



Ethiopian Public Health Institute (EPHI)

National Data Management Center (NDMC) for health

Working Guidelines

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## Abbreviations

AHRI	Armauer Hansen Research Institute
CSA	Central Statistics Agency
DBSU	Data Archiving, Banking and Sharing Unit
DMU	Data Mapping Unit
DBU	Disease Burden Unit
DCPU	Disease Control Priority Unit;
EPHI	Ethiopian Public Health Institute
EPHA	Ethiopia Public Health Association
ETU	Evidence Translation Unit
FMOH	Federal Ministry of Health
GBD	Global Burden of Disease
HPEU	Health Programs Evaluation Unit
HSDP	Health Sector Development Program
HSTP	Health Sector Transformation Plan
IHME	Institute for Health Metrics and Evaluation
ICT	Information, Communication and Technology
M&E	Monitoring and Evaluation
NDMC	National Data Management Center
PPD	Plan and Policy Directorate

## Summary

The Ethiopian Public Health Institute (EPHI) established the National Data Management Center (NDMC) in 2017 to create a coordinated and centralized system that continuously collects, stores, manages, analyzes and synthesizes, and disseminate public health and biomedical data available at EPHI, research institutes, academics and agencies in Ethiopia as well as data that can legitimately be accessed from international data repositories. In Ethiopia, data are collected and managed at different levels and data sources seemed to be independent without recognized national coordinating center. This approach has poorly supported the health policy that should be derived from comprehensive view of health and health related evidences across time, geography and population in Ethiopia. Ultimately, NDMC helps to improve the health status of nations and nationalities through synthesizing and disseminating high quality evidence, measuring and tracking health program performance at different levels and translating evidence to policy decisions in the country.

Well organized and capacitated NDMC primarily helps to process and manage already available data using rigorous scientific methods; creates research collaboration platform with local and international agencies; drives national research agenda and develop data sharing culture; and to use resources efficiently and build evidence synthesis and dissemination capacity in the country. The center will also conduct rigorous systematic reviews on national and sub-national priorities in health including but not limited to burden of diseases, impact evaluations, disease prevention and control as well as biomedical research. It responds to evidence queries from policy or program decision makers; provide support to academic institutions and jointly train post graduate students focusing on data science, evidence synthesis and dissemination.

The NDMC follows the following five strategies to build a data management system and to strengthen collaboration with national and international research institutes. The strategies are building research capacity for EPHI and key collaborators; establishing specific databases, generate data and share, and improve data availability and accessibility for local and international users; establish and strengthen local and international collaborations, ensure local and international funding to undertake the different health and health related researches and evidence utilization.

## Background

Generating, managing and synthesizing public health and biomedical data and making informed health decision is a priority in the Health Sector Transformation Plan (HSTP)<sup>1</sup> and Ethiopian Public Health Institute (EPHI) strategic documents<sup>2</sup>. Historically, there was a long standing impediment in tracking progress in the implementation of the Health Sector Development Program (HSDP)<sup>3</sup>and HSTP. Problems related to evidence-based policy formulation in Ethiopia include absence of relevant evidence, and if the evidence is available, it is either inaccessible or poorly analyzed and synthesized<sup>4</sup>.

In the context of this, Ethiopia has recently established Vital Events Registration Agency (VERA) that is currently on the process of being to be fully functional. The EPHI and Central Statistical Agency (CSA) have played significant roles in conducting different types of surveys. Furthermore, there are multiple data sources available at national and sub-national levels within different research institutes and agencies. However, there is no recognized national coordinating center to process and synthesize the data in order to address national and subnational interests<sup>5</sup>. Usually data are collected and managed at different levels and the available data sources are independent. This approach has poorly supported the health policy that should be derived from comprehensive view of health and health related evidences in Ethiopia<sup>6</sup>.

Ethiopia lacks National Data Management Center (NDMC) with a full capacity to pool all health and health related data available in the country, to process and manage the data with standard scientific methods and techniques, and provide policy relevant findings at national and subnational levels. EPHI is nationally mandated institute to lead public health research on national and sub-national priority health problems and evaluate strategies and initiatives, to establish a framework for the integration and effectiveness of researches conducted throughout the country and put in

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<sup>1</sup> Federal Ministry of Health Ethiopia, Health Sector Transformation Plan, 2016-2020

<sup>2</sup>The 2nd BSC Based EPHI's Strategic Management Plan: 2015/16 to 2019/20

<sup>3</sup> Federal Ministry of Health Ethiopia, Health Sector Transformation Plan, 2016-2020

