

# A HUMAN RIGHTS-BASED APPROACH TO DATA

## Leaving No One Behind in the 2030 Development Agenda

Participation



Disaggregation



Self-identification



Transparency



Privacy



Accountability



UNITED NATIONS  
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# Guidance Note to Data Collection and Disaggregation

OHCHR ([hrindicators@ohchr.org](mailto:hrindicators@ohchr.org)) welcomes comments or suggestions on this guidance note and any information on experiences, practices and research work relevant to the implementation of an HRBAD.

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# Introduction

In step with the 2030 Agenda for Sustainable Development (2030 Agenda) and its Sustainable Developments Goals (SDGs) adopted by Heads of State and Government at the United Nations Summit in September 2015 (A/RES/70/1), this note aims to provide general guidance and elements of a common understanding on a Human Rights-Based Approach to Data (HRBAD), with a focus on issues of data collection and disaggregation.<sup>1</sup>

As part of the 2030 Agenda, States explicitly reaffirmed *their commitment to international law and emphasized that the Agenda is to be implemented in a manner that is consistent with the rights and obligations of States under international law.*<sup>2</sup> They called for *leaving no one behind* and more systematic data disaggregation to help achieve and measure the goals.<sup>3</sup> As devising (or not) disaggregation of indicators is not a norm or value-neutral exercise, and the risks associated with this operation for the protection of the rights of data subjects cannot be denied, an HRBAD has much to offer in this context.

As outlined in this note, an HRBAD will help bring together relevant data stakeholders and develop communities of practice that improve the quality, relevance and use of data and statistics consistently with international human rights norms and principles. This note echoes the call for a *data revolution for sustainable development* which upholds human rights. It should be of interest to all policymakers, statisticians or data specialists (in government agencies or civil society organizations (CSOs)), development practitioners and human rights advocates eager to ensure respect, protection and fulfilment of human rights in the measurement and implementation of the 2030 Agenda.<sup>4</sup>

A preliminary set of principles, recommendations and good practices were formulated under the following headings of an HRBAD:<sup>5</sup>

- Participation
- Data disaggregation and collection by population group
- Self-identification
- Transparency
- Privacy
- Accountability

# Participation



Participation is central to a human rights-based approach. It is instrumental to the realization of all components of the HRBAD, as well as retaining trust in official and other relevant data and statistics.<sup>6</sup>

All data collection exercises should include means for free, active and meaningful participation of relevant stakeholders, in particular the most marginalized population groups.

Participation should be considered in relation to the entire data collection process: from strategic planning through identification of data needs, selecting and testing an appropriate collection methodology, data collection (for instance, hiring interviewers from particular communities to improve response rates), and to data storage, dissemination, analysis and interpretation.<sup>7</sup>

The process and decisions by which participants are selected should be clear and transparent. In some contexts, to ensure the protection of groups who may feel uncomfortable or even threatened by the data collection, CSOs, national human rights institutions<sup>8</sup> and other relevant stakeholders should participate, provided they are competent to represent the group's interest.

Capacity strengthening should be undertaken with participating groups and target populations to increase their statistical literacy and understanding of the purpose and process of data collection. Marginalized groups should be empowered in the process and use of the resulting data.<sup>9</sup>

The form of participation should be decided on a case-by-case basis. Options may include online consultations, public meetings, public submission (for instance, for topic development), working with communities, opening membership of thematic or advisory boards or committees to CSOs, and focal points or formal memoranda of understanding among organizations or departments, including between national statistical offices and human rights institutions.<sup>10</sup>

A participatory approach should enhance the relevance and reliability of collected data and compiled indicators. An HRBAD should help address concerns expressed by the target population groups themselves in accordance with international human rights standards. These groups may be, for example, women; children; indigenous peoples; minorities; persons with disabilities; migrants; homeless persons; older persons; the youth; lesbian, gay, bisexual, transgender and intersex (LGBTI) persons; refugees; people living with human immunodeficiency virus (HIV); people who use drugs; sex workers, etc.

An HRBAD should include equal participation of women and men and adopt a gender perspective throughout its process. This means disaggregating statistics by sex, as well as going beyond biological and physiological characteristics. In addition, statistical and data collection work should take into account the relationship between women and men based on socially or culturally constructed and defined identities, status, roles and responsibilities that may have been assigned to one or the other sex. Similar approaches should also be applied to other population groups, as relevant.

Recognizing the instrumental role that *Gender Statistics Focal Points* can play in national statistical offices or systems,<sup>11</sup> there is a need to integrate a human rights perspective in their work or to establish *Human Rights Focal Points* with a gender perspective.

