



## World Health Organization Data Principles

10 August 2020

### Introduction

The data principles of the World Health Organization (WHO) provide a foundation for continually reaffirming trust in WHO's information and evidence on public health. The five principles are designed to provide a framework for data governance for WHO. The principles are intended primarily for use by WHO staff across all parts of the Organization in order to help define the values and standards that govern how data that flows into, across and out of WHO is collected, processed, shared and used. These principles are made publicly available so that they may be used and referred to by Member States and non-state actors collaborating with WHO.

WHO's data principles are based on an internal consultation process involving data collection staff from WHO headquarters and regional offices who compiled and analyzed the data principles and best practices. The principles were reviewed in consultation with external experts, convened by WHO, in May-June 2020<sup>1</sup>.

### Background

Across the United Nations system there is increased recognition of the need to strengthen and improve data systems, including how they are governed and how data are managed within them. This recognition is reflected in the *Data Strategy of the Secretary-General for action by everyone, everywhere: with insight, impact and integrity*<sup>2</sup>, which was produced to help maximize the public value of the United Nations' extensive data assets.

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<sup>1</sup> Terms of reference of the External Expert Group on Data Sharing and biographies of its members are available on request.

<sup>2</sup> Data Strategy of the Secretary General for action by everyone, everywhere: with insight, impact and integrity. New York (NY): United Nations; 2020 ([https://www.un.org/en/content/datastrategy/images/pdf/UN\\_SG\\_Data-Strategy-one-pager.pdf](https://www.un.org/en/content/datastrategy/images/pdf/UN_SG_Data-Strategy-one-pager.pdf) summary accessed 25 July 2020, to be finalized in 2020).

In establishing the data principles, WHO notes:

- WHO's function as the directing and coordinating authority on international health within the United Nations system;
- United Nations General Assembly Resolution 70/1 of 2015, *Transforming our world: the 2030 Agenda for Sustainable Development*<sup>3</sup>, particularly the call for leaving no one behind to achieve universal health coverage<sup>4</sup>;
- the indivisible and integrated nature of the Sustainable Development Goals (SDGs)<sup>5</sup>, the targets set out under Goal 3: Ensure healthy lives and promote well-being for all at all ages<sup>6</sup>, and the centrality of health to many SDG targets;
- the *Report of the Inter-agency and Expert Group on Sustainable Development Goal Indicators*<sup>7</sup> of March 2017, and WHO's duties to curate and report health-related SDGs data and also as the relevant custodian agency for Goal 3 targets;
- the value of the Fundamental Principles of Official Statistics<sup>8</sup> in guiding WHO's statistical production activities and the processes that define this role, including the mandates of the United Nations Statistical Commission<sup>9</sup> and the Statistics Division within the United Nations Department for Economic and Social Affairs<sup>10</sup>.

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<sup>3</sup> Transforming our world: the 2030 Agenda for Sustainable Development. United Nations General Assembly Resolution A/RES/70/1, 21 October 2015. New York (NY): United Nations ([https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A\\_RES\\_70\\_1\\_E.pdf](https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_70_1_E.pdf), accessed 25 July 2020).

<sup>4</sup> Para. 26

<sup>5</sup> Sustainable Development Goals – Knowledge Platform. New York (NY): United Nations (<https://sustainabledevelopment.un.org/?menu=1300>, accessed 25 July 2020).

<sup>6</sup> Sustainable Development Goal 3. Ensure healthy lives and promote well-being for all at all ages. New York (NY): United Nations (<https://sustainabledevelopment.un.org/sdg3>, accessed 25 July 2020).

<sup>7</sup> Report of the Inter-agency and Expert Group on Sustainable Development Goal Indicators. Note by the Secretary-General. New York (NY): United Nations Economic and Social Council Document E/CN.3/2017/2, 15 December 2016. New York (NY): United Nations (<https://undocs.org/en/E/CN.3/2017/2>, accessed 25 July 2020).

<sup>8</sup> Fundamental Principles of Official Statistics. Resolution A/RES/68/261 adopted by the United Nations General Assembly on 29 January 2014. New York (NY): United Nations (<https://unstats.un.org/unsd/dnss/gp/fundprinciples.aspx>, accessed 25 July 2020).

