philippines, see the Guidelines for the protection of SEC registered non-profit organizations from money laundering and terrorist financing abuse (“NPO Guidelines”), available at [www.sec.gov.ph/wp-content/uploads/2018/11/2018MCNo15.pdf](http://www.sec.gov.ph/wp-content/uploads/2018/11/2018MCNo15.pdf).

<sup>35</sup> Submissions from Mujer y Mujer (Ecuador); the ASEAN SOGIE Caucus; Youth Voices Count (Asia-Pacific regional network). Joint civil society submission on privacy.

<sup>36</sup> Submissions from Germany; New Zealand; Right Here Right Now consortium; Alternatives Cameroun and others; Kenya National Commission on Human Rights. Joint submission from youth organizations (anonymity requested).

<sup>37</sup> Submissions from Alternatives Cameroun and others; Kenya National Commission on Human Rights; Queer Youth Uganda; The Fenway Institute. Joint submission by youth organizations.

<sup>38</sup> Submission from Kaos GL (Turkey); commission on gender and diversity (Argentina); Asian-Pacific Resource and Research Centre for Women and others. Joint submission from youth organizations.

part of AIDS programmes were allegedly shared with government officials who were empowered to enforce laws criminalizing homosexuality.<sup>39</sup>

24. Civil society organizations often carry out their own monitoring and reporting:<sup>40</sup> the mandate holder received extensive information on civil society efforts in contexts as diverse as Bolivia (Plurinational State of),<sup>41</sup> Brazil,<sup>42</sup> Cameroon,<sup>43</sup> Honduras,<sup>44</sup> Indonesia,<sup>45</sup> North Macedonia,<sup>46</sup> Pakistan,<sup>47</sup> Serbia<sup>48</sup> and Ukraine,<sup>49</sup> and in the Caribbean.<sup>50</sup> On the basis of this information and his own research, the Independent Expert observes that in multiple contexts it would appear that civil society organizations are attempting to fill the voids left by State inaction, including in areas fundamental to furthering the achievement of the Sustainable Development Goals. This work has been and will continue to be of exceptional value. Civil society organizations may in some cases be better placed to collect data related to sexual orientation and gender identity, as victims may not feel safe reporting to States whose agents may have perpetrated violations, are legally required to prosecute them, or will refuse to act to protect them.

25. The determination of civil society to fill gaps in order to further the protection of human rights does not relieve the State of its duty to obtain accurate information on the peoples, populations and communities under its jurisdiction, and to create environments conducive to obtaining and appropriately managing that information. In addition, the mandate holder is deeply concerned that reliance by States on civil society is not accompanied by the setting of proper conditions for its work, as there can be obstacles to legal registration of civil society organizations,<sup>51</sup> or a lack of proper financial support allowing civil society to ensure the sustainability of its efforts.

26. The challenges to proper data collection must be identified and addressed. For example, there are no universally accepted standards determining the classification of sexual orientation and gender identity. In many contexts, sexual orientation manifests itself in ways that do not necessarily fit the terms “lesbian”, “gay” or “bisexual”, and gender diversity goes beyond neat differentiations between “cis” and “trans” persons. Identities, behaviours, desires and expressions, and the terms used to describe them, vary from culture to culture and are based on language, history, religion, economic class, age, ethnicity and other cultural influences. Not taking into account the unique manner in which communities, populations and peoples define themselves, through concepts and terminology that are culturally appropriate and inclusive,<sup>52</sup> not only reflects the population inaccurately,

<sup>39</sup> Joint communication (OL IDN 2/2019) dated 13 February 2019 from three special procedure mandate holders. Available at <https://spcommreports.ohchr.org/TMResultsBase/DownloadPublicCommunicationFile?gId=24329>.

<sup>40</sup> See, for example, Chapter Four Uganda, *My Child is Different*. Available from <http://chapterfouruganda.com/sites/default/files/downloads/My-Child-Is-Different.pdf>. See also submissions from the Asian-Pacific Resource and Research Centre for Women and others; Youth Voices Count (Asia-Pacific regional network).

<sup>41</sup> Submission from Organización IGUAL.

<sup>42</sup> Submission from TODXS Núcleo.

<sup>43</sup> In the absence of government data, monitoring by non-State actors revealed a high level of violence and human rights violations against lesbian, gay, bisexual, trans and gender-diverse persons, with 1,134 cases recorded in 2018 (submission from Alternatives Cameroun and others).

<sup>44</sup> Submission from an individual in Honduras.

<sup>45</sup> Submission from Asian-Pacific Resource and Research Centre for Women and others.

<sup>46</sup> Submission from the LGBTI Support Centre.

<sup>47</sup> Submissions from the Asian-Pacific Resource and Research Centre for Women and others; Youth Voices Count (Asia-Pacific regional network).

<sup>48</sup> Submission from Da se zna!.

<sup>49</sup> The Nash Mir Center documented 358 acts of violence, discrimination and hate and other violations against lesbian, gay, bisexual, trans and intersex persons in 2018 (*Overcoming Obstacles: LGBT situation in Ukraine in 2018*, available at <https://gay.org.ua/en/blog/2019/02/05/overcoming-obstacles-lgbt-situation-in-ukraine-in-2018/>). Only two cases of hate crime based on sexual orientation were registered by the National Police in 2018 (submission from Ukraine).

<sup>50</sup> Submission from the Right Here Right Now consortium.

<sup>51</sup> Ibid.