## Data disaggregation and collection by population group



Data disaggregation and collection which allow for comparison of different population groups is central to an HRBAD and forms part of States' human rights obligations. Doing so reveals and assesses the extent of possible inequality and discrimination.<sup>12</sup>

An HRBAD requires a move from traditional data collection and analysis, which concentrate on national averages and risk masking underlying disparities. An HRBAD focuses instead on the most disadvantaged or marginalized and on inequalities among the population.<sup>13</sup>

Capacities and partnerships should be developed to enable States to meet their obligation to collect and publish data disaggregated by grounds of discrimination recognized in international human rights law. These include sex, age, ethnicity, migration or displacement status, disability, religion, civil status, income, sexual orientation and gender identity.

Use of official survey questionnaires in data collection carried out by relevant CSOs or integration of data produced by community-based mechanisms in official statistics should be explored. However, responsibilities in data partnerships, particularly in relation to data privacy and management, must be clearly defined.

This is necessary both for the data collection process and toward the data subject or respondent.

Applying a participatory approach, and the principle of self-identification (see next section), can help improve response rates among “hard-to-count” or marginalized populations. This is particularly relevant for those who may experience multiple forms of discrimination or simply be excluded from traditional household surveys (e.g., homeless persons<sup>14</sup> or persons in institutions) or administrative records (e.g., undocumented migrants<sup>15</sup>). In some contexts, CSOs and service providers may be in a better position than national statistical offices to reach these populations and collect data.

Decisions concerning data collection on particularly vulnerable or marginalized groups, including, “legally” invisible groups for instance, should be made in close partnership or consultation with the group concerned to mitigate associated risks.

Realization of the human right obligation to be registered immediately after birth impacts on the statistical system’s capacity to disaggregate data.<sup>16</sup> This obligation is instrumental for the accuracy of vital statistics and sampling design of surveys. It is often essential for the realization of other human rights, such as the rights to education, health and participation in public affairs.

The specific needs for data disaggregation at country level must be taken into account at the planning and design stage of data collection programmes. Appropriate methodologies may include oversampling, accessing administrative records, targeted sampling, comparative surveys of target population groups with other population groups living in the same areas<sup>17</sup>, random walks, respondent-driven sampling and individual questionnaire modules (intra-household disaggregation)<sup>18</sup>. These must be decided on a case-by-case basis, following a participatory approach as outlined earlier.

Data should be published in a format that permits detection of possible multiple and intersecting disparities and discrimination. Qualitative indicators and analysis of legal, institutional or cultural status of affected populations are also essential to enhance understanding and contextualization of the HRBAD.

## Self-identification



Data collection and categorization of populations in statistics are critical operations in relation to the identity of an individual or population groups. The respect and protection of personal identity is central to human dignity and human rights.

The overriding human rights principle *do no harm* should always be respected. The appropriateness and necessity of

inclusion of personal identity issues in data collection exercises should be carefully assessed.

Data collection exercises, whether through census, specialized population surveys or administrative records (e.g., vital statistics), should not create or reinforce existing discrimination, bias or stereotypes exercised against population groups, including by denying their identity(ies). Any objections by these populations must be taken seriously by the data producers.

*Do no harm* also means that nothing in this guidance note should be interpreted as an invitation, encouragement or endorsement of any initiative or practice seeking to introduce population categorizations in identification documents (e.g., ID cards) or central population registries which would discriminate against population groups and expose them to risks of serious human rights violations.<sup>19</sup>

Where a survey includes questions on personal identity, all persons conducting in-person interviews should receive gender and cultural awareness training. That training should include possible issues of historical legacy as it relates to both majority and minority populations.

Any categories of identity should be developed through a participatory approach., All questions on personal identity, whether in surveys or administrative data, should allow for free response as well as multiple identities.<sup>20</sup>

Similarly, the most personal identities should be assigned through self-identification, and not through imputation or proxy. These include for instance identities relating to religious beliefs, sexual orientation, gender identity and ethnicity.

Determination of identities such as ethnicity could also include objective criteria, such as language or place of residence, provided that related human rights safeguards to prevent abusive external determination are also in place.<sup>21</sup>

In some contexts, applying the principle of self-identification may involve including categories of identity beyond those currently listed in international treaties.

## Transparency



The principle of transparency is closely linked with those of participation (see first section) and accountability of an HRBAD (see final section). Also referred to as the right to information, it is a fundamental attribute of the freedom of expression. The *freedom to seek, receive and impart information* is specified in international human rights treaties.<sup>22</sup>

The United Nations Fundamental Principles of Official Statistics state that statistics play a fundamental role in the information system of a democratic society, and beyond serving the Government and the economy, in honouring a population's entitlement to public information.<sup>23</sup>

CSO's access to data and reports informing them of existing inequalities among population groups is essential to the realization of the right to information, and the monitoring and realization of human rights more generally. That data may relate to, for instance, access to education, health, protection from violence, work, participation, social security and justice.

