National Data Governance Framework: Information Systems for Health

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TECHNICAL TOOLS

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PAHO

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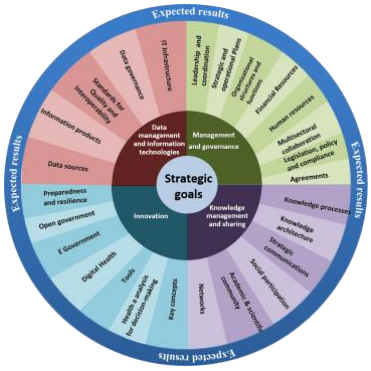
Information Systems for Health Toolkit

National Data Governance Framework: Information Systems for Health

IS4H-NDGF 1.0



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General clarifications

About data management

Data Management refers to the overall management of the availability, usability, integrity, privacy, and security of the technical health data managed by the Institution.

About the Country Data Governance Framework

The **Country Data Governance Framework (DGF)** is the institutional mechanism to establish the scope, goal, roles and responsibilities, objectives and key results (OKRs) and Guiding Principles for the management of technical data that is subject to the Policy for Data Management of the MoH. The implementation of the DGF Framework will be performed through the MoH's Policy for Data Management.

About the MoH Policy for Data Management

The **MoH Policy for Data Management** will set the operational rules for the technical data management processes in the institution, which will encompass the management and operative aspects of the full life cycle of data: 1) acquisition, storage, 2) use, 3) dissemination and 4) disposal.

Introduction

Rationale

- There is a new paradigm for data management in the world
- There is a need to improve health data collection and quality for better decision-making in public health. Quality data-based decisions will lead to improved health outcomes
- There is a need to identify, map, systematize and improve quality of information flows and health data management in the Americas, in a standardized and interoperable manner
- Lack of interoperable information systems for health data management has been challenging, due to the constant health data needs and environments changes– including big data, unstructured health data and data governance models
- There is a need for a different data analysis, knowledge exchange, predictive analysis and information generation. Something that can only be achieve through the development and implementation of a interoperable platforms
- Technical people spend more time in cleaning and standardizing data than analyzing.
- There is an exponential growth of topics and data needs a proper process for input, harvesting, standardization and outputs for analysis.

Premises

- Responsibility: Health Data Governance is an Institution wide issue, not an IT project;
- Trust: Health Data Governance ensures that data acquired, stored and shared by _____ can be trusted;
- Procedures: A set of controls and internal audit procedures must be implemented to ensure ongoing compliance with _____'s data governance rules and procedures;
- Coordination: Health Data Governance ensures that data requests for data sharing are coordinated with MoH.

Rapid assessment elements of Country's data management

- Policies: Review of policies on Health Data Governance and related issues such as: Health data privacy, health data management, health data ownership, among others;
- Processes: Identification of processes on Health Data management, if any;
- Standards: Inventory of technical standards for the adoption of technologies and/or for technical aspects related to Health Data management such as: Database design patterns; Interoperability, security, simulation of disasters, among others;
- Information flows: Mapping of information flows for health data management;

- ICT (Information and Communications Technology) Tools: Policies for the development, adoption, use and documentation of ICT Tools for technical systems development;
- HR Skills: Mapping of competencies and TORs for Health Data Management experts.
- Maturity level: Health Data Governance maturity level assessment

Scope

Technical Data[1] that is subject to the administrative authority of the institution were data is collected, stored or used at different levels.

Goal

The ultimate goal of the Data Governance Framework (DGF) is not just to protect the data managed by the institution, but to ensure effective and efficient data management processes for better (and informed) decisions and evidence-based policy making at different levels of government.

Institutional roles and responsibilities for Data Management

Committee

Membership

- _____, Chair
- _____, Technical Secretariat represented by the Information System Unit (or equivalent)
- IT Sector, Technical liaison with any IT policy or mechanism
- One Member of each Technical Department of the institution

Main responsibilities (Committee)

- To establish the scope, goal, roles and responsibilities, Objectives and Key Results (OKRs) and Guiding Principles for the management of technical data that is subject to the administrative authority of the institution.
- To monitor the implementation of the Policy for Data Management that will set the operational rules for the technical data management processes in the institution.
- To provide technical and managerial guidance, and to ensure convergence of initiatives, investments and actions among the different entities.

Main responsibilities (Technical Secretariat)

- Enforce the policy set by the Data Governance coordinating body;
- Monitor data privacy and quality;

[1] Health data include also socioeconomic and demographic data, produced or managed by the MOH.

- Coordinate the definition and revision of SOPs;
- Coordinate with the IT Department the adoption of ICT Tools, security and hardware when needed;
- Understand the usage of data in the technical units and other institutions;
- Prepare and share reports metrics and issues to the Health Data Governance Board, and to the appropriate authorities as requested;

Main responsibilities (Members: Owners or custodians of the data assets)

- Enforce the policy set by the data governance board;
- Monitor data privacy and quality of their own data sets;
- Prepare and share reports metrics and issues to the Health Data Governance Coordinating Body, and to the appropriate authorities as requested.

Monitoring and Evaluation

Objectives and key results

Objectives and Key Results (OKRs) is part of the DGF Monitoring and Evaluation mechanism for setting, communicating and analyzing short-term results in policy implementation. The goal of the OKRs is to connect teams and individual objectives for ensuring convergence in one unified direction and under a common vision established by a corporate policy.