<sup>52</sup> Submission from the Asian-Pacific Resource and Research Centre for Women and others.

decreasing the quality of data for all, but by definition violates the right of those persons to self-determination. Other challenges include the risk of underreporting due to language and cultural differences in the phrasing of survey questions, the experience of social desirability bias, on the part of respondents, and selection bias in the case of household surveys.<sup>53</sup> Respondents noted a variety of approaches drawn from social science practices that could be employed to respond to those challenges.<sup>54</sup>

## IV. Overview of guiding principles and practical examples

### A. Current efforts to increase knowledge about lesbian, gay, bisexual, trans and gender-diverse persons

#### 1. Global

27. UNDP and the World Bank are carrying out a series of activities to strengthen inclusion approaches, including the development of the proposed lesbian, gay, bisexual, transgender and intersex inclusion index<sup>55</sup> to track outcomes in the areas of education, safety, health, economic well-being and political and civil participation.

28. The Joint United Nations Programme on HIV/AIDS (UNAIDS) supports the collection of HIV/AIDS-related data, in particular on men who have sex with men and on trans persons, which it identified as key populations. It has, for example, developed regional indicators to assess violence and discrimination against lesbian, gay, bisexual, trans and gender-diverse persons.

29. The UNDP regional programmes “Being LGBTI in ...” and “SOGI and rights”, currently being rolled out in 53 countries and territories in Africa, Asia and the Pacific, Eastern Europe, Central Asia, Latin America and the Caribbean, address current research gaps on stigmatization, discrimination and violence.<sup>56</sup>

30. The United Nations Educational, Scientific and Cultural Organization (UNESCO) has supported the development, by the International LGBTQI Youth and Student Organization, of an inclusive education index to measure the progress of 47 European countries in the implementation of the ministerial commitment to ensuring safe and inclusive learning environments for LGBTQI learners.<sup>57</sup> It is developing a technical brief to help in monitoring and evaluating school violence based on sexual orientation, gender identity and gender expression through national and international surveys.

#### 2. Regional

31. Since 2008, surveys carried out by the European Union Agency for Fundamental Rights across the European Union and some candidate countries have provided invaluable information on the situations of lesbian, gay, bisexual, trans and gender-diverse persons. Historically the surveys focused on discrimination, harassment and violence, but have been expanded to data in, among other fields, employment, education and health care.<sup>58</sup> The surveys follow the standards of Regulation (EU) 2016/679 of the European Parliament and of the Council on general data protection.<sup>59</sup> The Office for Democratic Institutions and Human Rights of the Organization for Security and Cooperation in Europe includes in its annual reporting on hate crime reports of physical assaults and murders. It has determined

<sup>53</sup> Submission from Chile.

<sup>54</sup> See, for example, the submission from *Mujer y Mujer*.

<sup>55</sup> See <http://documents.worldbank.org/curated/en/608921536847788293/A-Set-of-Proposed-Indicators-for-the-LGBTI-Inclusion-Index>.

<sup>56</sup> Submission from UNDP.

<sup>57</sup> See [https://en.unesco.org/sites/default/files/call\\_for\\_action\\_2016\\_05\\_18-en.pdf](https://en.unesco.org/sites/default/files/call_for_action_2016_05_18-en.pdf).

<sup>58</sup> See <https://fra.europa.eu/en/publication/2013/eu-lgbt-survey-european-union-lesbian-gay-bisexual-and-transgender-survey-results>.

<sup>59</sup> See <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679>.

that trans persons are particularly at risk and that serious physical assaults are common features of crime against lesbian, gay, bisexual, trans and gender-diverse persons.<sup>60</sup>

32. The Inter-American Commission on Human Rights, through its Rapporteurship on the Rights of Lesbian, Gay, Bisexual, Trans and Intersex Persons, maintained a registry on violence from 1 January 2013 to 31 March 2014. During that period, the Commission recorded 594 killings of persons who were – or were perceived as – lesbian, gay, bisexual, trans or intersex. It further identified that over 80 per cent of the trans women killed were 35 years of age or younger.<sup>61</sup>

33. In the African context, following the adoption in 2014 of African Commission on Human and Peoples' Rights resolution 275, the Network of African National Human Rights Institutions initiated a project to strengthen its capacity to respond to violence and discrimination faced by persons of diverse sexual orientations and gender identities.<sup>62</sup>

### 3. National

34. State-led censuses and national population surveys are prime instruments for the collection of data on lesbian, gay, bisexual, trans and gender-diverse persons and their communities, and the mandate holder received abundant information on State measures in this respect:

- Surveys to identify sexual orientation, gender identity, gender expression or sexual behaviours have been conducted in Costa Rica,<sup>63</sup> Ireland (sexual behaviour),<sup>64</sup> Kenya (intersex only),<sup>65</sup> and the United Kingdom of Great Britain and Northern Ireland.<sup>66</sup>
- In the United States, data about cohabiting same-sex couples have been collected since the 2000 national census,<sup>67</sup> enabling a dramatic increase in the understanding of the lives and conditions of same-sex couples. Similar censuses have been carried out since 2010 in Argentina,<sup>68</sup> and since 2011 in the Bolivarian Republic of Venezuela.<sup>69</sup>
- The 2011 censuses in India and Nepal were the first in the world to include a third gender option.
- In Bangladesh, censuses have been carried out since the recognition of trans persons and hijras<sup>70</sup> as third gender in a 2013 ruling; most recently, a third gender option was included in voter forms.<sup>71</sup>
- In Pakistan, trans persons and hijras were included in the 2017 national census.<sup>72</sup>
- In New Zealand<sup>73</sup> and the United States,<sup>74</sup> measures are being taken by researchers to standardize the use of terminology around sexual orientation and gender identity

<sup>60</sup> See <http://hatecrime.osce.org/taxonomy/term/235?year=2015>.