<sup>9</sup> United Nations Statistical Commission – Overview. New York (NY): United Nations (<https://unstats.un.org/unsd/statcom/>, accessed 25 July 2020).

<sup>10</sup> Welcome to UNSD. Home page of the United Nations Statistical Commission. New York (NY): United Nations (<https://unstats.un.org/home/>, accessed 25 July 2020).

WHO contributed to the development of international standards on public health statistics within the Committee for the Coordination of Statistical Activities<sup>11</sup>, and participates in multi-stakeholder and inclusive processes such as the Road to Bern<sup>12</sup> series of events leading up to the United Nations World Data Forum.

### WHO's mandate

WHO is a specialized agency of the United Nations<sup>13</sup>, established through the adoption of its Constitution by Member States, and is responsible for international public health. WHO's work is grounded in values of integrity, professionalism and respect for diversity<sup>14</sup>, reflecting the principles of human rights, universality and equity, as established in WHO's Constitution<sup>15</sup>.

As a United Nations specialized agency, WHO has an obligation under international law to protect personal and non-personal sensitive data. As such, WHO recalls:

- Article 12 of the Universal Declaration of Human Rights and Article 17 of the International Covenant on Civil and Political Rights, that recognize the right to individual privacy, including the right to privacy over personal information; and
- the General Assembly's *Guidelines for the Regulation of Computerized Personal Data Files*<sup>16</sup> adopted via Resolution 45/95 in December 1989, as well as the *Principles on Personal Data Protection and Privacy*<sup>17</sup> adopted by the United Nations High Level Committee on Management (HLCM) in October 2018, which set out a basic framework

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<sup>11</sup> Committee for the Coordination of Statistical Activities. New York (NY): United Nations (<https://unstats.un.org/unsd/ccsa/>, accessed 25 July 2020).

<sup>12</sup> Road to Bern. United Nations World Data Forum 2021 (UNWDF). United Nations and Swiss Federal Statistical Office (<https://roadtobern.swiss>, accessed 25 July 2020).

<sup>13</sup> Charter of the United Nations (<https://www.un.org/en/charter-united-nations/>, accessed 25 July 2020)

<sup>14</sup> Our values, our DNA. Geneva: World Health Organization (<https://www.who.int/about/who-we-are/our-values>, accessed 25 July 2020)

<sup>15</sup> Constitution of the World Health Organization. Geneva: World Health Organization ([https://www.who.int/governance/eb/who\\_constitution\\_en.pdf](https://www.who.int/governance/eb/who_constitution_en.pdf), accessed 25 July 2020)

<sup>16</sup> Guidelines for the Regulation of Computerized Personal Data Files. Adopted by the United Nations General Assembly in Resolution 45/95 of 14 December 1990. New York (NY): United Nations (<https://www.refworld.org/docid/3ddcfaac.html>, accessed 25 July 2020)

<sup>17</sup> Principles on Personal Data Protection and Privacy. New York (NY): United Nations (<https://www.unsceb.org/privacy-principles>, accessed 25 July 2020)

for the processing of personal data by, or on behalf of, the United Nations System organizations in carrying out their mandated activities.

Article 2 of WHO's Constitution sets out responsibilities and duties that require robust data governance processes. Functions that depend on data-sharing include:

- to act as the directing and coordinating authority on international health work;
- to establish and maintain such administrative and technical services as may be required, including epidemiological and statistical services;
- to promote and conduct research in the field of health;
- to provide information, counsel and assistance in the field of health; and,
- to assist in developing an informed public opinion among all peoples on matters of health.

The collection, analysis, publication and dissemination of health-related data is a core part of WHO's mandate. WHO's data principles build on these functions and establish the foundation from which WHO will strive to enhance and strengthen its ability to meet its obligations regarding public health-related data. WHO's data principles are relevant to monitoring WHO's Thirteenth General Programme of Work (GPW 13)<sup>18</sup> and consider the views of Member States on data sharing as expressed during the 146<sup>th</sup> session of the WHO Executive Board<sup>19</sup>.

