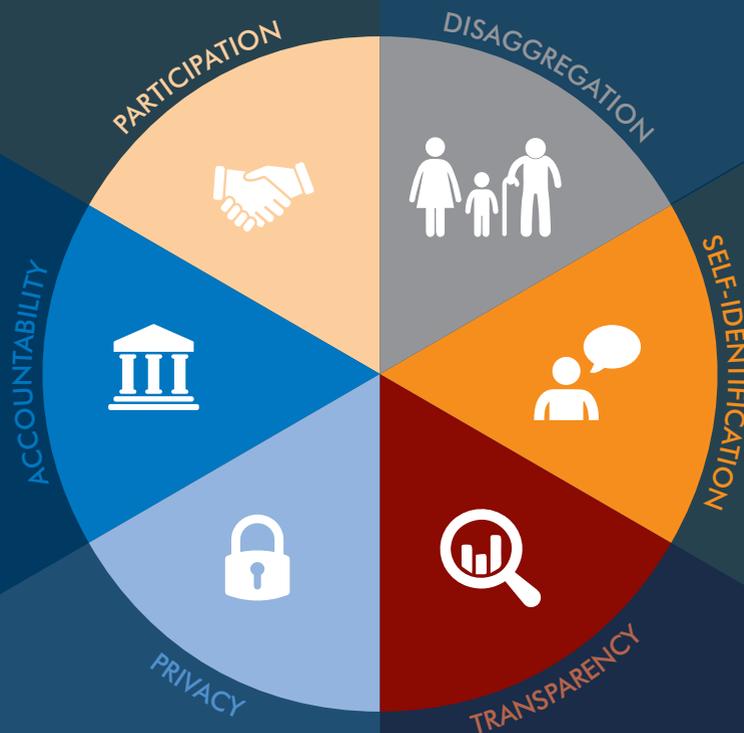


A HUMAN RIGHTS-BASED APPROACH TO DATA

LEAVING NO ONE BEHIND IN THE 2030
AGENDA FOR SUSTAINABLE DEVELOPMENT



GUIDANCE NOTE TO DATA COLLECTION AND DISAGGREGATION

OHCHR thanks the numerous experts and organizations from the human rights, development and statistics communities who took part in the development and validation of the guidance outlined in the present note, including the experts who attended a meeting on a Human Rights-Based Approach to Data (HRBAD) in Geneva. This meeting was made possible with the financial support of the Government of Finland.

OHCHR (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.¹

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.*² They pledged to *leave no one behind* and for more systematic data disaggregation to help achieve and measure the goals.³ As devising disaggregation of indicators (or not) 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 helps 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 draws from internationally agreed principles for statistics⁴ and echoes the call for a *data revolution for sustainable development*⁵, 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.⁶

A preliminary set of principles, recommendations and good practices were formulated under the following headings of an HRBAD:

- ✓ Participation
- ✓ Data disaggregation
- ✓ Self-identification
- ✓ Transparency
- ✓ Privacy
- ✓ Accountability

PARTICIPATION



Participation of relevant population groups in data collection exercises, including planning, data collection, dissemination and analysis of data

KEY PRINCIPLES:

- ✓ Consider a range of processes that facilitate and encourage participation
- ✓ Clearly communicate how participatory processes are conducted and the outcomes of these exchanges
- ✓ Ensure that the views of vulnerable or marginalized groups, and groups who are at risk of discrimination, are represented
- ✓ Maintain knowledge holdings and institutional memory in relation to information gathered through participatory processes

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.⁷

→ **Involvement of groups of interest in all aspects of data collection activities**

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.⁸

In some contexts, it may not be possible or appropriate to engage directly with certain groups. This may be the case where:

- their legal status makes engagement with government agencies difficult or risky
- social stigma and negative stereotypes create negative ramifications for publicly identifying with the group

- the group is so marginalized and/or disadvantaged as to lack of access, ability or resources to engage productively in participatory processes

Where appropriate, CSOs, National Human Rights Institutions⁹ and other relevant stakeholders should participate on behalf of these groups to provide relevant perspectives and information (provided they are competent to represent the group's interests).

→ **Decision-making about participation should be transparent and equitable**

The process and decisions by which participants are selected and groups are engaged with should be clear and transparent. Groups who wish to be involved in participatory processes should be able to access the relevant agencies for this purpose.

Participation is most effective when the groups involved are able to engage with research and data and see opportunities for its application in their own contexts. 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 not only in terms of understanding data collection processes, but in the use of the resulting data (see 'Accountability' below).¹⁰

Where input from members of the public is sought, the outcomes of these consultation processes should be made publicly available. Information provided by members of the public through participatory processes should be retained and appropriately archived to contribute to organizational knowledge holdings. Information gathered through previous consultations and participatory processes should be reviewed to avoid over-burdening vulnerable groups.