<sup>61</sup> See [www.oas.org/en/iachr/multimedia/2015/lgbt-violence/lgbt-violence-registry.html](http://www.oas.org/en/iachr/multimedia/2015/lgbt-violence/lgbt-violence-registry.html).

<sup>62</sup> See [www.nanhri.org/our-work/thematic-areas/sogie-project/](http://www.nanhri.org/our-work/thematic-areas/sogie-project/).

<sup>63</sup> Submissions from Costa Rica; Centro de Investigación y Promoción para América Central de Derechos Humanos (Costa Rica).

<sup>64</sup> Submission from Ireland.

<sup>65</sup> Submission from the Kenya National Commission on Human Rights.

<sup>66</sup> See United Kingdom, Office for National Statistics, "Sexual orientation, UK: 2017", available at [www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2017](http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2017).

<sup>67</sup> Submission from the American Psychological Association.

<sup>68</sup> Submissions from Argentina; Office of the Ombudsman (Argentina); commission on gender and diversity (Argentina).

<sup>69</sup> Submission from the Ombudsman's Office of the Bolivarian Republic of Venezuela.

<sup>70</sup> A term referring to individuals who adopt a feminine gender identity with respect to, among other things, clothing and roles, and that includes trans persons and eunuchs.

<sup>71</sup> Submissions from the Asian-Pacific Resource and Research Centre for Women and others; Inclusive Bangladesh; Youth Voices Count (Asia-Pacific regional network).

<sup>72</sup> Submissions from the Asian-Pacific Resource and Research Centre for Women and others; Inclusive Bangladesh; Youth Voices Count (Asia-Pacific regional network).

to ensure consistency. In Colombia, the Bogotá Multipurpose Survey includes questions regarding self-identification of sexual orientation and gender identity.<sup>75</sup>

- Argentina noted that a gender identity category will be incorporated in the national population, households and housing census in 2020;<sup>76</sup> Australia and Ireland are considering incorporating questions on sex and gender in their 2021 national censuses;<sup>77</sup> the Office for National Statistics of the United Kingdom recommended including questions on gender identity and sexual orientation in the 2021 censuses in England and Wales;<sup>78</sup> and New Zealand will include questions about sexual orientation and gender identity and a third response for the question on sex in 2023.<sup>79</sup>

#### 4. Assessing violence and discrimination

35. Submissions highlight studies and surveys conducted or envisaged by State bodies to understand attitudes towards lesbian, gay, bisexual, trans and gender-diverse persons, their situations and the extent and forms of violence against them, for instance same-sex partner violence.<sup>80</sup> Additionally, the role of national human rights institutions and equality bodies in data gathering is of evident and extraordinary value; many submissions highlighted information on the work such bodies have carried out in the collection and analysis of data and in reporting on complaints of violations.<sup>81</sup> Several stakeholders noted that police records of hate-motivated crimes helped provide a better understanding of the nature and extent of violence against lesbian, gay, bisexual, trans and gender-diverse persons.<sup>82</sup> In the United States, for example, in 2014 hate crimes based on sexual orientation and gender identity comprised more than one fifth of all reported hate crimes; the Bureau of Justice Statistics reported disproportionate rates of sexual assault against gay and bisexual men and trans women in state prisons.<sup>83</sup>

36. The Kenya National Commission on Human Rights reported that it had added non-binary markers on sexual orientation and markers on sexual characteristics in its complaints management system and complaints collection forms, and that information was recorded upon consent from the complainant. The national human rights institution of Ghana noted that in situations where same-sex relations or gender diversity was criminalized, the institution could register complaints from the lesbian, gay, bisexual, trans and gender-diverse community in a confidential manner, ensuring safe storage of the information. In such situations, receipt of complaints should be accompanied by a policy to protect privacy.

37. One submission highlighted the first release in the United Kingdom of statistics on asylum claims based on sexual orientation, in 2018.<sup>84</sup> Another highlighted the lack of data

<sup>73</sup> Submission from New Zealand.

<sup>74</sup> See The Fenway Institute, *Gathering Sexual Orientation Data on Statewide Behavioral Risk Factor Surveillance Surveys*. Available from [https://fenwayhealth.org/documents/the-fenway-institute/policy-briefs/COM484\\_BRFSS\\_Brief.pdf](https://fenwayhealth.org/documents/the-fenway-institute/policy-briefs/COM484_BRFSS_Brief.pdf).

<sup>75</sup> Submission from Colombia.

<sup>76</sup> Submissions from Argentina; Office of the Ombudsman (Argentina); commission on gender and diversity (Argentina).

<sup>77</sup> Submissions from Australia and Ireland.

<sup>78</sup> Submission from the United Kingdom.

<sup>79</sup> Submission from the Human Rights Commission of New Zealand.

<sup>80</sup> Submissions from Belgium; Bosnia and Herzegovina; Denmark; Portugal; government of Flanders; National Consultative Commission on Human Rights (France); Federal District Human Rights Commission (Mexico).

<sup>81</sup> Submissions from Argentina; Bosnia and Herzegovina; Norway; Serbia; Sweden; Unia (Belgium); Da se zna! (Serbia); Right Here Right Now consortium; Human Rights Commission of New Zealand; Ombudsman's Office of the Bolivarian Republic of Venezuela.