The legal, institutional and policy frameworks under which national chief statisticians and statistical systems operate should be publicly available. This helps ensure trust in the statistical information produced.<sup>24</sup>

Metadata (data describing the data) and paradata (data about the process by which the data were collected) should be available and standardized, as relevant, across data collectors and data collection instruments. Doing so facilitates accessibility, interpretation and trust.

Data should be disseminated as quickly as possible after collection. Dissemination should be in an accessible language and format, taking into account considerations such as disability, language, literacy levels and cultural background.

Fulfilment of the right to information by the production of statistical information implies that CSOs should be able to publish and analyse statistics without fear of reprisal. CSOs should also seek to comply with international human rights and statistical standards, including the United Nations Principles for Official Statistics, for their data collection, storage and dissemination of statistical information and analysis.

## Privacy



Access to information must be balanced with the rights to privacy and data protection. With the increasing use of big data<sup>25</sup> and the demand for data disaggregation to measure the 2030 Agenda, there is a critical need to ensure the protection of these rights, as acknowledged in the call for a *data revolution*.

The right to privacy is closely linked with self-identification and personal identity issues. The Human Rights Committee defined privacy as *a sphere of a person's life in which he or she can freely express his or her identity, be it by entering into relationships with others or alone*.<sup>26</sup>

Personal data, including but not limited to data on ethnicity, sexual orientation, gender identity or health status, should be handled only with the express consent of the individual concerned.

Data collected to produce statistical information must be strictly confidential, used exclusively for statistical purposes and regulated by law.<sup>27</sup> As stated in the International Covenant on Civil and Political Rights, *No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.*<sup>28</sup>

Data should not be published or publicly accessible in a manner that permits identification of individual data subjects, either directly or indirectly. Data should be secured against both natural and human dangers, and deleted when no longer required.<sup>29</sup>

An independent body at the national level with appropriate powers to ensure compliance should supervise data protection at all stages of collection, processing and storage carried out by government or CSOs.

Clear harm mitigation strategies with assigned responsibilities, reporting obligations, access to remedies and compensation for data subjects, should be in place in case of data leaks or other security breaches.

## Accountability



Accountability is central to a human rights-based approach. In the context of the HRBAD, it refers to *data collection for accountability* as well as *accountability in data collection*.<sup>30</sup>

As state institutions, national statistical offices are themselves human rights *duty-bearers*. They have obligations to respect, protect and fulfil human rights in their daily exercise of statistical activities.

Independent statistics, free from political interference, are fundamental tools to inform and hold those in power accountable on their policy actions (or inactions) through measuring their impact on the protection and realization of human rights.

Appropriately anonymized microdata should be made available to academics, CSOs and other stakeholders to facilitate the development of accountability systems. Publication of relevant and disaggregated indicators can aid accountability by supporting CSOs in formulating human rights claims and possible recourse to complaints systems backed up by evidence.

Putting collected data back in the hands of disadvantaged population groups and strengthening their capacity to use them is essential for accountability.<sup>31</sup>

The quality and reliability of data must be ensured. Data collectors should be free to challenge any incorrect analysis made by users.<sup>32</sup>

To improve measurement of human rights and implementation of the 2030 Agenda, adequate budgets at national and international levels should be allocated to support national statistical offices. This will enable them to undertake data collection for marginalized groups, ensure participatory and gender-sensitive approaches, and provide capacity strengthening to alternative data collectors.

Accountability is strengthened by combining the use of indicators with benchmarks,<sup>33</sup> improved data visualization and communication tools, more systematic reference to relevant human rights standards (e.g., international human rights treaty provisions potentially measured by SDG indicators cited in relevant metadata) and recommendations from national and international human rights mechanisms.

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<sup>1</sup> "Data" is used as a generic term, including but not limited to statistics. It is seen as encompassing a wide range of quantitative or qualitative standardized information compiled by national statistical offices as well as other governmental or non-governmental entities, whether at local, national, regional or global level.

<sup>2</sup> See, for instance, para 18 in A/RES/70/1.

<sup>3</sup> For instance, target 17.18 in the 2030 Agenda requests that SDG indicators are *disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts*.

