Data Governance Working Group under the HDC
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I.   Background and purpose

The purpose of the Governance Working Group will be to provide support for improved **governance of health data and the digital technologies that process it**. This support will prioritize development of global goods to establish/strengthen governance structures for countries/Ministries of Health to provide oversight for the appropriate collection, use and dissemination of health data throughout its lifecycle, ensuring that they meet quality and integrity standards. The Governance Working Group (GWG) of the Health Data Collaborative (HDC) will support the creation and use of standards for:

❏ Legislation, standards, policy and guidelines

❏ Leadership and governance structures and processes for digital and data (digital solution selection, M&E requirements, alignment of vertical health programs)

❏ Shared accountability mechanism between the Government, partners, donors and communities

❏ Technical and financial harmonization of resources at country level

❏ Processes and systems for data & indicators selection, storage, use and reuse

❏ Data privacy, data protection, data standards, access and open data

II.   Governance Working Group Objectives:

The primary objective will be to support the advancement of mutually beneficial digital health and data governance priority areas (e.g. data protection, privacy, next-generation data manipulation tools, guidance to governments, capture of best practices, frameworks and guidelines) specific objectives include:

❏ To develop **best practice principles, frameworks, and toolkits** for data and digital health governance that can be adopted by national governments, alliances, and WG member organizations. To include a specific focus on ensuring accountability by global actors to host governments and beneficiary communities.

❏ To support HDC secretariat in maintaining a **repository** that serves to support knowledge sharing in shared priority areas of the working group members; to include templates, model policies, and standards that community members can contribute to and use.

❏ To serve as an **advocacy accelerator** for the larger HDC, supporting translation of technical needs into recommendations, identifying and responding to global health priorities (e.g. COVID-19), building connections to digital and data governance leadership and venues in the global health community, and promoting the overarching priorities of the WG membership.

III.   Scope of Work and Proposed Products

The proposed scope of work builds on the HDC processes (e.g. regular convening, open membership and access to meeting materials) to surface shared priorities and support progress towards understanding and executing related data and digital health governance priorities.

This WG is well placed to support the development of the following products (born out of the objectives in the previous section):

1. To develop a proposed digital and data governance **framework** or guidance for decision makers in LMICs (e.g. key considerations – acknowledging that implementation will vary but this group can propose a set of standard considerations). We anticipate that primary users will be Ministries of Health responsible for management of health information system tools, digital and data governance and decision-making, selection of digital and data tools and systems, it will be in keeping up with the rapid evolution of digital health.

- ❏ This work will build on existing tools, such as: The Missing Maps Project (See governance structure) / Humanitarian Data Exchange/ OpenStreetMap/The Global Healthsites Mapping project/MoH/ PATH/Palladium/WHO/PIH/GDHI/SOCI/others Docs & strategies

- ❏ And will be harmonized with the work on maturity models so that guidance is based on maturity of system (and considers challenges at varying levels of the health system associated with moving from paper to digital)

2. To develop a set of Principles or **Best Practice** for Data and Digital Health Governance (e.g. define how our community should work/ local-governments-using-open-geospatial-data-to-make-a-difference). This work will address and draw on existing resources in the following topics (non-exhaustive list):

- ❏ Data management and Responsible Use including foundational principles re: open data, rationale for sharing, etc.

- ❏ Privacy and security of health data

- ❏ Mechanisms for accountability

- ❏ Source materials: GDPR, USAID's Responsible Data guidelines, WHO-PATH paper on digital and data governance

- ❏ Others…

3. To contribute to a **Repository**/Knowledge Sharing Platform, to include:

- ❏ Model policies (e.g. Data sharing, Biometrics (PIH), Maturity models)

- ❏ Existing tools and frameworks (framework for implementing organizations - tool to help each implementing partner/member org review each of the key risks and priorities)

Note: The working group will seek funding of proposed activities described in the scope of work, in alignment with the objectives of the group. If dedicated-funding is provided for direct in-country support in line with this scope and the GWG global goods, that work may be included. These products/global goods will need to be prioritized given GWG bandwidth and funding mechanisms and resource mobilizations.

IV.   Membership, and Leadership

The GWG membership is opt-in and voluntary. As a joint endeavor between the HDC, the DH&I WG, and other HDC WGs, all HDC Working Group members are invited to join. The GWG will prioritize working in partnership with other WGs, the DH&I WG's leadership, and similar communities and initiatives across the global health space. Other HDC WGs will represent their data and digital governance needs through a Governance Advisory Group (see Leadership, below). This group will ensure that GWG-produced global goods address broader stakeholder data- and digital- governance needs.

Monthly Governance WG virtual meetings will be convened around specific technical focus areas as determined by the group, with agenda shared beforehand and follow up items shared following the call with open access to all WG members. The current membership of GWG includes individuals from:

a.   Private sector

b.   Implementing organizations

c.   Donor groups

d.   Academia

The membership of the GWG will be expanded to include representatives from Ministries of Health/government and civil society so that the range of HDC stakeholders are represented.

Leadership

The GWG leadership will consist of not less than two co-chairs who will run monthly meetings, ensure accountability for WG activities, and engage with other WGs. Co-chairs will be nominated by members of the WG and chosen based on a vote annually.

Given the cross-cutting needs of this work, we propose that other HDC WGs represent their data and digital governance needs through a Governance Advisory Group comprised of co-chairs (or another designated representative) from each of the other WGs.

V.   Modus Operandi

The GWG will incorporate other HDC WGs such as Community data, Civil registration and vital statistics, and other small working groups. The issue of data- and digital- governance is cross-cutting and requires inputs, support and use across all health data and digital workstreams. The GWG will share and gather inputs on development of frameworks, tools and guidelines. At the same time GWG will provide inputs to products being developed by other HDC WGs.

The GWG will ensure coordination and links with other HDC working groups (e.g. Community data, and others) to align activities and products. The GWG will participate in quarterly HDC calls and HDC annual meetings to ensure coordination. In addition to the Governance Advisory Group, members of each of the other HDC working groups are invited to join GWG for regular engagement.

The GWG will also engage with HDC pathfinder countries to gather inputs and implementation of frameworks, tools and guidelines. This will be done through the HDC secretariat.

V.   Proposed Timeline

Building on the efforts of the existing SWG, we expect to produce the following proposed products:

#	Topic/Proposed Products	Oct 2020 - Mar 2021	April 2021 - Sept 2021	Oct 2021 - Mar 2022	April 2022 - Sept 2022
1	Landscape of existing Digital Health Governance frameworks	X			
2.	Develop a Data and Digital Health Governance framework		X		
3.	Best Practice for Data and Digital Health Governance			X	X
4.	Repository/ knowledge sharing platform			X	X