WHO's functions in times of public health emergencies are further elaborated in the International Health Regulations (2005) adopted by all Member States<sup>20</sup>.

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<sup>18</sup> Thirteenth General Programme of Work 2019–2023. Geneva: World Health Organization; 2020 (<https://www.who.int/about/what-we-do/thirteenth-general-programme-of-work-2019---2023>, accessed 25 July 2020)

<sup>19</sup> Data and innovation: draft global strategy on digital health. Report by the Director-General to the 146<sup>th</sup> session of the WHO Executive Board, 4-8 February 2020. Document EB146/26, item 20. ([https://apps.who.int/gb/ebwha/pdf\\_files/EB146/B146\\_26-en.pdf](https://apps.who.int/gb/ebwha/pdf_files/EB146/B146_26-en.pdf), accessed 25 July 2020).

<sup>20</sup> International Health Regulations (2005), third edition. Geneva: World Health Organization; 2016 (<https://www.who.int/ihr/publications/9789241580496/en/>, accessed 25 July 2020)

## Implementation

WHO is committed to strengthening the global ecosystem of public health data. This includes building internal data governance capacities. The WHO data principles act as the foundations for data-related policies, plans and programme implementation.

In 2018, WHO established the Data, Analytics and Delivery for Impact (DDI) Division, promoting data as a strategic asset. In 2020, WHO strengthened its data coordination and governance by instituting a two-level internal data governance system with: a strategic Data Governance Committee, chaired by the Assistant Director-General for DDI and the Deputy Director-General, and an operationally grounded, federated structure known as the Data Hub and Spoke Collaborative, chaired by the Director of Data and Analytics (DNA), DDI. This two-level governance system aims to promote ownership of data governance issues as an area of strategic importance, as well as to increase accountability and efficiency and to streamline the end-to-end processes and systems for collecting, storing, analyzing, disseminating and using data. Beyond internal stakeholders, WHO will also seek advice as necessary from external expert groups such as the Reference Group on Health Statistics<sup>21</sup> and the External Expert Group on Data Sharing<sup>22</sup>.

WHO's data principles will support implementation of WHO data-related policies, such as:

- the WHO policy on open access<sup>23</sup>;
- the WHO policy on the use and sharing of data collected by WHO in Member States outside the context of public health emergencies (2017)<sup>24</sup>;
- the policy statement on data-sharing by WHO in the context of public health emergencies (2016)<sup>25</sup>;
- the WHO policy on personal data protection (draft, to be adopted in 2020).

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<sup>21</sup> Reference Group on Health Statistics (RGHS). Geneva: World Health Organization (<https://www.who.int/healthinfo/RGHS/en/>, accessed 25 July 2020).

<sup>22</sup> Terms of reference of the External Expert Group on Data Sharing and biographies of its members are available on request.

<sup>23</sup> <http://origin.who.int/publishing/openaccess/en/>

<sup>24</sup> WHO policy on the use and sharing of data collected by WHO in Member States outside the context of public health emergencies. Geneva: World Health Organization (<https://www.who.int/about/who-we-are/publishing-policies/data-policy>, accessed 25 July 2020).

<sup>25</sup> Policy statement on data sharing by WHO in the context of public health emergencies. Wkly Epidemiol Rec. 2016;18:237-40 ([https://apps.who.int/iris/bitstream/handle/10665/254440/WER9118\\_237-240.pdf](https://apps.who.int/iris/bitstream/handle/10665/254440/WER9118_237-240.pdf), accessed 25 July 2020).

DDI will facilitate consultation with, and feedback from, WHO technical departments and WHO regional and country offices as data-related policies and data principles are operationalized. This will strengthen confidence and ensure coherence. Requests for clarification or issues raised by Member States may be referred to the Data Governance Committee on a case-by-case basis, as appropriate, for its consideration and advice which shall be communicated to the relevant Member State.

## Data Principles

### 1. WHO shall treat data as a public good

WHO shall make every effort to release data publicly and to share when safe and ethical to do so. Unless there is a legitimate justification to the contrary,<sup>26</sup> WHO shall make data open<sup>27</sup> and accessible to the public in line with data being a public good.