<sup>4</sup>Hibret Tilahun, Jessica Flannery& Peter Berman. Review of Local and Global Practices Global Practices on Evidence-Informed Health Policy: Recommendations for Ethiopia. Feb 2016

<sup>5</sup> Federal Ministry of Health. Information Revolution Roadmap. April 2016

<sup>6</sup>Hibret Tilahun, Jessica Flannery& Peter Berman. Review of Local and Global Practices Global Practices on Evidence-Informed Health Policy: Recommendations for Ethiopia. Feb. 2016

place national health research database, and provide assistance to regions and other entities conducting research<sup>7</sup>. Accordingly, EPHI is currently leading the establishment of a national data management center, under the leadership of the Federal Ministry of Health (FMoH), to store, analyze, synthesize and disseminate nationally relevant evidence to inform policies and programmes. CSA has the mandate to provide technical guidance and assistance to government agencies and institutions in their endeavor to establish administrative recordings, registrations and reporting systems; and build the capacity required for providing directives and consultations in database creation and development of administrative records and registration systems<sup>8</sup>. Armauer Hansen Research Institute (AHRI) is also mandated to undertake biomedical, clinical and medical biotechnology research and adapt and implement scientific technologies to improve clinical care, conduct clinical trials and build capacity of higher education<sup>9</sup>. EPHI will continue to receive support from CSA and AHRI to improve its impact in generating relevant evidence to health policy in Ethiopia.

National Data Management Center (NDMC) will have nine units for which few of them may start functioning later: Training and Capacity Building (TBC) Unit; Strategy, Engagement and Grant (SEG) Unit; Research Priority Setting Unit; Data Mapping Unit; Data Archiving, Banking and Sharing (DBS) Unit; Disease Burden Unit; Health Programs Evaluation Unit; Biomedical Unit; Disease Control Priority Unit; Evidence Translation Unit; and M&E Unit. The roles and responsibility of the units is described below; disease burden, evaluation and biomedical units are responsible for generating evidence and more units could be created as the demand arises. Existing EPHI directorates and programs handle major activities of the units on evidence translation to policy, and monitoring and evaluation.

In 2016, the FMoH has developed Information Revolution Roadmap aiming to maximize the availability, accessibility, quality, and use of health information for decision making through the appropriate use of information, communication and technology (ICTs) to positively impact the access, quality, and equity of healthcare delivery at all levels. This objective will be achieved

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<sup>8</sup> A proclamation to establish Central Statistical Agency No.442/2005

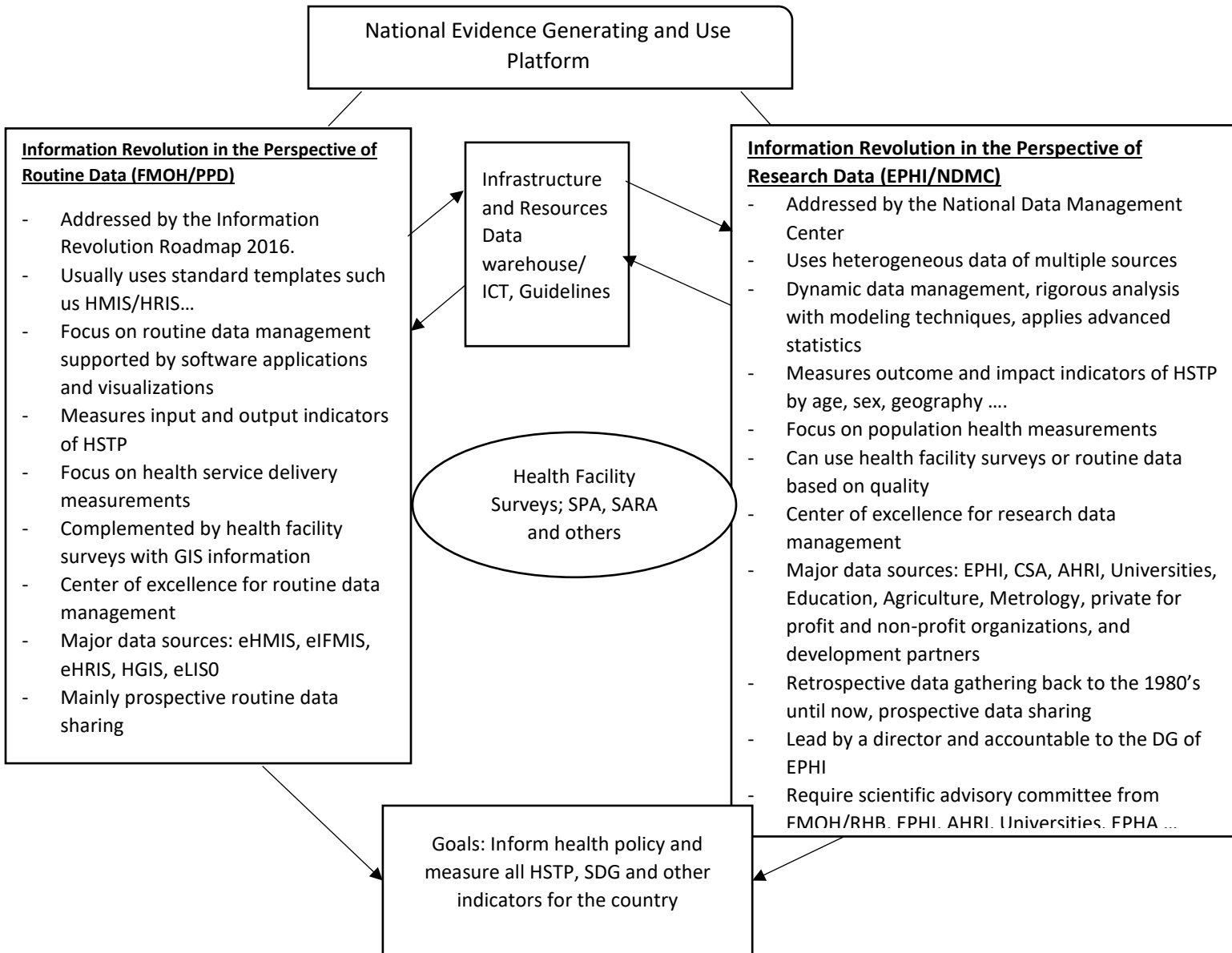
<sup>9</sup> Council of Ministers Regulation to provide for the establishment of Armauer Hansen Research Institute No.376/2016