<sup>82</sup> Submissions from Argentina; Belgium; Germany (sexual orientation only); Ireland; Norway; Serbia; Sweden; Ukraine; government of Flanders; Women's Initiatives Supporting Group (Georgia); an individual from Honduras; The Fenway Institute; Swedish Federation for Lesbian, Gay, Bisexual and Transgender Rights (RFSL); Ombudsperson of Guatemala.

<sup>83</sup> Submission from The Fenway Institute.

<sup>84</sup> Submission from UNHCR.

on violence against lesbian, gay, bisexual, trans and gender-diverse sex workers, despite research showing that 65 per cent of trans women murdered worldwide were sex workers.<sup>85</sup>

## 5. Understanding the lives and situations of lesbian, gay, bisexual, trans and gender-diverse persons

38. Several stakeholders noted that surveys and studies had supported assessments of the situations of lesbian, gay, bisexual, trans and gender-diverse persons in various areas of life, including with regard to their safety, well-being, health, education and employment.<sup>86</sup> Some stakeholders reported that, in some States, data was collected on the political participation of<sup>87</sup> and access to social security by<sup>88</sup> such persons.

39. In relation to education and bullying, several States and non-State actors reported measures to assess school violence against lesbian, gay, bisexual, trans and gender-diverse students.<sup>89</sup> The Netherlands reported that the government commissioned a biannual safety-at-school “monitor” that provided information on the perceived and actual safety of lesbian, gay, bisexual, trans and gender-diverse scholars and students. Serbia noted that it had conducted a survey on, among other things, violence against lesbian, gay, bisexual, trans and gender-diverse students. Portugal indicated that acts of violence based on sexual orientation perpetrated in schools were registered in an electronic platform. In Cyprus, the code of conduct against racism also covers bullying on the basis of sexual orientation and gender identity.<sup>90</sup> The International LGBTQI Youth and Student Organization provides information on inclusive laws, policies, and practices in the field of education across European Union member States and has developed the Inclusive Education Index (see para. 30 above) for assessing the degree of implementation by States, regional trends and gaps.<sup>91</sup>

40. Denmark and Ireland expressed the intention to collect data on discrimination in the field of employment in 2020 and 2019, respectively.

41. Submissions show that States that have gathered data about access to health care learn that sexual and gender minorities experience significant obstacles in accessing such care and experience higher rates of certain diseases.<sup>92</sup> In the United States, for example, questions on sexual orientation and/or gender identity were included in many public health surveys and several other surveys collected data on sexual orientation and gender identity pertaining to social determinants of health.<sup>93</sup>

42. In the context of the global HIV response, data has been collected on key populations, including men who have sex with men and trans persons. This approach has led to an increase in available data, but only relating to (cis) men and trans women, with the caveat that such data does not provide accurate information about sexual orientation or gender identity.<sup>94</sup> Submissions show that in countries where same-sex sexual acts are criminalized, data on the health of sexual and gender minorities are often collected

<sup>85</sup> Submission from Syndicat du travail sexuel (France).

<sup>86</sup> Submissions from Belgium; Canada; Chile; Costa Rica; Ecuador; France; Mexico; the Netherlands; New Zealand; Norway; Spain; the United Kingdom.

<sup>87</sup> Submission from an individual in Honduras.

<sup>88</sup> Submissions from the National Consultative Commission on Human Rights (France); National Human Rights Commission of Mexico.

<sup>89</sup> See, for example, submissions from International LGBTQI Youth and Student Organization (IGLYO) and Pink Embassy Albania.

<sup>90</sup> International LGBTQI Youth and Student Organization, *LGBTQI Inclusive Education Report* (2018).

<sup>91</sup> Ibid.

<sup>92</sup> Submissions from Denmark; Sweden; the United Kingdom; National Consultative Commission on Human Rights (France); Human Rights Commission of New Zealand; an individual from Honduras.

<sup>93</sup> Submissions from the American Psychological Association and The Fenway Institute.

<sup>94</sup> Submission from UNDP.

exclusively in the context of HIV programmes, for instance in Cameroon,<sup>95</sup> India,<sup>96</sup> Kenya<sup>97</sup> and Pakistan.<sup>98</sup>

## B. Good and best practices for managing risk

### 1. Global and regional standards

43. Well-accepted global standards addressing the human rights aspects of research provide an overarching frame for any data collection and management activity:

- The Nuremberg Code, which serves as the basis for additional development of codes of research ethics
- The Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects, adopted by the World Medical Association
- The International Ethical Guidelines for Health-related Research Involving Humans, issued by the Council for International Organizations of Medical Sciences in collaboration with the World Health Organization
- The Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks, adopted by the World Medical Association, which addresses the increasingly common practice of maintaining databases of personal information
- The Universal Declaration on Bioethics and Human Rights, adopted by UNESCO
- The Fundamental Principles of Official Statistics, adopted by the Statistical Commission and endorsed by the General Assembly, and the detailed set of implementation guidelines issued by the Statistical Commission,<sup>99</sup> which identify minimum legal frameworks to safeguard the human rights of individuals who provide data, as well as standards relating to institutional duties of statistical agencies
- The guidelines entitled *A Human Rights-Based Approach to Data* issued by the Office of the United Nations High Commissioner for Human Rights, which explicitly include sexual orientation and gender identity in relation to the disaggregation, self-identification, transparency, privacy, accountability and participation standards.