<sup>4</sup> In *A World that Counts: Mobilising the data revolution for sustainable development*, 2014 ([www.undatarevolution.org](http://www.undatarevolution.org)), on p. 23: "Any legal or regulatory mechanisms, or networks or partnerships, set up to mobilize the data revolution for sustainable development should have the protection of human rights as a core part of their activities, specify who is responsible for upholding those rights, and should support the protection, respect and fulfilment of human rights."

<sup>5</sup> This draft is a working document which does not purport to provide definitive answers, but rather to help start building and exchanging on common practices among of variety of human rights data stakeholders, whether data producers, users or subjects, in particular in the context of the implementation of the SDG indicator framework.

<sup>6</sup> The International Covenant on Civil and Political Rights explicitly recognizes a right of citizens to participate in public affairs in Article 25. This is supplemented by more general rights to participation in treaties including the International Covenant on Economic, Social and Cultural Rights (arts. 13.1 and 15.1), Convention on the Elimination of All Forms of Discrimination Against Women (art. 7), the Convention on the Rights of the Child (art. 12), the Convention on the Rights of Persons with Disabilities (art 29), as well as in Declarations, including the Universal Declaration of Human Rights (art. 21), the Declaration on the Right to Development (arts. 1.1, 2 and 8.2), the Declaration on the Rights of Indigenous Peoples (art. 5, 18, 19 and 41) and the Millennium Declaration (para 25).

<sup>7</sup> The [Principles and Recommendations for Population and Housing Census: the 2020 Round](#) (Revision 3 - DRAFT) p. 221, also provide some recognition of the importance of participation, for instance for indigenous peoples, and especially as a means to improve data quality: "Involvement of the indigenous community in the data development and data-collection processes provides the arena for capacity-building and helps to ensure the relevance and accuracy of the data collection on indigenous peoples".

<sup>8</sup> In particular internationally accredited National Human Rights Institutions based on the [Paris Principles](#) (A/RES/48/134) and the rules of procedure of the International Coordinating Committee of National Institutions (ICC).

<sup>9</sup> Implementation of data collection processes empowering population groups include for instance the People Living with HIV Stigma Index ([www.stigmaindex.org](http://www.stigmaindex.org)) and the Indigenous Navigator ([www.indigenousnavigator.org](http://www.indigenousnavigator.org)) initiatives.

<sup>10</sup> A strong call in this regard was made in the [Mérida Declaration](#) adopted at the twelfth International Conference of the International Coordinating Committee of National Institutions for the Promotion and Protection of Human Rights (ICC) that took place in Mérida, Yucatán, Mexico from 8 to 10 October 2015.

<sup>11</sup> Gender Statistics Focal Points are already in place in many national statistical offices. See, for instance, the Report of the Secretary-General to ECOSOC, E/CN.3/2013/10 (19 December 2012), para 5-6.

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<sup>12</sup> While this is implicit in earlier treaties, and was elaborated by international human rights treaty bodies in General Comments and consideration of State reports, more recently adopted treaties make specific reference to the need for data collection and disaggregated statistics. See, for example, Article 31 of the Convention on the Rights of Persons with Disabilities.

<sup>13</sup> Application of the three perspectives of *average*, *deprivation* and *inequality* has been recommended and illustrated in [“Human Rights Indicators: A Guide to Measurement and Implementation”](#) (HR/PUB/12/5) available in Arabic, English, French and Spanish, p. 127-128.

<sup>14</sup> Regarding the definition of homelessness and in addition to standard definitions developed by official statistics organizations (e.g., definition of homelessness in the UN Principles and Recommendations for Population and Housing Censuses), definitional elements developed by CSOs are also useful to consider (e.g., European Typology on Homelessness and Housing Exclusion (ETHOS) suggested by FEANTSA includes: rooflessness (without a shelter of any kind, sleeping rough); houselessness (with a place to sleep but temporary in institutions or shelter); living in insecure housing (threatened with severe exclusion due to insecure tenancies, eviction, domestic violence); and living in inadequate housing (in caravans on illegal campsites, in unfit housing, in extreme overcrowding).

<sup>15</sup> Regarding data collection practices, challenges and opportunities for migrant populations, including undocumented migrants, see for instance [“Measuring Hard-to-Count Migrant Populations: Importance, Definitions, and Categories”](#) (working paper prepared by UNECE, Conference of European Statisticians, Geneva, 17-19 October 2012).

<sup>16</sup> Article 24.2 of the International Covenant on Civil and Political Rights, article 7.1 of the Convention on the Rights of the Child.

<sup>17</sup> See, for instance, “Integrated household surveys among Roma populations: one possible approach to sampling used in the UNDP-World Bank-EC regional Roma survey 2011”, Roma Inclusion Working Papers UNDP Europe and the CIS, Bratislava Regional Centre, 2012

<sup>18</sup> The implementation of such individual questionnaires can also help measure intra-household discrimination.