This principle also applies to data such as vital registration, survey data and the results of estimation and research, and situations in which data have been shared with WHO by non-Member State entities (including private-sector data producers) that collaborate with WHO on common projects.

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<sup>26</sup> Exemptions to data disclosure should be considered in light of WHO's mandate, existing data-sharing policies, the information disclosure policy, and (with regard to individuals' rights to privacy and data protection) the *United Nations Principles on Personal Data Protection and Privacy* and WHO's personal data protection policy (once adopted), and broader potential risks (whether political, reputational, or related to safety and security or otherwise). Common legitimate exemptions to open data publication include:

- a specific request from a Member State not to share the data;
- data shared between WHO and third parties, including Member States and implementing partners, where there is an expectation of confidentiality;
- data that, if disclosed, may endanger the safety or security of any individual or have an impact on the exercise of their human rights;
- data that, if disclosed, may endanger the security of a Member State or prejudice the security or conduct of any operation or activity undertaken by WHO;
- data shared, either internally or externally, with the intended use that it be used solely for organizational operations (e.g. draft documents, emails, etc.);
- financial data if disclosure would harm either the financial interests of WHO or a partner;
- data that, if disclosed, would undermine a policy dialogue with a Member State or an implementing partner; and
- other types of data which, because of their content or the circumstances of their creation, must be deemed confidential.

<sup>27</sup> See "What is open Data?" at: <https://opendatahandbook.org/guide/en/what-is-open-data/> (accessed 25 July 2020).

WHO will:

- *Provide clear guidance:* In situations where legitimate reasons prevent the sharing of data, WHO will provide clear guidance on other possible ways in which the data may be accessed, such as for research purposes. The guidance will be consistent with WHO's applicable rules and policies, including data-sharing policies (and their applicable licensing terms and conditions), information disclosure policy and personal data protection policy (currently in draft). Informed consent is almost always needed for research. For routine data collection for purposes of public health surveillance, informed consent is not the default and is not always required.<sup>28</sup> For personal data, the consent of the data subject should be the preferred basis for processing the data.
- *Ensure transparency:* Treating data as a public good requires WHO to be transparent about how data are collected, used and shared. Adherence to this principle therefore requires that complete metadata about data sets should be released along with the data sets themselves and together with any explanatory notes that may be required to provide context on data provenance, scope and limitations, application and (re-)use, traceability and sharing. This is guided by three WHO policies: the disclosure policy<sup>29</sup>, the policy on the use and sharing of data collected by WHO in Member States outside the context of public health emergencies<sup>30</sup> and the policy on open access<sup>31</sup>.

## 2. WHO shall uphold Member States' trust in data

WHO shall uphold the trust placed in it by Member States when the Organization processes data that Member States have shared with it and placed under WHO's control.

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<sup>28</sup> See page 40 of WHO guidelines on ethical issues in public health surveillance. Geneva: World Health Organization; 2017 (<https://apps.who.int/iris/bitstream/handle/10665/255721/9789241512657-eng.pdf;jsessionid=8A35157EF2806FF141C148928F8530AF?sequence=1>, accessed 25 July 2020).

<sup>29</sup> [https://www.who.int/docs/default-source/documents/about-us/infodisclosurepolicy.pdf?sfvrsn=c1520275\\_10](https://www.who.int/docs/default-source/documents/about-us/infodisclosurepolicy.pdf?sfvrsn=c1520275_10)

<sup>30</sup> WHO policy on the use and sharing of data collected by WHO in Member States outside the context of public health emergencies. Geneva: World Health Organization (<https://www.who.int/about/who-we-are/publishing-policies/data-policy>, accessed 25 July 2020).