44. In particular, United Nations agencies and other global entities are vigorously developing guidance. For example, the Principles on Personal Data Protection and Privacy, adopted by the High-level Committee on Management in October 2018, set out a framework for the processing of personal data by United Nations organizations, or on their behalf. They are aimed at harmonizing personal data protection standards across the United Nations system, facilitating accountability in data processing and ensuring respect for the human rights and fundamental freedoms of individuals, in particular the right to privacy. 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. Global Pulse, an initiative of the Secretary-General, is aimed at ensuring that big data is harnessed safely and responsibly, with a specific focus on digital data. ILO has developed a code of practice entitled “Protection of workers’ personal data”. The International Committee of the Red Cross has developed the *Handbook on Data Protection in Humanitarian Action*.

45. At the regional level, the European Union is regulating data protection and privacy for all individuals in the European Union and the European Economic Area. Legal safeguards concerning the collection of data on sexual orientation are contained in

<sup>95</sup> Submission from Alternatives Cameroun and others.

<sup>96</sup> Submissions from UNDP; Youth Voices Count (Asia-Pacific regional network).

<sup>97</sup> Submission from the Kenya National Commission on Human Rights and joint submission from youth organizations.

<sup>98</sup> Submissions from the Asian-Pacific Resource and Research Centre for Women and others; an individual from Pakistan.

<sup>99</sup> See <https://unstats.un.org/unsd/dnss/gp/impguide.aspx>.

Regulation (EU) 2016/679. Article 9 of the Regulation states that the processing of personal data revealing, among other things, sexual orientation is prohibited unless specific conditions are fulfilled. Based on the various submissions received from European Union or European Economic Area member States,<sup>100</sup> the Independent Expert notes that the Regulation has been transposed or is in the process of being transposed into national legislation in several States.

## 2. Emergence of human rights principles in data collection and management

46. The submissions received included examples of safeguards adopted in the context of the collection, use and storage of data related to sexual orientation and gender identity and measures adopted to mitigate the associated risks. In the opinion of the Independent Expert, particularities specific to sexual orientation and gender identity should be identified and, when relevant and necessary, taken into account in the design of data collection and management exercises. The mandate concurs with UNDP that related standards should develop first as self-enforced standards and later as mandatory international standards.<sup>101</sup>

### (a) Do no harm

47. The principle of “do no harm” should always be respected. The decision to initiate and continue data-related activities, especially in the context of negation, stigmatization and hostile legal frameworks, should be made on the basis of an assessment of threats and risks to the safety, resources and rights of those involved in the activity and of the larger community of lesbian, gay, bisexual, trans and gender-diverse persons. Such an assessment should be made with the participation of the affected communities, peoples or populations.

48. The design of data collection and management systems, including, most importantly, considerations regarding evaluation of consent, must be subject to an ethical review<sup>102</sup> and a review by an independent body to ensure compliance with human rights standards.<sup>103</sup> Approaches to this have varied. Agencies may establish such bodies within the public administrative structure, and a common institutional approach to ensure accountability is through research ethics committees, sometimes referred to as institutional review boards. For example, the Universal Declaration on Bioethics and Human Rights states that ethics committees should be established in each country in order to assess ethical, legal and social issues related to all research involving human beings.

### (b) Self-determination

49. 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 established in universal and regional human rights instruments.<sup>104</sup> The Office of the United Nations High Commissioner for Human Rights has stated that devising disaggregation of indicators (or not) is not a norm- or value-neutral exercise.<sup>105</sup> It has also stated 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.<sup>106</sup> In addition, the concepts of sexual orientation and gender identity vary greatly across the world; a rich diversity of sexual orientations, gender identities and gender expressions exist in all regions as a result of long-established cultures and traditions. Some of those and other identities transcend Western concepts of gender identity, gender

<sup>100</sup> Belgium; Denmark; France; Germany; Ireland; the Netherlands; Norway; Portugal; Serbia; Spain; Sweden. See also the submission from the Greek National Commission for Human Rights.

<sup>101</sup> Submission from UNDP.

<sup>102</sup> Discussion at the meeting of experts coorganized by the Independent Expert and UNDP, 14 February 2019.

<sup>103</sup> Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks, para. 19.

<sup>104</sup> A/73/152, para. 20.

<sup>105</sup> *A Human Rights-Based Approach to Data*, p. 2.

<sup>106</sup> *Ibid.*, p. 12.

expression or sexual orientation and, depending on the language, the terms “sex”, “gender”, “gender identity” and/or “sexual identity” are not always used or distinguished.<sup>107</sup>

50. Within this context, it is the obligation of the State to recognize and respect self-determination and to ensure that categories of identity are drawn from those set by the members of the local population.

**(c) Privacy and confidentiality**

51. The right to privacy is recognized as a fundamental right under international human rights instruments,<sup>108</sup> establishing a personal sphere within which an individual may determine whether and how personal information is disclosed. One means through which individuals maintain control over their own personal information is the process of consent, whereby they are provided with the ability to limit the use of personal data to lawful purposes or to the purposes consented to when they first disclosed elements or facets of their private life,<sup>109</sup> which include their sexual orientation and gender identity.<sup>110</sup> The right to information entails the right of data subjects to be informed about the collection of their data. For instance, the law on personal data protection adopted in Georgia provides that data subjects have certain rights to “control the process”, as they are entitled to ask questions regarding the kind of data that is being processed, the purpose of the data processing, the legal basis for the data processing, how the data was collected, to whom the data was submitted; and the grounds for and purpose of the submission of the data.<sup>111</sup>

52. States that have transposed into national legislation Regulation (EU) 2016/679 have strong privacy regulations, as the Regulation requires anonymization of data following collection and compilation. It also requires that data such as names and addresses be deleted after a defined time interval has expired.<sup>112</sup>

53. Various submissions contained references to legal safeguards and good practices in relation to privacy and confidentiality.<sup>113</sup> In particular:

- The general law on the protection of personal data covering federal, state and municipal authorities and other entities and organizations in Mexico, as well as transparency laws in that country, treat issues related to sexual orientation, gender identity and gender expression as confidential personal data, providing for special protection of such data.<sup>114</sup>
- The Privacy Act 1993 of New Zealand contains 12 information-privacy principles that guide the way government agencies and businesses handle personal information, including in relation to the collection, storage, accuracy, retention and disclosure of, and access to, personal information.<sup>115</sup>
- In North Macedonia, the Law on Personal Data Protection defines the responsibilities of the persons authorized to process personal data, as well as fines that are to be imposed on authorized persons who have acted contrary to the statutory authorizations and exposed any such data to a third, unauthorized, person.<sup>116</sup>

<sup>107</sup> A/73/152, para. 3; see also para. 4.

