Data Policy
Family Health Bureau
Ministry of Health

Contents

Preamble

The data policy of an institution incorporates all the procedures and guidelines related to the management, archiving, and sharing of data encountered during its routine operations.

Family Health Bureau (FHB) is the focal point in the Ministry of Health responsible for the policy analysis, strategic planning, technical guidance, monitoring and evaluation, and research functions related to the Reproductive, Maternal, Newborn, Child, Adolescent and Youth Health (RMNCAYH) programmes. FHB is recognized as one of the leading institutions contributing to the monitoring of epidemiological and service indicators related to RMNCAYH of Sri Lankan citizens.

While performing its routine functions FHB manages a considerable amount of data. FHB regularly coordinates and supervises the data generation actions related to the; a) service performance statistics, b) disease, death, nutrition status and fertility surveillance, c) health system resources that happen at various preventive and curative RMNCAYH program implementation sites.

FHB routinely collects the data related to the following thematic areas:

1. *Morbidity and mortality related to pregnancies, infants, children, adolescents, youths, and women of reproductive ages,*
2. *Nutrition surveillance status,*
3. *Child birth, fertility, subfertility and contraceptive usage,*
4. *Service performance and logistic coordination related to RMNCAYH programs,*
5. *MCH services, morbidity and mortality data related to private sector providers,*
6. *Research, and surveys conducted by the research unit of the FHB and post graduate research sponsored by FHB.*

Most above mentioned data items are collected in the form of aggregated data while limited amount of them are gathered as individually focused data.

Data related functions of the FHB involve:

1. *The development, implementation and M & E of data generation, retrieval, analysis and dissemination of data related to the morbidity, mortality, nutrition status and fertility surveillance systems,*
2. *The development and update of the eRHMIS system (both manual and online) which covers health service and health system statistics related to the monitoring of RMNCAYH programs,*
3. *Training of relevant health staff on data generation, data entry, and data processing,*
4. *The coordination and monitoring of data processing and entering data into a national data base system,*
5. *Analyzing, and reporting the information produced in the eRHMIS system*
6. *Broader Dissemination of RMNCAYH information produced in the FHB data network to relevant stakeholders.*

As such, FHB generates and handles a considerable amount of data on a routine basis and has a country wide data network which connects RMNCAYH related data generating points from preventive and curative institutions around the country. In order to maximize the dissemination and usage of these data for relevant decision making, so that they will be used for the benefit of RMNCAYH programs in particular and general public in general, while preserving the ethical rights and confidentiality of people and institutions involved, a presence of a data policy becomes an indispensable need.

This document clarifies the current policy and practice on the use of data handled by the Family Health Bureau within the broader framework of the data policies of the Ministry of Health and the Government.

1 Introduction

A data policy of an institution incorporates all the procedures and guidelines related to the management, archiving, and sharing of data encountered during its routine operations.

Family Health Bureau (FHB) is the focal point in the Ministry of Health responsible for the policy analysis, strategic planning, technical guidance, monitoring and evaluation, and research functions related to the Reproductive, Maternal, Newborn, Child, Adolescent and Youth Health (RMNCAYH) programmes. The bureau is responsible for the designing, updating, supervising and implementation of the preventive Health Management Information System (HMIS) that covers the RMNCAYH programmes implemented in various levels of the health system. FHB is recognized as one of the leading institutions contributing to the monitoring of epidemiological and service indicators related to RMNCAYH of Sri Lankan citizens.

FHB has the formal responsibility for ensuring the generation, analyzing, and dissemination of data that are required for the management of the above mentioned programmes. As such, FHB regularly coordinates and supervises the data generation, gathering, and processing actions related to the following thematic areas

1. *Morbidity and mortality related to pregnancies, infants, children, adolescents, youths, and women of reproductive ages,*
2. *Nutrition surveillance data,*
3. *Child birth, fertility, subfertility and contraceptive usage,*
4. *Service performance and logistic coordination related to RMNCAYH programs,*
5. *MCH services, morbidity and mortality data related to private sector providers,*
6. *Research, and surveys conducted by the research unit of the FHB and post graduate research sponsored by FHB.*

Most above mentioned data items collected in the form of aggregated data while limited amount of them are gathered as individually focused data. As such these data involve varying degrees of sensitivity and security concerns.