<sup>19</sup> See, for instance, W. Seltzer and M. Anderson, “The dark side of numbers: the role of population data systems in human rights abuses”, *Social Research*, vol. 68, No. 2 (2001).

<sup>20</sup> A personal sense of identity and belonging cannot in principle be restricted or undermined by a State-imposed identity. The Committee on the Elimination of Racial Discrimination has held that identification as a member of a particular ethnic group “shall, if no justification exists to the contrary, be based upon self-identification by the individual concerned” (General Recommendation 8, Membership of racial or ethnic groups based on self-identification, 1990).

<sup>21</sup> The Principles and Recommendations for Population and Housing Censuses, *ibid*, provide consistent guidance on ethnicity (“the subjective nature of the term ... requires that information on ethnicity be acquired through self-declaration of a respondent and also that respondents have the option of indicating multiple ethnic affiliations”, p. 220) but relatively less on related needs and modalities of participation of concerned populations in the data collection process.

<sup>22</sup> For instance, Article 19 of the International Covenant on Civil and Political Rights.

<sup>23</sup> “Official statistics provide an indispensable element in the information system of a democratic society, serving the Government, the economy and the public with data about the economic, demographic, social and environmental situation. Official statistics that meet the test of practical utility are to be compiled and made available on an impartial basis by official statistical agencies to honour citizens’ entitlement to public information”. The Fundamental Principles of Official Statistics were endorsed by the United Nations General Assembly on 29 January 2014 (A/Res/68/261). In the context of discussions on SDG indicators, this right to public information was increasingly referred to, in particular by civil society groups, who underlined a role for official statistics that should go beyond own government’s needs.

<sup>24</sup> See also Principle 7 of the United Nations Fundamental Principles of Official Statistics.

<sup>25</sup> Extremely large data sets associated with new information technology and which can be analysed computationally to reveal possible patterns, trends and correlations.

<sup>26</sup> Human Rights Committee, *Coeriel and Aurik v the Netherlands* (1994), Communication No. 453/1991, para. 10.2.

<sup>27</sup> Principle 6 of the United Nations Fundamental Principles of Official Statistics, *ibid*.

<sup>28</sup> Article 17 of the International Covenant on Civil and Political Rights. The Human Rights Committee has clarified further that: *The gathering and holding of personal information on computers, data banks and other devices, whether by public authorities or private individuals or bodies, must be regulated by law. Effective measures have to be taken by States to ensure that information concerning a person’s private life does not reach the hands of persons who are not authorized by law to receive, process and use it, and is never used for purposes incompatible with the Covenant. In order to have the most effective protection of his private life, every individual should have the right to ascertain in an intelligible form, whether, and if so, what personal data is stored in automatic data files, and for what purposes. Every individual should also be able to ascertain which public authorities or private individuals or bodies control or may control their files. If such files contain incorrect personal data or have been collected or processed contrary to the provisions of the law, every individual should have the right to request rectification or elimination* (Human Rights Committee, General Comment 16, UN doc. ICCPR/C/21/Add. 6, para 10).

<sup>29</sup> See, for instance, guidance on data encryption and anonymity available in a recent report of the Special Rapporteur on the promotion and protection of the right to freedom of opinion and expression ([A/HRC/29/32](#)) and United Nations

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High Commissioner for Refugees (UNHCR), [Policy on the Protection of Personal Data of Persons of Concern to UNHCR](#) (2015).

<sup>30</sup> Accountability from a human rights perspective means that the State, or those in authority, who have obligations under international human rights law (duty-bearers) must be held accountable to the population affected by their decisions and actions and who have corresponding rights under the same standards (rights-holders). For a detailed discussion about accountability, see [Who will be accountable? Human Rights and the Post-2015 Development Agenda](#), Joint publication from OHCHR and the Center for Economic and Social Rights, 2013.

<sup>31</sup> The recommended framework of *structural*, *process* and *outcome* indicators developed through a collective work of human rights experts and statisticians also aims to strengthen human rights accountability by linking traditional socio-economic indicators with States' human rights policy efforts and commitments (see [Human Rights Indicators: A Guide to Measurement and Implementation](#), *ibid*).

<sup>32</sup> See also Principle 4 of the United Nations Fundamental Principles of Official Statistics.

<sup>33</sup> Benchmarks and indicators are not exactly the same and it is useful to distinguish them for purposes of accountability. A benchmark is a predetermined value of an indicator against which progress can be measured (e.g., quantitative targets to be achieved in a given timeframe, value of the same indicator for different population groups).