Goal: MoH implements a set of official and well documented policies on Health Data Governance, which refers to the overall management of the availability, usability, integrity, privacy, and security of the health data, internal and external, managed by the institution			
Objective 1	Develop a comprehensive situation analysis on databases, technological applications, IT infrastructure and IT organizational structure		
Key result		**Score**	**Comment**
KR 1	Inventory of databases and information products		Data bases, publications, technical reports, visualizations, etc
KR 2	Inventory of technological applications		Non administrative software
KR 3	Inventory of IT Infrastructure		Key hardware and connectivity
KR 4	Mapping of the IT related staff across the institution		Location (and functions) of the IT department within the Ministry. If it exists

Objective 2	Develop a Technology Readiness Level Assessment		
Key result		**Score**	**Comment**
KR 1	Technology Readiness Level Assessment report		Technology readiness measures the extent to which MOH IT infrastructure is suited for DGF implementation
KR 2	Technology Readiness Risk Assessment report		Risk assessment to point out possible risk associated with technology transition and adoption that can be mitigated as necessary.

Objective 3	Define the Country Health Information Architecture		
Key result		**Score**	**Comment**
KR 1	Mapping of the Health-related information flows		Understood as the path that health data takes from its original place to its end use or reuse.
KR 2	Mapping of the main data collection mechanisms across the institution		Some examples are: Interviews, Questionnaires, Surveys, Observations, Focus Groups, Case Studies, Documents and Records.
KR 3	Mapping of roles and responsibilities of the “data managers”		Staff involved in data collection, aggregation, analysis and dissemination
KR 4	Decision on corporate standards for databases design and IT solutions		Development, adoption, visualizations, Database design patterns, Interoperability, Information security, Simulation of disasters, etc

Objective 4	Establish the main foundations for the sustainability of the Information Systems for Health initiative, as measured by:		
Key result		**Score**	**Comment**
KR 1	Conceptual framework for Data Governance		The DGF is the mechanism to establish the scope, goal, roles and responsibilities, OKRs for the management of technical data that is subject to the administrative authority of the institution.
KR 2	First draft of a Data Management Policy		The Country Policy for Data Management will set the operational rules for the technical data management processes
KR 3	Terms of reference (TORs) for implementing the MOH Data Governance committee		The Committee should be an advisory board, lead by __, which works to provide technical and managerial guidance, and to ensure convergence of initiatives, investments and actions among the different entities.

Guiding Principles (GP)

GP 1: Follow the 8 principles of Open Government Data[2]:

1. **Complete**: All public data is made available.
2. **Primary**: Data is as collected at the source, with the highest possible level of granularity, not in aggregated or modified forms.
3. **Timely**: Data is made available as quickly as necessary to preserve its' value.
4. **Accessible**: Data is available to the widest range of users for the widest range of purposes.
5. **Machine processable**: Data is reasonably structured to allow automated processing.
6. **Non-discriminatory**: Data is available to anyone, with no requirement of registration.
7. **Non-proprietary**: Data is available in a format over which no entity has exclusive control.
8. **License-free**: Data is not subject to any copyright, patent, trademark or trade secret regulation. Reasonable privacy, security and privilege restrictions may be allowed.

[2] Source: https://opengovdata.org/

GP 2: Focus on ethical principles for data use:

- The highest priority is to respect personal information behind the data.
- As much as possible explain objectives and methods for use, analysis and decisions based on collected data.
- Strength privacy and confidentiality issues on legislation and policies.
- Promote regular trainings on the importance of ethical use of data, privacy and confidentiality.
- IT developers and data administrators should give due consideration to privacy, security and confidentiality on applications development and databases designs.

GP 3: Unlock the value of unstructured data:

Unstructured data refers to content does not have a pre-defined structure or is not organized in a pre-defined manner. Unstructured data is typically free text, but may contain structured data such as dates, numbers, videos, audios, and facts as well.

GP 4: Promote quality data as a critical factor of success:

Quality data in health play a significant role in improving policy and decision-making, as well in the planning, development and maintenance of health care services.[3]

GP 5: Adopt standards as much as possible:

The adoption of standards is the only possible solution to achieve interoperability between applications and databases of an integrated health information system.

GP 6: Always strengthen the management of vital statistics:

The process of civil registration produces vital statistics, which are public goods essential for decision-making, distribution of resources, policy-making, , should be prioritized and strengthened.[4]

Alignment of Data Governance within the Data Revolution for Sustainable Development[5]:

On the 29 August 2014 Secretary-General Ban Ki-moon named an Independent Expert Advisory Group on the Data Revolution for Sustainable Development to provide him with inputs to shape "an ambitious and achievable vision" for a future development agenda beyond 2015. Key recommendations to follow:

1) Develop a global consensus on principles and standards,
2) Share technology and innovations for the common good,
3) New resources for capacity development,
4) Leadership for coordination and mobilization and
5) Exploit some quick wins on SDG data.

[3] Adapted from http://www.globalhealthworkforce.org/resources/who_improving_data_quality.pdf
[4] Adapted from: Plan of Action for the Strengthening of Vital Statistics 2017-2022 http://iris.paho.org/xmlui/handle/123456789/34197
[5] Source: http://www.undatarevolution.org/wp-content/uploads/2014/12/A-World-That-Counts2.pdf

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