Where groups have participated in data collection processes, data collectors should ensure that the resulting data is shared appropriately with these groups. This 'return' of data should be meaningful to the population of interest and delivered in culturally appropriate ways. This demonstrates the impact of their inputs and encourages their ongoing use of data and engagement with the activities of the data collector.

→ **Data collectors should proactively consider participation options and groups to be represented**

To facilitate the participation of population groups at risk of being left behind, it is necessary to identify vulnerable groups, namely the groups most at risk of not enjoying their human rights. This should be done proactively through discussion with National Human Rights Institutions, CSOs and other relevant experts.

The form of participation should be decided on a case-by-case basis. Options may include:

- Online consultations, with appropriate access provisions and publicity to ensure relevant groups are aware of the consultation process
- Public meetings, in locations that are easily accessible for vulnerable groups and with appropriate publicity and engagement to encourage participation
- Community visits, which may incorporate public meetings, meetings with key stakeholders and representatives and discussion with community members about issues relevant to data collection
- Public submissions processes (for instance, for topic development), with clear and transparent information about use of information submitted and decision-making processes
- Ongoing engagement and relationship-building with communities to encourage participation, establish dialogues and incorporate perspectives in data collection processes
- Including relevant CSOs in thematic or advisory boards or committees convened by the data collector
- Creating advisory groups to facilitate regular engagement with vulnerable groups and frequent input on data collection processes
- Establishing focal points within data collection organizations who are responsible for seeking information and perspectives from groups of interest
- Formal memoranda of understanding among organizations or departments, including between national statistical offices and human rights institutions, to facilitate information sharing and collaborative work.¹¹

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 within National Statistical Systems more broadly),¹² 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



Disaggregation of data allows data users to compare population groups, and to understand the situations of specific groups. Disaggregation requires that data on relevant characteristics are collected

KEY PRINCIPLES:

- ✓ More detailed data than national averages is key in identifying and understanding inequalities
- ✓ Data should be disaggregated by key characteristics identified in international human rights law
- ✓ Collection of data to allow disaggregation may require alternate sampling and data collection approaches
- ✓ Birth registration is foundational for robust data sets that allow accurate disaggregation

Data collection and disaggregation that allow for comparison of population groups are central to an HRBAD and forms part of States' human rights obligations. Disaggregated data can inform on the extent of possible inequality and discrimination.¹³

→ **Disaggregation allows more detailed data analysis to identify inequalities**

An HRBAD requires a move from traditional data collection and analysis, which concentrate on national averages and risk masking underlying disparities. An HRBAD incorporates data on the most disadvantaged or marginalized in national/large-scale data collections. As a result, it provides data that identify and measure inequalities among population groups.¹⁴

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.

Where possible, data should be published in a format that permits identification and analysis of multiple and intersecting disparities and discrimination. Individuals may experience discrimination and inequality along multiple axes (for example, gender and disability). Analyzing data at the subgroup level allows for understanding of multiple and intersecting inequalities.

Qualitative indicators and contextual information, including the legal, institutional or cultural status of affected populations, are also essential to enhance understanding and contextualization of data collected within a HRBAD.

→ **Disaggregation requires more intensive data collection**

Disaggregation of data relies on the collection of data about personal characteristics (e.g. religion, gender) and other relevant information (e.g. location). To allow data to be disaggregated by variables of interest, relevant information must be sought from all individuals within a dataset (either a survey sample or through administrative data capture). Where information is collected or recorded inconsistently, it will not be possible to disaggregate the full data set;

this can introduce bias and other data quality issues. Where information relevant for disaggregation is collected directly from individuals, the principle of self-identification (see below) should be considered.

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 in the interests of 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 persons¹⁵ or persons in institutions) or administrative records (e.g., undocumented migrants).¹⁶ In some contexts, CSOs and service providers may be in a better position than National Statistical Offices to reach these populations and collect data. Similarly, CSOs may be

able to advise National Statistical Offices on engagement, participation and data collection approaches with hard to reach populations.

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.

Collection of detailed data to allow disaggregation is dependent on effective data collection and data management systems. Disaggregation requires not only that data collection approaches include relevant characteristics, but that data recording systems can incorporate new data items as needs arise. Further, data processing software must allow for appropriate data storage and varied cross-tabulation and data analysis. It is important that data collectors have the resourcing to acquire and maintain data collection instruments and data management systems that accommodate detailed datasets.