through the existing routine data system revolution by the Plan and Policy Directorate (PPD) at FMOH, and health and health related research data revolution by NDMC at EPHI. The FMOH and EPHI will closely work to put in place the required rules and regulations on data processing and sharing in the country.

As indicated in Figure 1 below, the routine data and the research data complement each other and will sustainably track progress and effectiveness of the different health interventions to inform national health policy. Both evidence sources are equally important to inform FMOH, and they can share infrastructure, ICT resources, guidelines and manuals, and data for their specific needs.



Figure 1: A Framework for routine data of Plan and Policy Directorate (PPD)/FMOH and research data of NDMC/EPHI, Ethiopia



Well organized and capacitated NDMC primarily helps; to process and manage already available data using rigorous scientific methods; to create research collaboration platform with local and international agencies; to drive national research agenda and develop data sharing culture; and to use resources efficiently and build evidence synthesis and dissemination capacity in the country. The center will also conduct rigorous systematic reviews and meta-analysis of published articles; respond to evidence queries from policy or program decision makers; potentially host international

review groups; provide support to academic institutions and train postgraduate students in evidence synthesis and dissemination.

The NDMC initiative will use opportunities including information revolution policies and strategies of the country, locally available research infrastructures, technology and internet, high demand for quality data for health decision, available local and international research collaborators, and available multiple health and health related data sources to achieve its vision. This will help to optimize the use of data. The NDMC protects data from disasters, fire and flood, and improper storage of information. Establishing NDMC helps to improve efficiency of the statistical system, privacy of the individual, physical security of the data center, protection of the data, and reliability of the operations.

Moreover, the NDMC provides easy national and international access to quality data, significantly improving efficiency in obtaining and analyzing population health data, managing and reduce the cost of investment to generate data and promoting use of research findings for evidence informed decisions. Additional benefits of the NDMC include prevention of data loss, reduction in data storage costs and facilitating scientific research by research institutes and researchers. The NDMC will integrate the nation's information system, and improve data exchange and information sharing at local and international levels. As part of a national health policy to make information resources widely available and accessible to all, EPHI has developed the NDMC to facilitate public use of data. The NDMC bridges mainly between the people who collect the data and the people who use evidence for decision making. Main role of the NDMC will be collecting all available data found from EPHI and other sources in the country, store data with standardized formats, process data, analyze and synthesize the data, and share data to researchers and research institutes. The aim of the NDMC is to turn all information collected by various institutes for Ethiopia at local and international levels, efficiently and without errors into evidence that can be used for policy transformation.