The routine data related functions of the FHB involve:

1. *The development, implementation and M & E of data generation, retrieval, analysis and dissemination of data related to the morbidity,mortality and nutrition surveillance systems,*
2. *The development and update of the HIMS system (both manual and online) which covers health service and health system statistics related to the monitoring of RMNCAYH programs,*
3. *Training of relevant health staff on data generation, data entry, and data processing,*
4. *The coordination and monitoring of data processing and entering data into a national data base system,*
5. *Analyzing, and reporting the information produced in the HMIS and surveillance system*
6. *Dissemination of RMNCAYH information (service and system statistics, surveillance information) produced in the FHB data network to relevant stakeholders.*

FHB routinely collects, compile and analyse the following types of data:

1. *Morbidity and mortality statistics related to pregnant mothers, children (perinatal, infant, and child up to 5 years), school children and out of school adolescents, youth, newly married couples, and women of reproductive ages,*
2. *Child births,*
3. *Maternal and child nutrition status,*
4. *Contraceptive usage,*
5. *RMNCAYH related service performance,*
6. *Health system statistics such as infrastructure, human resource and logistics,*
7. *RMNCAYH morbidity, mortality and service provision statistics related to private sector institutions,*
8. *Research data.*

As such, FHB generates and manages a considerable amount of data on a routine basis through its data network. In order to maximize the dissemination and usage of

these data, so that it will be used for the benefit of RMNCAYH programs in particular and general public in general, while preserving the ethical rights and confidentiality of people and institutions involved, a presence of a data policy becomes an indispensable need.

Many stakeholders contribute to the generation, supply management, and archiving of the data related to the FHB's functions.

1.1 Partners of the FHB Data Network

Many partners are involved in the FHB data network. The largest group of partners include the Medical Officer of Health Teams who routinely generate the data related to the RMNCAYH programs. Every PHM is mandated to keep daily records of their service statistics and report them to the MOH level as Monthly Returns. In addition, the MOH team staff who conduct field clinics and field weighing posts keep the records of both service statistics and client health indicators. Clinic and field weighing post related data are also reported to MOH in the form of clinic returns on monthly basis. In addition, MOH level data include the annual system statistics related to MOH divisions and nutrition month data. PHIs provide the school health related data to the FHB data network. Dental Therapists attached to MOH divisions maintain records so their routine work performance statistics and these records will be transferred to eRHMIS system at the MOH level. SPHMs, PHNSs and MOHs contribute to the data network through supervision and facilitation functions. At the MOH level, these data are entered into the online national level eRHMIS data base by MOH staff.

MOMCHs also contribute to the FHB data network by coordinating the MOH based data management and also entering their routine performance statistics to the eRHMIS data base.

Curative institutions also participate in the FHB data network. The institutional data fed in to the FHB data network include: a) Maternal Mortality returns, b) Lactation management center monthly return, c) Neonatal monthly returns (SCBU), d) Feto-infant death surveillance return, e) Birth defects surveillance data, f) CHDR stock position return, f) NRP – Monthly feedback summary form, g) Monthly Family Planning stock return (H1158). All curative institution-based data are communicated through hard copies except Birth defects surveillance data which are supposed to be sent in both hard and electronic formats.

FHB research unit is involved in the gathering of research data.

FHB routinely interacts with the Medical Statistics Unit of the Ministry of Health, Medical Supplies Division of the Ministry of Health, Register General Department, Department of Census and Statistics, Ministry of Education and Child Secretariat for exchanging relevant operational data such as Birth and death registrations, estimated births, etc..

1.2 The Users of the FHB Data

Data gathered in the FHB data network is utilized by people from many stakeholder institutions. They include:

1. *Policy makers from the Ministry of Health,*
2. *Members of other vertical health programs,*
3. *Provincial and district administrators,*
4. *Program Managers and Program Staff of FHB*
5. *Provincial and district CCPs, MOMCHs, REs, and MOs Planning*
6. *MOHs and other members of the MOH teams*
7. *Professional bodies*
8. *University academic staff & Other researchers*
9. *Patients/Clients*
10. *Other Ministries such as the Ministry of Education, Ministry of Women's and Child affairs*
11. *Media Personnel*
12. *RMNCAYH clients and General Public*

1.3 Current Data Sharing Context

Currently, several mechanisms are in place for sharing the data & information generated from the FHB data network.