→ **Disaggregation rests on the foundations of vital administrative systems and population census and may require new methodologies**

A foundational step in the generation of disaggregated data is birth registration, which is a key component in the right of everyone to recognition everywhere as a person before the law.¹⁷ A thorough and accurate system of vital statistics (births, deaths, marriages and divorces) is critical in ensuring robust and up to date population estimates at national and sub-national levels and maintaining accurate and effective survey sampling frames.

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. Where standard sample design fails to yield sufficient representation of specific populations of interest, alternate sampling and data collection approaches should be considered. Appropriate methodologies may include those outlined below.

For random sampling:

- oversampling – increasing the number of units within an established sample design to increase the likelihood of populations of interest being included
- targeted sampling – designing samples using existing information about the geographic distribution of the population of interest. Targeted sampling may be informed by census data, administrative records, information about patterns observed by organizations engaged with the population of interest or other sources
- comparative surveys of target population groups with other population groups living in the same areas¹⁸

For non-random sampling, where populations of interest cannot be reliably identified within existing sample frames:

- random route sampling – applying a relatively random selection procedure within geographic areas known (or thought) to have a high proportion of residents who are part of the population of interest
- respondent-driven sampling,¹⁹ which draws on community-level knowledge and networks to develop survey samples
- individual (as opposed to household-level) questionnaire modules (intra-household disaggregation).²⁰

These and other methodological approaches should be considered on a case-by-case basis, following a participatory approach as outlined above.

SELF-IDENTIFICATION



For the purposes of data collection, populations of interest should be self-defining. Individuals should have the option to disclose, or withhold, information about their personal characteristics

KEY PRINCIPLES:

- ✓ Data about personal characteristics should be provided by the individuals to whom the data refers (at the individual's discretion)
- ✓ Data collection activities should be conducted in accordance with the human rights principle of 'doing no harm'

The respect and protection of personal identity is central to human dignity and human rights. Categorization of populations in statistics, and the detailed data collection that makes disaggregation possible, are important in identifying and addressing inequality and social issues. These processes are not norm- or value-neutral, however, and data collectors should remain cognisant of the norms and values that inform their decision-making in relation to personal identity characteristics.

➔ **Data collection activities should not have a negative impact**

The overriding human rights principle *do no harm* should always be respected. Historically, there have been cases of misuse of data collected by National Statistical Offices (and others), with extremely detrimental human rights impacts.²¹ Other principles outlined in this guidance note address the measures that data collectors must take to ensure that data on personal characteristics, when collected for reasonable statistical purposes, is kept safe and used only for the benefit of the groups it describes and society as a whole.

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. Data collectors should only include characteristics that relate to personal identity in data collection exercises where it is necessary and appropriate to do so. Questions about personal identity characteristics should be voluntary and a non-response option should be provided; this is especially important where personal characteristics may be sensitive.

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 that seeks to discriminate against population groups and expose them to risks of serious human rights violations (or which has this effect).²²

Where a survey includes questions on personal identity, all persons conducting in-person interviews should receive appropriate training (this may include gender and/or cultural awareness training). This

training should include possible issues of historical legacy as it relates to both majority and minority populations.

→ **Populations of interest should be self-defining**

In order to allow disaggregation of data, groups and/or categories must be defined prior to data collection. Many populations of interest for data collection are, by necessity, self-defining. That is, the parameters of the population cannot be imposed by an external party. Rather they are set by the members of the population and communicated via their (individual) decisions to disclose, or not disclose, their personal identity characteristics (e.g. their indigenous status, religion or sexual orientation). Any categories of identity should be developed through a participatory approach, to ensure respondents with these characteristics are optimally able to engage with the data collection. In some contexts, applying the principle of self-identification may involve including categories of identity beyond those currently listed in international treaties or recognised by national law.

All questions on personal identity, whether in surveys or administrative data, should allow for free response as well as multiple identities.²³ Personal identity characteristics



(particularly those that may sensitive, such as religion, sexual orientation, gender identity or ethnicity) should be assigned through self-identification, and not through imputation or proxy.

In some cases, it may be necessary for logistical, political or other reasons to use demographic characteristics to identify a particular population. For example, if a particular ethnic minority is not recognised by the State but is understood to reside exclusively in one location. In this case, data about an individual's place of residence may be thought to denote, ipso facto, their ethnicity. Where data is used in this way to identify particular groups, data collectors should ensure that their handling and publishing of that data does not imply self-identification where disclosure of personal information relating to ethnic identity has not occurred. Data should be accurately described to make clear that the parameters established for a particular group have been set according to place of residence, in this example, and not the self-identification of group members.