<sup>108</sup> Universal Declaration of Human Rights, art. 12; International Covenant on Civil and Political Rights, art. 17.

<sup>109</sup> Human Rights Committee, general comment No. 16 (1988) on the right to privacy, para. 10.

<sup>110</sup> Discussion at the meeting of experts coorganized by the Independent Expert and UNDP, 14 February 2019.

<sup>111</sup> Submission from the Women’s Initiatives Supporting Group (Georgia).

<sup>112</sup> See also submissions from, among others, Ireland and Spain.

<sup>113</sup> Submissions from Ireland; Portugal; Serbia; Spain; Sweden; Venezuela (Bolivarian Republic of); The Fenway Institute; National Human Rights Commission of Mexico; Ombudsman’s Office of the Bolivarian Republic of Venezuela.

<sup>114</sup> See submissions from Mexico; the National Human Rights Commission of Mexico; Amicus (Mexico).

<sup>115</sup> Submission from the Human Rights Commission of New Zealand.

<sup>116</sup> Submission from the LGBTI Support Centre.

- In the United Kingdom, the privacy of persons who have a gender recognition certificate or who have applied for one is protected by law, and the disclosure of “protected information” acquired in an official capacity is an offence.<sup>117</sup>
- In the context of the national socioeconomic survey in Chile and in order to safeguard the confidentiality of the information collected and prevent third parties from having access to information that facilitates the identification of the households surveyed, the ministry responsible for social development does not take cognizance of or store information that makes it possible to identify individually the members of each household and/or to locate their domicile at a level of aggregation lower than that of the commune.<sup>118</sup>
- In Kenya, the Access to Information Act of 2016 limits access to information that may, *inter alia*, endanger the safety, health or life of any person or involve the unwarranted invasion of the privacy of an individual. In the context of criminalization of same-sex conduct and experiences of stigmatization, confidentiality and anonymity are maintained with regard to sexual orientation and gender identity. Additionally, data already collected is secured through encryption.<sup>119</sup>

54. Historically, the confidentiality of health-related information has been of particular importance. Submissions highlighted examples of legislative provisions restricting public access to information to protect document secrecy and imposing a duty of confidentiality,<sup>120</sup> or protecting and keeping confidential the health information of individuals through policies and procedures while allowing the flow of important health information necessary to provide high-quality care.<sup>121</sup>

**(d) Lawful use**

55. The principle of lawful use limits the use of data to those purposes provided for by law, including international human rights law, and limits access to data to those individuals whose involvement is necessary to accomplish those purposes. This is particularly important when data is collected for the purposes of administering programmes, delivering services, enforcing law and evaluating programmes. In such cases, individuals may not be directly informed about how their data will be used and maintained, and may not be provided with an opportunity to consent to such use.

56. Conversely, the collection and management of data to enable criminal prosecution of same-sex relations or on the basis of sexual orientation and gender identity is, by definition, a violation of the principle of lawful use. The mandate holder has already concluded that legislation, public policy and jurisprudence that criminalize same-sex relationships and particular gender identities are *per se* contrary to international human rights law,<sup>122</sup> and therefore any measures, including data collection and management, conducive to their implementation are equally contrary to international human rights law.

57. Several submissions referred to national safeguards and related standards regarding security, information technology security and physical security.<sup>123</sup> In Portugal, for example, statistical confidentiality is aimed at safeguarding the privacy of citizens and ensuring confidence in the National Statistical System, and the data collected on individuals cannot be given, disclosed or used for purposes other than those that are exclusively statistical.

**(e) Participation**

58. Participation is central to a human rights-based approach to data. The right to participate in public affairs, including the right of minorities to participate in governance

<sup>117</sup> Submission from the United Kingdom.

<sup>118</sup> Submission from Chile.

<sup>119</sup> Submission from the Kenya National Commission on Human Rights.

<sup>120</sup> Submission from Sweden.

<sup>121</sup> Submission from The Fenway Institute.

<sup>122</sup> A/HRC/38/43, para. 20 (b).