## Vision

Be center of excellence in generating, synthesizing and translating public health and biomedical evidences in Ethiopia

## Mission

This mission is to improve the health of the public through presenting high quality evidence for decision making to the Federal Ministry of Health. The mission encompasses;

1. Establishing a centralized system that continuously collects and archives all available health related data/information to serve as a national repository of research data to ensure safe storage and open sharing in Ethiopia
2. Availing health and health related data/information for the public and on demand according to the nature of the data/information
3. Managing and process the data, synthesize available health related evidence from local and international research institutes and researchers
4. Measuring health progress with the applications of robust scientific methods and providing timely quality evidence for Ethiopia.
5. Translating research evidence for public health policies and programs

## Goals

The goal of NDMC is to create a system of data management and evidence synthesis to improve public health practice and policy through generation of high quality evidence for Ethiopia.

This is to build databases, data management and evidence synthesize approaches on health and health related data through pooling all available data in the country and abroad for Ethiopia. The ultimate goal of the national data management center is to maximize the utilization of available data related to health and to fill the gaps on evidence informed health decision through the application of rigorous scientific method sat national and sub-national levels.

## Specific objectives

The following are specific objectives of the center;

1. To generate disease burden and health risk factor estimates that are essential for planning and resource allocation.
2. To manage and process available data on health interventions and health policy and provide evaluation estimates on the health policy, economic evaluation/cost-effectiveness to the national and sub-national health strategies and interventions through Evaluation Unit and make findings available for academic and research purpose for local and global users;
3. To manage data and deliver disease control priority estimates in Ethiopia through Disease Control Priority Unit; and make findings available for academic and research purpose for local and global users;
4. To manage data and deliver biomedical and basic sciences research findings through Biomedical Unit and improve scientific knowledge and practices in Ethiopia, and make findings available for academic and research purpose for local and global users;
5. To conduct in-depth analysis and evidence synthesis on different research questions on, but not limited to, maternal, neonatal, nutrition, malaria, tuberculosis, HIV/AIDs, NTDs and other infectious diseases, non-communicable disease and provide findings for policy decisions;
6. To map, collect and archive historical and contemporary health and health related data from different sources and make available for public use as required
7. To identify national public health research priorities through analysis of gaps in evidence such as expansion of Health and Demographic Surveillance Sites (HDSS) sites, morbidity and cause of death surveys, biomedical research etc.

## NDMC Organogram, Units and Responsibilities

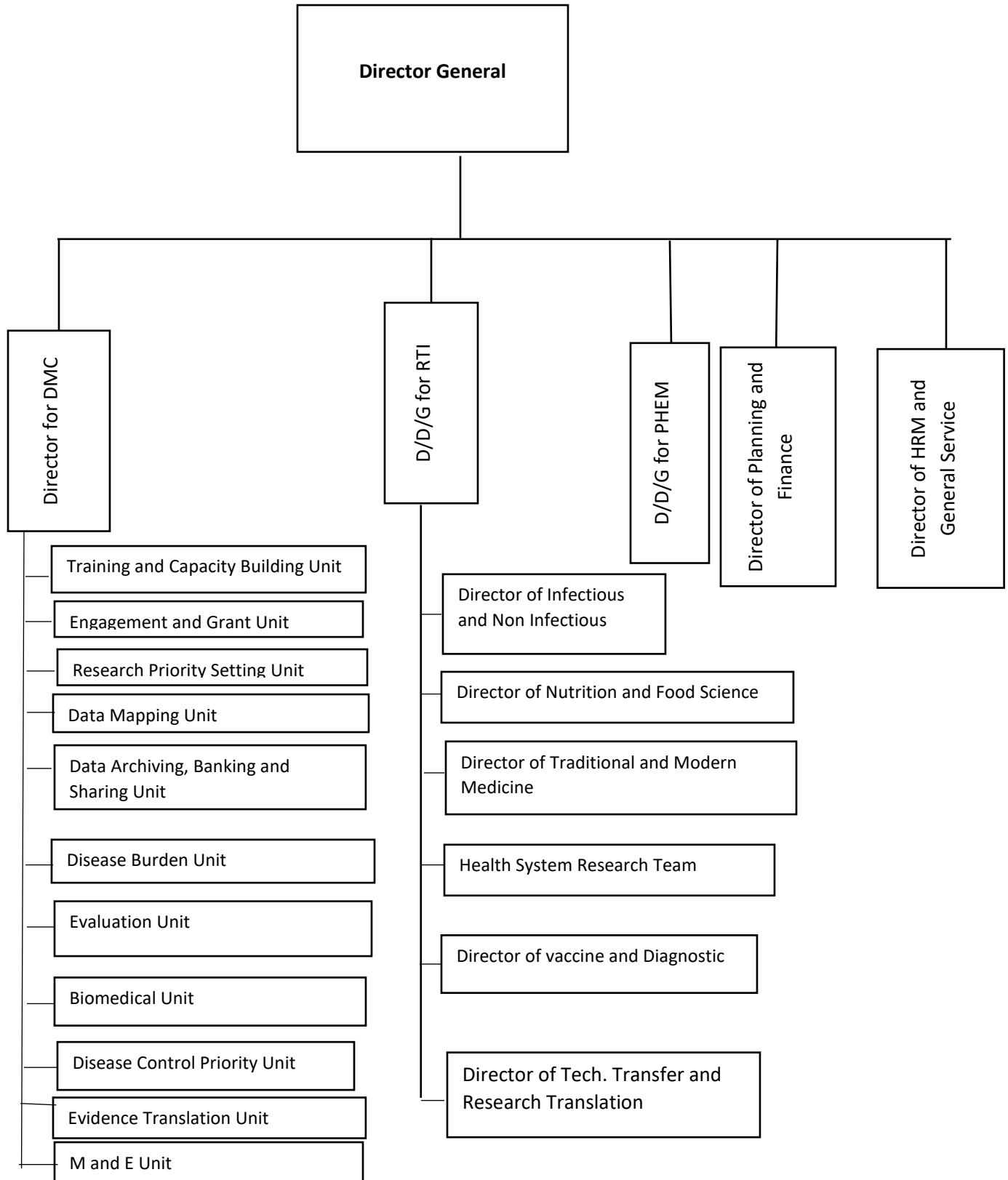
The NDMC will be accountable to the Director General and will be aligned with the different directorates of EPHI. Primarily, NDMC is intended to leverage both public health and biomedical data of EPHI and will be integrated with the different EPHI directorates' including IT case team, Technology Transfer and Research Translation Directorate, Monitoring and Evaluation Directorate. The EPHI structure with NDMC structural (Fig 1) arrangement indicates that NDMC is designed to serve centrally to the different directorates of EPHI and to give fast managerial decision on data and resources and to attract local and international partners (visit EPHI website

