



To provide a review of principles and good practices for governing health data, in preparation for a WHO Hosted Global Health Data Governance Summit

1. Background

WHO is planning a multi-partner Health Data Governance Summit in the last week of June (day to be confirmed), which may be co-hosted by another partner. A draft concept note and agenda are available upon request. The Summit has three outcomes:

1. Review of the current global landscape of health data, to make a case for health data being a global public good.
2. Review of principles and good practices for governing health data.
3. Encourage consensus for health data as a global public good and identify good practices for health data governance.

The June 2021 summit will consider the case for health data being a global public good and the elements of good health data governance. This will (a) provide materials (with background context and references) and a presentation to achieve the summit’s first outcome and make a case for health data as a global public good; and (b) contribute to strengthening WHO’s Data Governance framework and Data Journey (below).

The June 2021 summit will be followed by subsequent events, when partners will have the opportunity to potentially align political, technical and financial support for operationalizing and building capacity for (a) health data as a global public good; and (b) the good practices for data governance standards, structures and solutions identified in June 2021.

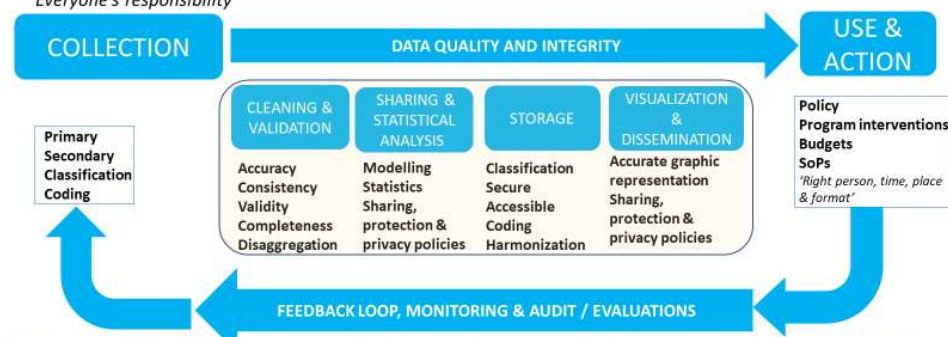
Data & Health Statistics Governance Framework

The necessary standards, solutions and structures that ensure quality and integrity of all aspects of WHO’s data & Health Statistics



WHO's data & health statistics journey

'Getting the right data to the right person, at the right time in the right place and right format':
Everyone's responsibility



Collecting and using quality data with integrity: a) is part of health system strengthening, b) depends on strong governance, and c) occurs at all 3 levels of WHO. Individual steps may not be linear, can vary and evolve over time. But all are necessary.

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The COVID 19 pandemic has raised the profile of the need for quality, timely, complete and accurate data for decision makers at all levels. WHO is strengthening its data governance before and during the COVID-19 pandemic - as part of recommendations made for WHO's transformation process, health information systems contributing to Universal Health Coverage (UHC) goals and reducing fragmentation and reporting burden. The [UN Secretary General's Data strategy](#) is guiding much of the multilateral system's data governance, but many other models for governing health data should be considered.

The outcomes mentioned above will provide the June 2021 Health Data Governance Summit with the necessary review of good practices for data governance principles and good practices - focusing on health data, but there could be examples beyond the health sector worthy of consideration for improving health outcomes. Data principles and ways of governing health data should include reviews to highlight best practices in collecting, storing, sharing, analysing, validating, presenting and using data at different levels. This will provide stakeholders with information to understand proposed best practices when eventually committing pledges to support evidence-based best practices.

Several recurrent data gaps have been identified. Consideration should be given to gaps in governing data for Research and clinical trials, surveillance (animals, public health, environmental), Patients/individual identifiers (using security and privacy sharing models), disaggregated data and tracking communities left behind.

Several recurrent themes for governing data have also been identified. The following themes should be included in the review: principles, good practices in data sharing and data storage but also consider themes such as mapping partners and best practices and evidence behind best practices, support consensus and resource alignment for health-related SDG data work, data principles, data sharing policies and their implementation, open data (including privacy and security), accountability frameworks. One paradigm that may be worth considering as structuring approaches to health data governance is the data journey: collection, storage, sharing, validation, use and reuse and Partnerships (public private) for data sharing.

The Summit participants will include a wide range of background from multiple constituencies from global, regional, national and community levels. Consideration should be given to this diversity of approaches when providing a review of health data principles and best practices for health data governance. Participants will include [Health Data Collaborative](#) (7 constituencies² and related working groups including [data and digital governance](#)), [SDG 3 GAP](#) partners, research and academia, innovative partners engaged with data sharing and governance from emergency and non-emergency contexts.

2. Planned timelines (subject to confirmation)

Start date: 17 May 2021
Total duration: 2 months

End date: 16 July 2021

3. Requirements - Work to be performed

Objective 1: To provide a review of good practices in data principles and governance standards, solutions and structures for health data by 23 June 2021, for circulation to health data governance summit participants.

Output 1.1: Review of good practices (with evidence) of data principles and their potential for use.

Output 1.2: Review of good practices (with evidence) of governance standards, solutions and structures for health data that considers themes along the data journey, including but not limited to such as themes as data collection, storage, sharing policies, privacy and security, analysis and validation, visualization and use and reuse and use of partnerships. This may include, but not limited to, administrative, survey health data, research and clinical trials, surveillance (animals, public health, environmental), patients/individual identifiers (using security and privacy sharing models), disaggregated data and tracking communities left behind.

Objective 2: To provide a review of good practices in applying data principles and health data governance mechanisms in different contexts by 23 June 2021, for circulation to health data governance summit participants.

Output 2.1: Review good practices of data principles and examples of how these are or can be applied practically in different contexts (such as fragile, low income, middles income or high-income contexts).

Output 2.2: Review good practices of data governance and examples of how these are or can be applied practically in different contexts (such as fragile, low income, middles income or high-income contexts).

Overall objectives 1 and 2 should be presented in one document, with a brief executive summary (maximum 2 pages), clear references and diagrams and list of any interviewees. The final products should also be considered for peer review and publication, as way of ensuring quality control and sharing the analysis.

Objective 3: To provide a presentation available to the Health Data Governance Summit with main findings of the review of good practices for data principles and governance of health data

Output 3.1: Draft presentation for summit summarizing with key findings and trends in objective 1 and 2.

4. Characteristics of the Provider

The supplier should have demonstrated proven broad expertise, experience and understanding of:

- a) how data, statistics and research findings are collected, stored, shared, validated, analysed and used;
- b) global health environment;
- c) country mechanisms for collecting, storing, sharing and using data;
- d) mechanisms for using data and context of global health ecosystem;
- e) health data governance;
- f) contextual knowledge of COVID-19 data systems.

The supplier should be able to relate to and understand country and multiple regionally based institutions and ministries collecting and using data.

5. Place of assignment

The supplier can be based anywhere, travel is not expected as part of the assignment, and will be in regular contact through the internet, meetings and will present findings remotely at the data governance summit.