<sup>123</sup> See, for instance, the Privacy Act 1988 of Australia.

issues that affect them, is explicitly recognized in human rights treaties.<sup>124</sup> Ensuring participation is good practice, in particular with regard to maximizing the impact of data collected; communities are more likely to identify the best indicators for assessing their quality of life,<sup>125</sup> as they speak from the perspective of lived experiences.<sup>126</sup>

59. When designing relevant measures, it is important that the communities concerned are represented in their full diversity, including with respect to age, race, religion, ethnicity, migration status, education level and all other intersecting identities.<sup>127</sup> Meaningful participation is defined as the ability to participate on equal terms with others, including in all stages of data-collection activity, such as the design of the research methodology, the collection and analysis of the data, the compilation of the research report, the dissemination of the results and the implementation of the recommendations;<sup>128</sup> at the same time, the confidentiality of data and privacy of the research participants must be preserved.<sup>129</sup> In phobic environments, meaningful participation requires additional monitoring.<sup>130</sup>

60. During the consultation process, the mandate holder received consistent information to the effect that the involvement of lesbian, gay, bisexual, trans and gender-diverse persons in activities related to collecting data in their communities would help in weighing the risks when considering whether to collect data or not. The involvement of civil society in the design and the process of data collection was highlighted as a positive approach in various submissions received by the Independent Expert.<sup>131</sup> For example, a youth advisory group was established to provide support in developing the LGBTI+ National Youth Strategy 2018–2020 of Ireland and in designing the consultation process.<sup>132</sup>

61. In some States, the obligation to consult has even been prescribed by law. For instance, in Mexico the National Institute of Statistics and Geography is obliged by law to carry out consultations regarding statistical and geographic activities.<sup>133</sup> The Constitution of Kenya, 2010 requires all government agencies to facilitate public participation in policymaking and policy implementation, and the Government is in the process of developing a national public participation policy.<sup>134</sup> The Federal Anti-Discrimination Agency in Germany recommends that, in addition to providing legal data protection, the Government should also follow guidelines from civil society, which go beyond legal requirements.<sup>135</sup>

62. Historically, the development of scientific knowledge about violence and discrimination based on sexual orientation and gender identity has been heavily influenced by homophobic and transphobic assumptions. These assumptions have played a significant role in perpetuating such violence and discrimination. The growth in the number of scientists, researchers and other professionals with diverse sexual orientations or gender identities has helped bring biased assumptions to light, encouraged unbiased research and supported the capacity of communities to participate in public policy discussions.

<sup>124</sup> International Covenant on Civil and Political Rights, art. 25; International Covenant on Economic, Social and Cultural Rights, arts. 13 (1) and 15 (1); Convention on the Elimination of All Forms of Discrimination against Women, art. 7; Convention on the Rights of the Child, art. 12; Convention on the Rights of Persons with Disabilities, art. 29.

<sup>125</sup> Submissions from Syndicat du travail sexuel (France); UNDP.

<sup>126</sup> Submissions from Belgium; government of Flanders; American Psychological Association; Youth Voices Count (Asia-Pacific regional network); Humraz Male Health Society; COC Netherlands.

<sup>127</sup> Joint submission by youth organizations.

<sup>128</sup> Ibid.

<sup>129</sup> Submission from Subversive Front (North Macedonia).

<sup>130</sup> Submission from Women's Initiatives Supporting Group (Georgia).

<sup>131</sup> Submissions from Canada; Costa Rica; Ireland; Norway; Uruguay.

<sup>132</sup> Submission from Ireland.

<sup>133</sup> Submission from Mexico.

<sup>134</sup> Submission from the Kenya National Commission on Human Rights.

<sup>135</sup> Submission from Germany.

**(f) Transparency and accountability**

63. The principle of transparency is derived from a number of rights, including the right to information, a fundamental element of the freedom of expression. Article 19 of the International Covenant on Civil and Political Rights enshrines the freedom to seek, receive and impart information. Transparency is necessary for the realization of the right to participate. Principles of statistical practice and bioethics also recognize the necessity of transparency in the conduct of data collection and research.

64. The principle of transparency must be applied with regard to two broad groups of people. First, a minimum of information concerning data collection, processing and use must be provided to data subjects at the moment of collection as part of the process of obtaining consent. Several stakeholders highlighted the importance of informed consent and transparency, stating that people were entitled to have full knowledge about the objectives of any data collection activity, how the data would be used and who would use it or have access to it.<sup>136</sup>

65. Second, information about data-related activities must be made available to the general public, which includes the data subjects, users of data and customers of public data-producing organizations. Anyone participating in public policy discussions where data is relevant should be able to understand the data and its significance to the discussion. Information should be provided on, *inter alia*, the existence of all efforts to collect data, for either statistical or administrative purposes, on the uses of such data, on how the data will be maintained and on whether and how the public can access such data. Transparency regarding the sources, methods and procedures used to produce official statistics should enable users to judge the fitness of the use of the data. A lack of visibility of existing research data resources and future data collection poses serious obstacles to access.<sup>137</sup>

66. Transparency is achieved through various measures. As a minimum, States must create a legal framework applicable to the data-related activities of public agencies,<sup>138</sup> including the administrative consequences for violating that framework, as well as rules guiding access to information.

67. Several States have adopted legislative measures related to transparency. For example, in Mexico, the general law on transparency and access to public information establishes common transparency obligations for all regulated entities.<sup>139</sup> In a move to ensure more transparency, particularly regarding how data is used to develop policies and deliver services, the United Kingdom adopted the Freedom of Information Act, which gives individuals the right to access recorded information held by public sector organizations, including the Office for National Statistics.<sup>140</sup> In Argentina, in accordance with the law on protection of personal data (Law 25.326), citizens can exercise their right to rectify information that the State and private entities possess about them. Hence, data related to a person stored in data banks must be processed in such a way that that person can have full access to the data.<sup>141</sup> In the Dominican Republic, any person may go to the competent judicial authority to request the updating, rectification or destruction of information that unlawfully affects their rights, or to object to the treatment of that data.<sup>142</sup>

**(g) Impartiality**

68. The impartiality of statistical agencies is essential for the credibility of official data and to maintain trust in the operations of those agencies. Statistical agencies must be free

<sup>136</sup> See, for example, the submission from the Asian-Pacific Resource and Research Centre for Women and others.