TRANSPARENCY



Data collectors should provide clear, openly accessible information about their operations, including research design and data collection methodology. Data collected by State agencies should be openly accessible to the public



KEY PRINCIPLES:

- ✓ Official Statistics are part of the public's right to information
- ✓ Information about how data is collected should be publicly available
- ✓ Data should be disseminated as quickly as possible after collection

→ Transparency of public information

The principle of transparency is closely linked with those of participation (see first section) and accountability in 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.²⁴

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.²⁵

CSOs' 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. Such 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.²⁶

→ **Data dissemination and accessibility**

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.²⁷

→ **Civil Society Organizations as data users and data collectors**

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



Data disclosed to data collectors should be protected and kept private, and confidentiality of individuals' responses and personal information should be maintained



KEY PRINCIPLES:

- ✓ Privacy and confidentiality must be considered alongside access to information
- ✓ Information that identifies individuals or discloses an individual's personal characteristics should not be made public as a result of data dissemination
- ✓ Data collectors must have robust data protection mechanisms and procedures
- ✓ When personal data is released, this should only be done with the permission of the individual concerned (or their appropriate representatives)

Data collected to produce statistical information must be strictly confidential, used exclusively for statistical purposes and regulated by law.²⁸ 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.*²⁹

→ Privacy and confidentiality

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.*³⁰

Data should not be published or publicly accessible in a manner that permits identification of individual data subjects, either directly or indirectly.

Access to information must be balanced with the rights to privacy and data protection. With the increasing use of big data³¹ 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*.³²

Data that relates to personal characteristics, and in particular sensitive personal characteristics (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. In some cases, such as human rights monitoring, it is necessary and useful to publish data that identifies individuals. This may occur when an individual has been the victim of a crime/human rights violation and the publication of information about the incident is necessary to hold the perpetrators to account. This should only be done where strictly necessary, and only where permission has been given by the individual concerned. In the case of persons who are deceased or who have been kidnapped, detained or disappeared, permission could come from their family or close associates. Data collectors should consider the impacts on the individual and on those associated with them in every case before publishing data of this nature.

→ **Data protection**

Data should be secured against both natural and human dangers, and

disposed of appropriately when no longer required.³³ 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.

Data collectors (and data custodians) must have data collection and data management systems that are equipped to protect the privacy of individuals at every stage in the statistical process. Data agencies should have appropriate resourcing to adapt to emerging data security threats.

If data is shared between data collection agencies, or where data is collected in partnership, agencies concerned may have varying requirements and practices around privacy and data protection. In these cases, the practices of the agency with the strictest privacy and data protection requirements should be upheld by all agencies handling the data.

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.

ACCOUNTABILITY



Data collectors are accountable for upholding human rights in their operations, and data should be used to hold States and other actors to account on human rights issues

Key Principles:

- ✓ Data can, and should, be used to hold human rights actors to account
- ✓ National Statistical Offices are human rights duty-bearers and are accountable for respecting, protecting and fulfilling human rights

Accountability from a human rights perspective means that the State, or those in authority, must be held accountable to the population affected by their decisions and actions. This relates to the obligations of the State, or those in authority, under international human rights law (duty-bearers) and the corresponding rights of the population (rights-holders) under the same standards.³⁴ 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*.

→ National Statistical Offices are accountable for human rights

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 for their policy actions (or inactions). This can be done through measuring their impact on the protection and realization of human rights.

Data collectors are also accountable for the impact of their data collection activities and the publication of data. One aspect that data collectors should consider is the impacts of publishing and disseminating data, particularly data collected for purposes other than official statistics. The publication of data can pose a risk to those to whom the data refers, as well as to those who collected the data. When an organization publishes data that is already publicly available, they should be aware of the impacts of increasing the visibility or accessibility of that information. If an organization with significantly greater status/more users reproduces information that has been stored publicly in a less accessible location or format, this changes the publication risk. Data collectors/producers must consider the impact on individuals (and their families and associates) or groups of making sensitive information accessible to a wider audience. When organizations reproduce data collected elsewhere, they should consider whether this introduces the original data collector to increased attention or reputational risk.

→ **Data can be used to hold human rights actors to account**

Appropriately anonymized microdata should be made available to academics, CSOs and other stakeholders to facilitate the development of accountability systems. The publication of relevant and disaggregated indicators can aid accountability by supporting CSOs in formulating human rights claims, for example, by adding evidence to submissions to the United Nations Human Rights Monitoring Mechanisms.³⁵ Data can also add weight to submissions to complaint mechanisms, both to demonstrate issues and provide context to events and observations.