The varying levels of access to the eRHIMS data base are given to the selected stakeholders depending on their data needs and relevance. They include program managers of the FHB, MOMCHs and MOHs and their staff.

The evaluation unit of the FHB routinely analyses and produces summary information from the data gathered by the MOHs units around the country. This information is disseminated as an annual report, newsletters and through the FHB website. Individual program units of the FHB also produce reports based on the data and information related to their programs (e.g. Maternal Death Analyses, Nutrition Month Data summaries etc.)

The patient related data such as data on morbidities and mortalities of various target groups, nutrition statistics, family planning usage etc are shared on personal requests made by various seekers such as personnel form other programs, Ministries, researchers.

The reports of the research studies conducted by the FHB is disseminated as hard copies as well as through the FHB website.

2 Purpose of the FHB Data Policy

The purpose of FHB data policy is to ensure the generation and proactive sharing of timely, accurate and updated RMNCAYH related data within an appropriate scope, adopting technically efficient methods, while preserving the privacy, confidentiality, and rights of data owners, generators and seekers, and thereby optimizing the decision making processes at policy making, program planning, implementation levels, as well as help RMNCAYH related decision making by relevant clients.

3 Scope of the Policy

The scope of the FHB data policy covers all the RMNCAYH *data generated by the MOH teams, hospitals and FHB program units, both in electronic and manual formats. The policy focusses on the creation of a framework that will support the proactive sharing and use of RMNCAYH* data generated by the FHB data network.

4 Data policies

4.1 DATA MANGEMENT SCOPE AND QUALITY

4.1.1 Governance

- *D/MCH is deemed to be the custodian of the FHB data network*

- *D/MCH shall delegate this custodianship to appropriate program personnel from FHB for practical purposes*

4.1.2 Relevance & Scope

- *Monitoring and Evaluation (M& E) Unit of FHB shall periodically review the relevance and scope of RMNCAYH data variables and indicators and update them depending on needs*
- *Program managers in charge of surveillance systems shall ensure the relevance and scope of relevant surveillance systems according to the contextual environments*
- *Both formal and informal opinions of users of FHB Data shall be sought when exercising above two functions*

4.1.3 Accuracy, Completeness, Timeliness

- *M & E unit of FHB shall routinely check the accuracy, completeness and timeliness of data entered in to the eRHMIS system using appropriate methods*
- *Relevant data entry checks should be inbuilt to the eRHMIS system to minimize data errors.*
- *M & E Unit with the help of MOMCHs will undertake random field checks of the accuracy of data entered into the eRHMIS and practical issues faced by the field workers who generate the data.*

4.1.4 Duplication

- *D/MCH and relevant program managers of FHB should review the individual surveillance systems and prevent the duplication of data items within different surveillance systems and look for opportunities of merging systems if appropriate*
- *M & E unit should look for the potential duplications of data gathering between the eRHMIS system and other related data systems maintained by the Ministry of Health and other vertical institutions*
- *Possibilities for sharing and linking these data items between different data systems should be sought and advocated to prevent duplication*

4.1.5 Technical and Operational Efficiency

- *M & E unit should ensure that all electronic formats used in the data system are up to date and chosen and implemented with appropriate technical supervision and skills*

- *The systems should be developed in such a manner that they are user friendly, and minimize human efforts and encourage seamless data transfer from point to point.*
- *FHB should organize the appropriate data portals that present the analyzed data (DASHBOARDs) sought by many stakeholders on a frequent basis*
- *Options should be provided to use open formats, to support interoperability and accessibility and migration*

4.1.6 Networking

- *M & E unit should look for intra and inter-ministerial common data interests and look for the potential building of data network linkages*
- *The possibility of linking with private health sector data networks should be sought*

4.2 DATA COLLECTION

4.2.1 Designing Data Systems

- *M & E unit of the FHB shall review and update of indicators, data formats, and electronic data systems in a periodic manner*
- *M & E Unit should be equipped with both skills and ICT equipment, software and connectivity required for updating and changing the electronic data systems to keep inline with the current advancements of ICT science and national data policies*
- *M & E unit shall ensure the sustenance and maintenance of the web based eRHMIS system through the national network and expand the system depending on the timely needs*
- *When selecting data systems, attention should be paid to the transferability and linkages with the other national data systems.*