<sup>31</sup> <http://origin.who.int/publishing/openaccess/en/>

*WHO will:*

- *Provide impartial and inclusive consultation:* Upholding Member States' trust in data requires an impartial and inclusive process for consulting with Member States prior to the use of their data by WHO. Consultations with Member States will be transparent, predictable, proportionate, inclusive and coordinated processes with streamlined communication that allows Member States and WHO to easily prepare for, respond to and participate in discussions.
- *Secure storage and processing:* Ensure that data shared with WHO by Member States are securely and confidentially stored and processed – applying principle 4.
- *Apply human rights and the right to privacy:* Uphold the highest standards of data protection and respect for human rights, including the right to privacy, with regard to any personal data and data aggregates of groups of individuals included in WHO-controlled data sets. This is especially important for data sets requiring careful handling and particular attention, such as sensitive medical data, and data on vulnerable and marginalized individuals and groups, including children. Require Member States and non-State actors who share data with WHO to confirm that the data have been collected in accordance with applicable national laws, including data protection laws aimed at protecting the confidentiality of identifiable persons.

### **3. WHO shall support Member States' data and health information systems capacity**

WHO shall support Member States' capacity-building activities, aiming for sustainability and sharing of best practices wherever it can – specifically for the development of sound data governance, health management information systems, public health statistics, health-related data science and health data innovation.

*WHO will:*

- *Respond to Member States' requests for support:* This may include both technological and human capacity for health information systems, technical assistance with data collection processes supporting data analysis, and efforts to improve data quality and accurately monitor health trends, to generate reliable information, and to inform decision-making. This includes WHO's role in supporting the convening and coordination of partner support for data and health information systems.



- *Advance evidence-based decision-making by focusing on sustainable health information management systems (HMIS) and digital development systems:* Strengthen capacity to collect, analyze, disseminate and use national and subnational disaggregated data to develop and monitor country policies and plans.
- *Align with nationally owned monitoring and evaluation processes, structures and budgets:* Reduce Member States' reporting burdens and increase sustainable locally-owned solutions, with clear criteria for each Member State using data.

#### **4. WHO shall be a responsible data manager and steward**

WHO will ensure that all data made available to it are processed, maintained, analyzed, disseminated and used in accordance with international standards and best practices in health data management. This includes all relevant United Nations data governance standards and guidance that apply to WHO pursuant to its mandate, including the standards referenced in the preamble.

WHO shall ensure that all data it produces are of consistently high standards that include transparent audit trails and common reference years, as well as being timely, accurate, comparable and (where technically and legally possible) accessible.

*WHO will:*

- *Apply international scientific data standards:* As a responsible data manager and steward, WHO shall abide by applicable international scientific data processing standards such as, among others, the *FAIR Guiding Principles for scientific data management and stewardship*<sup>32</sup> and the *Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER)*<sup>33</sup> for estimations.
- *Maintain and strengthen partnerships with relevant stakeholders:* WHO recognizes that standards will evolve and the Organization will therefore monitor its internal data

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<sup>32</sup> FAIR Principles. Leiden, Hamburg and Paris: GO FAIR (<https://www.go-fair.org/fair-principles/>, accessed 25 July 2020).

<sup>33</sup> Guidelines for Accurate and Transparent Health Estimates Reporting (GATHER) (<http://gather-statement.org>, accessed 25 July 2020).

governance functions and work with relevant stakeholders to bridge the digital divide in health data governance<sup>34</sup>.

- *Strengthen the quality of SDG monitoring efforts:* As custodian agency for health-related SDG targets, WHO shall support Member States' efforts to report SDG-related data;
- *Adapt to specific contexts:* Where necessary, WHO will consider adapting approaches and methods to report rare events or data originating from low-population Member States.

## 5. WHO shall strive to fill public health data gaps

WHO will support Member States to fill data gaps in public health data, using empirical data collection and predictive, transparent and coherent modelling methods with proven validity.

*WHO will:*

- *Use transparent models and methods:* Member States use a range of health indicators to monitor population health and guide resource allocations. However, challenges arise from the lack of data, inconsistent methods and often underdeveloped data governance and standards at all economic levels. WHO will therefore support Member States to generate coherent estimates (that may be based on disparate or incomplete sources of data) that are all open to scrutiny, transparent, available to the public and have proven validity.

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<sup>34</sup> Bridging a different digital divide: digital and data governance for health (draft document). Geneva and Seattle (WA): World Health Organization and PATH (<https://path.ent.box.com/s/1mqunwxc4evg37okfbaazcaha9vigwqm>, accessed 25 July 2020).