<sup>137</sup> OECD Principles and Guidelines for Access to Research Data from Public Funding (2007).

<sup>138</sup> The implementation guidelines for the Fundamental Principles of Official Statistics provide guidance as to the types of legal framework necessary.

<sup>139</sup> Submission from the National Human Rights Commission of Mexico.

<sup>140</sup> See [www.gov.uk/make-a-freedom-of-information-request/organisations-you-can-ask-for-information](http://www.gov.uk/make-a-freedom-of-information-request/organisations-you-can-ask-for-information); submission from the United Kingdom.

<sup>141</sup> Submission from the Office of the Ombudsman (Argentina).

<sup>142</sup> Submission from the Dominican Republic.

from indirect or direct external influence, must have the necessary resources and staff with the appropriate skills, and must operate in a manner that is free from conflicts of interest and consistent with their functions and duties.

69. The impartiality of statistical agencies is maintained, in part, by precisely defining how they can use data. As established in the Fundamental Principles of Official Statistics (principle 6), individual data collected by statistical agencies for statistical compilation are to be strictly confidential and used exclusively for statistical purposes.

## V. Conclusions and recommendations

70. In accordance with considerations of due diligence, and given that persons with diverse sexual orientations and gender identities live all across the globe, the duty to understand the manner in which these traits in a person's identity have an impact on their exposure or vulnerability to violence and discrimination is a key element in the obligation of States to prevent, prosecute and punish violations of human rights.

71. However, information about the lived realities of lesbian, gay, bisexual, trans and gender-diverse persons around the world is, at best, incomplete and fragmented; in some areas it is non-existent. The mandate holder stresses the seriousness of this finding: it means that in most contexts policymakers are taking decisions in the dark, left only with personal preconceptions and prejudices or the prejudices of the people around them.

72. The disaggregation of data to allow comparison of population groups therefore forms part of a State's human rights obligations. 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.

73. The Independent Expert sets out below a number of recommendations, and invites constructive responses from States, civil society and other stakeholders.

74. While taking measures to collect and manage data on sexual orientation and gender identity, States must bear in mind that these are, in almost every context, highly stigmatized characteristics that trigger multiple forms of violence and discrimination. In particular, States are called to bear in mind the international human rights framework in contexts in which it is currently, or has been historically, the policy of the State to deny the existence of lesbian, gay, bisexual and trans or other gender-diverse persons.

75. Similarly, when designing and adopting methodologies for data collection and management, fundamental consideration must be given to the manner in which communities, populations and groups identify themselves, including their identification or not under acronyms such as LGBT.

76. States that criminalize sexual orientation and/or gender identity are called upon to take into account, as part of a foundation of compliance with the international human rights law framework, that said forms of criminalization are per se contrary to international human rights law and that, therefore, measures conducive to their implementation – such as data collection carried out with the purpose of prosecuting persons on the basis of their sexual orientation – are, by definition, also violations. The Independent Expert recommends that States repeal such laws, including laws that criminalize consensual same-sex relations, or gender identity or expression.

77. The Independent Expert wishes to acknowledge and applaud the role of civil society in the collection and management of data concerning violence and discrimination based on sexual orientation and gender identity. He is convinced that in certain contexts, this work is what has protected persons from violence and discrimination. States must acknowledge that work, recognize the expertise residing within civil society, and support and protect the sustainability of those efforts.

78. The Independent Expert recommends that States design and implement comprehensive data collection procedures in order to be able to uniformly and accurately assess the type, prevalence, trends and patterns of violence and discrimination against lesbian, gay, bisexual, trans and gender-diverse persons. Data should be disaggregated by community, but also by other factors, such as race, ethnicity, religion or belief, health status, age, class, caste and migration or economic status.

79. Data should inform the policies and legislative actions of States with a view not only to prevent further acts of violence and discrimination but also to address gaps in investigation, prosecution, remedies provided and sociocultural and economic inclusion.

80. In order to prevent the misuse of collected data, States should follow a human rights-based approach. The overriding human rights principle of “do no harm” should always be respected; all activities must take into consideration the principles of self-determination, privacy and confidentiality, lawful use, participation, right to information, transparency, accountability and impartiality in the terms expressed in the present report and other relevant human rights sources.

81. In order to combat and address the structural causes of underreporting and underrepresentation in data, the Independent Expert recommends that States create effective systems for recording and reporting hate crimes based on sexual orientation and gender identity. In addition, States should adopt anti-discrimination legislation that includes sexual orientation and gender identity among the prohibited grounds of discrimination, and develop specific programmes and policies to end the spiral of discrimination, marginalization and exclusion, which have a negative impact on the rights of lesbian, gay, bisexual, trans and gender-diverse persons, including their rights to health, education, work and an adequate standard of living, and on their access to justice.

82. In recognition of the crucial role played by civil society and human rights defenders in the provision of an evidence base for public policy, and in the creation of capacity and legitimacy to collect and manage data, States must nurture safe spaces within which civil society organizations can carry out their work, and must support the work of civil society and human rights defenders in the collection and use of data. Within this context, the Independent Expert urges States to take measures to protect defenders and supporters of the rights of lesbian, gay, bisexual, trans and gender-diverse persons from attacks, intimidation and other abuse. National human rights institutions can play a key role in facilitating safe spaces.

83. The Independent Expert further recommends that States ensure the immediate removal of any legal obstacles to the functioning of organizations working towards the protection and promotion of the rights of persons of diverse sexual orientations and gender identities, including provisions aimed at, used for or designed with the intention of criminalizing their work.