Putting collected data back in the hands of disadvantaged population groups and strengthening their capacity to use them is essential for accountability. When data is used by the groups affected by policymakers to advocate for change, it adds weight to their arguments and assists decision-makers in understanding the issues and devising solutions. As an example, Donnelly, McMillan and Browne³⁶ describe the use of data by public housing residents in advocating for improvements to their dwellings. By measuring and demonstrating the problems (which included dampness



and drainage issues) and engaging with public housing officials, the residents secured a number of practical responses and improvements to the safety and quality of their housing.

To make the use of data for accountability more concrete, OHCHR has recommended a framework of *structural*, *process* and *outcome* indicators that assess commitment to, and progress toward, human rights standards.³⁷ This framework was developed through collaborative work between human rights experts and statisticians. By linking traditional socio-economic indicators with States' human rights policy efforts and commitments, the framework provides a language and a structure in which to use data to pursue accountability of human rights actors. The use of this framework has been promoted by international, regional and national human rights mechanisms.

The quality and reliability of data must be ensured. Data collectors should be free to challenge any incorrect analysis made by users. This is consistent with Principle 4 of the United Nations Fundamental Principles of Official Statistics.

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,³⁸ 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.

ENDNOTES

- 1 “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.
- 2 See, for instance, para. 18 in A/RES/70/1.
- 3 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*.
- 4 See [Fundamental Principles of Official Statistics](#), A/RES/68/261 (2014).
- 5 In *A World that Counts: Mobilising the data revolution for sustainable development*, 2014 (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.”
- 6 *Ibid.*
- 7 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).
- 8 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”.
- 9 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).
- 10 Implementation of data collection processes empowering population groups include, for instance, the People Living with HIV Stigma Index (www.stigmaindex.org) and the Indigenous Navigator (www.indigenousnavigator.org) initiatives.
- 11 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.

- 12 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.
- 13 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.
- 14 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.
- 15 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).
- 16 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).
- 17 Human Rights Council, 2014, Report of the Office of the United Nations High Commissioner for Human Rights, ‘Birth registration and the right of everyone to recognition everywhere as a person before the law’, A/HRC/27/22.
- 18 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
- 19 For a review of methodologies, see Heckathorn, D. (2011) ‘Snowball Versus Respondent-Driven Sampling’, *Sociological Methodology*, 41 (1) pg 355-366.
- 20 The implementation of such individual questionnaires can also help measure intra-household discrimination.
- 21 Luebke, D. & Milton, S. 1994. ‘Locating the Victim: An Overview of Census-Taking, Tabulation Technology, and Persecution in Nazi Germany’. *IEEE Annals of the History of Computing*, Vol. 16 (3).
- 22 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).
- 23 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).
- 24 For instance, Article 19 of the International Covenant on Civil and Political Rights.
- 25 “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.
- 26 See also Principle 7 of the United Nations Fundamental Principles of Official Statistics.
- 27 See article 31 of the Convention on the Rights of Persons with Disabilities.
- 28 Principle 6 of the United Nations Fundamental Principles of Official Statistics, *ibid*.
- 29 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).
- 30 Human Rights Committee, *Coeriel and Aurik v the Netherlands* (1994), Communication No. 453/1991, para. 10.2.
- 31 Extremely large data sets associated with new information technology and which can be analysed computationally to reveal possible patterns, trends and correlations.
- 32 See [‘A World That Counts: Mobilising the Data Revolution for Sustainable Development’](#), (2014) report of the Independent Expert Advisory Group on a Data Revolution for Sustainable Development.
- 33 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 High Commissioner for Refugees (UNHCR), [Policy on the Protection of Personal Data of Persons of Concern to UNHCR](#) (2015).
- 34 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.
- 35 See Box 3, page 26 - "[Human Rights Indicators: A Guide to Measurement and Implementation](#)" (HR/PUB/12/5).
- 36 See Donnelly, D., McMillan, F. and Browne, N. (2009), 'Active, free and meaningful: resident participation and realising the right to adequate housing in north Belfast', cited in "[Human Rights Indicators: A Guide to Measurement and Implementation](#)" (HR/PUB/12/5).
- 37 [Human Rights Indicators: A Guide to Measurement and Implementation](#), *ibid.*
- 38 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).



“ We can only monitor progress if we have data that is disaggregated by sex, age, race, ethnicity, income, migration status, disability and other characteristics relating to the grounds of discrimination prohibited by human rights law. Only if we track progress for different population groups, in all countries, can we ensure that no one is indeed being left behind.”

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