World Health Organization

Terms of Reference
RFP-2021-DDI-DNA-CNG-0001

To provide a review of the current landscape of health data, to make a case for health data being a global public good, in preparation for a WHO hosted Global Health Data Governance Summit
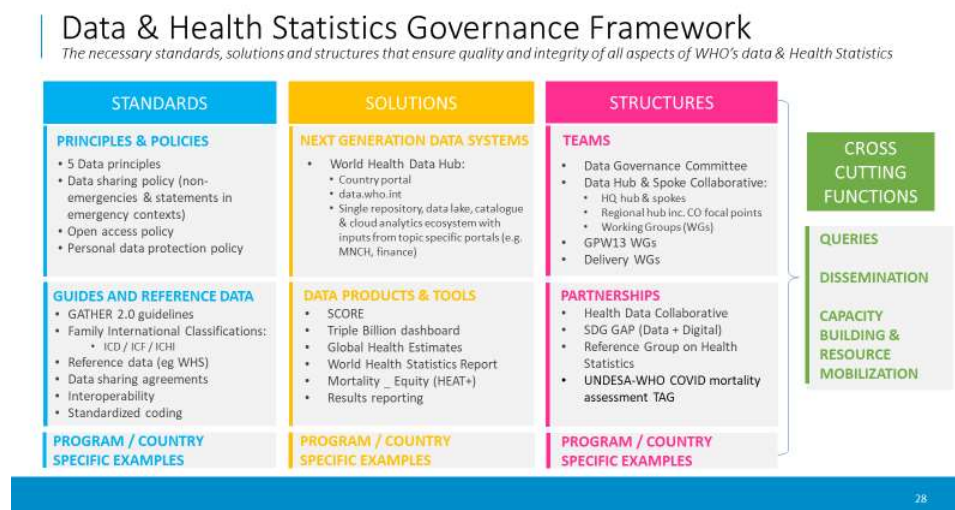
1. Background

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.
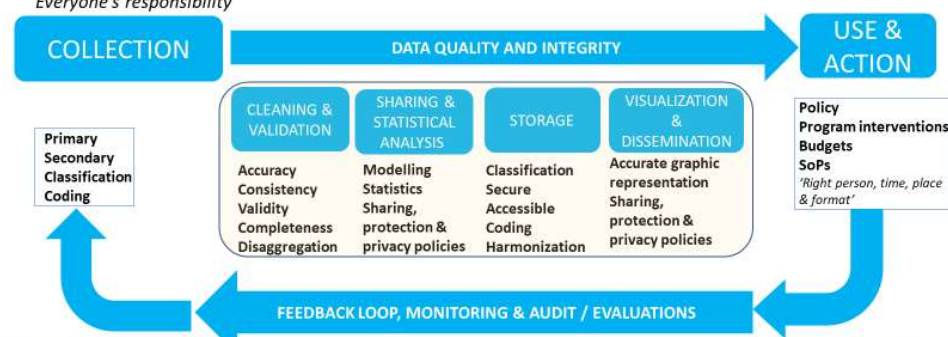
The June 2021 summit will consider the case for health data being a global public good and the elements of good health data governance. This will (a) provide materials (with background context and references) and a presentation to achieve the summit's first outcome and make a case for health data as 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

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 outcomes mentioned above will provide the June 2021 Health Data Governance Summit with the necessary context of health data, demonstrate the complexity and fragmentation of current mechanisms by which data is collected, stored, shared, analysed, visualized and used at different levels. The outcomes mentioned above should address the issues and complexities highlighted in low- and middle-income countries and certain situations such as complex emergencies. This will provide stakeholders with information to better understand the landscape of health data and the case for health data to be considered a global public good.

Several recurrent data gaps have been identified. Consideration should be given to gaps in 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 (especially those in complex emergencies).

Several recurrent themes for governing data have also been identified. The following themes should be included in the review: mapping partners and good practices; support consensus and resource alignment for health-related SDG data work; data principles: data sharing policies; open data (including privacy and security); accountability frameworks; 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 backgrounds from multiple constituencies from global, regional, national and community levels. Consideration should be given to this diversity of approaches when providing an equitable overview of the landscape. Participants will include Health Data Collaborative (7 constituencies[2] 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   End date: 16 July 2021
Total duration: 2 months

3. Requirements - Work to be performed

Objective 1: To provide a review and context of the current health data ecosystem by 23 June 2021, for circulation to health data summit participants.

    Output 1.1: Review of global, regional and national health data ecosystems, showing connections, fragmentation and differences between sources of data sets used for decision makers at different levels.

    Output 1.2: Review and diagrammatic representation of the health data ecosystem, including global health partners and digital data ecosystems.

    Output 1.3: Highlight of potential gaps in current data ecosystem (including 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.

Overall, this objective 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 product should be considered for peer review publication, as a means for quality assurance and sharing the analysis.

Objective 2: To provide a summary of attributes, definitions and benefits of global public goods and the case for health data to be a global public good.

    Output 2.1: Provide a definition for global public good for health data, comparing with other definitions.

    Output 2.2: Build case (pros and cons) for why health data fits the attributes of global public good.

Objective 3: To provide a presentation available to the Data Governance Summit with main findings of the review and case for data to be a global public good.

    Output 3.1: Draft presentation for summit summarizing 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.