4.2.2 Capacity Building

- *M & E unit of FHB shall assess the training needs of the field /hospital staff who are involved in data generation, data entry, and maintaining of data systems*
- *M & E unit shall organize and conduct the appropriate capacity building programs for the data handling personnel*

- *M& E unit staff should be provided with the appropriate data analytical and reporting skills*
- *Whenever an update is done the relevant data generators and handlers shall be duly informed and trained by FHB*

4.3 ACCESS & UTILIZATION

4.3.1 Promoting Data Utilization

- *FHB shall make both print and electronic publications related health service and system data summaries and surveillance information and make these freely available for all relevant stakeholders, general public*
- *FHB shall time to time create events, and fora that will promote the data utilization practices by the administrators, program planners, and implementors. E...g training workshops, data dissemination sessions etc…*
- *FHB shall make media releases related to important RMNCAYH information as and when they are raised through Health Promotion Bureau*

4.3.2 Access to FHB Data

- *FHB shall maintain an electronic web-based data portal that presents organized health service and system data and surveillance information that are intended for decision makers, program planners, implementers, RMNCAYH clients, general public and media personnel.*
- *The relevant people are given an appropriate level of access depending on the scope and level at which they operate. e.g. Program Managers of FHB is given full access to the data related to the relevant program area, while MOMCHs of a particular district is given full access to the data pertaining to his or her district while giving limited access to the data related to other districts for the comparison purposes.*

- *FHB shall publish and disseminate annual and quarterly reports based on RMNCAYH data.*

- *Personnel other than those from UN organizations INGOs and NGOs seeking data from FHB needs to formally apply for their data needs to D/MCH stating the intended purpose, method of use, and scope of data sought. D/MCH decide to release / not to release the data that is sought based on the recommendations*

made by the data management committee of the FHB. The Data management committee will be appointed by the FHB and will comprise of Deputy Director FHB, CCP M & E, CCP research and Relevant Program Manager.

- *UN organizations, INGOS, NGOs shall apply for relevant RMNCAYH data produced by the FHB data network through Secretary Health*

- *Use of FHB data for international collaborative studies will be allowed after due approval is given by the Secretary Health and DGHS.*

- *Staff members of FHB who are interested in using FHB data for research purposes should also follow the same procedure mentioned above for other data seekers.*

- *An attempt will be made to share the data as much as possible, provided the purpose provided by the seeker suggest the rational and scientific utilization of data for potential evidence generation or decision making related to the public interest.*

- *Upon receiving the approval for data, the data seeker should sign a formal MOU with the FHB director which acknowledges the data receipt and assert that the data will be used only for the stipulated purpose and the data ownership of FHB is duly acknowledged in any publication produced based on them.*

- *Whenever patient related individual data is released (e.g. data on maternal deaths) FHB should make sure that the identity of clients and institutions is removed.*

- *FHB shall make the non-restricted information such as aggregated RMNCAYH data summaries, guidelines, IEC materials on its website and manual copies freely available to anyone who deem that are necessary.*

4.3.3 Transparency

- *The use of the eRHMIS system and appropriate access given to data handlers are supposed to make the data management process transparent*
- *FHB provides a common forum to discuss the data related issues during MCH reviews held in districts.*

- *FHB shall make sure stakeholders at all levels are participating in the review and update of the data system and M& E framework.*

4.3.4 Pricing

- *All data generation products of the FHB are deemed to be public goods and therefore should be released free of charge.*
- *However, reproduction and distribution costs, publication charges should be allowed.*

4.4 Data Policy for Funded Research

- *FHB shall identify and publish the relevant research questions/needs and invite post graduate trainees to conduct research studies based on them*
- *FHB shall solicit funds or provide its own fund to facilitate Post Graduate (PG) research depending on the program needs.*
- *In the case of FHB funding a PG research, methodologically sound TOR should be prepared by the relevant program unit and an appropriate MOU should be signed by the researcher and FHB to ensure the researcher is responsible for submitting a quality research output. In such cases, FHB should appoint a suitable inhouse expert to technically supervise the student.*

STORAGE & DELETION

4.5 Time Limits and Retention

- *FHB shall keep electronic copies of HMIS and Surveillance data in the open data system for a period of 10 years and there after archive them in a suitable manner*