for the details of the EPHI organogram<sup>10</sup>). In addition, NDMC builds strong partnership through a comprehensive and transparent national data sharing policy with several data sources outside EPHI; Federal Ministry of Health, Central Statistics Authority, Vital Events Registration Agency (VERA), National Planning Commission, local universities, local and international NGOs (Figure 2 and 3).

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<sup>10</sup><http://www.ephi.gov.et/index.php/2014-04-09-13-52-44/2014-04-09-13-53-29/organizational-structure>

Figure 2: Organogram for National Data Management Center



## Roles and Responsibilities of Units

### Training and Capacity Building (TCB) Unit

This unit targets building the research capacity of the center and its key partners, including selected universities, to enable to support to the center to achieve its goals and objectives. The unit develops short and long term plans for training and capacity building activities. Trainings focus on big data science and heterogeneous data management with advanced statistical and mathematical techniques and applications, different software and technology applications, systematic review and evidence synthesis, evidence to policy translation and so on. The unit coordinates EPHI's fellowship program, its design and implementation, and PhD and postdoctoral fellowship trainings in collaboration with local and international universities. In addition, the unit identifies local and international training opportunities for colleagues who directly or indirectly serve the center. The unit organizes technical workshops and short term advanced trainings on different issues; this may include methods and techniques on epidemiological and burden of disease, disease control priority, evaluation and biomedical data management, evidence synthesis and systematic reviews. The unit coordinates its trainings with the Public Health Training Center at EPHI.

### Strategy, Engagement and Grant (SEG) Unit

The unit focuses on three major activities of the center; devising and communicating research data strategies, engaging local and international research partners and collaborators, and facilitating and securing research grant from government sources and funding organizations. The unit learns from strategic advisory board and scientific advisory committee guidance, the research priority unit, local and international health policies and other sources to devise national research strategies and directions and facilitates for decision and implementation with EPHI and FMOH leadership. Establishing and strengthening strong partnership and collaboration are key strategies for advancing the center's success that requires strong engagement team with strong research communication skills. This helps to create credible collaboration and partnership platform on data generation and evidence use. The engagement and advocacy with major data sources in the country is to develop data sharing culture according to institutional and national data sharing guidelines. The third major activities of the unit are identifying grant sources, coordinating technical advisors and writing grants for funding.

## Research Priority Setting Unit

There are different data types with different data sources that require prioritization using criteria such as evidence demand for policy, magnitude and severity of the issue, availability of data, availability of resources and feasibility among others. This unit works for retrospective and prospective data management prioritization. It closely works with SEG unit and leads the data mapping, archiving and data banking activities of the center. The unit annually develops and releases thematic research areas to the EPHI, share major data sources in the country to research partners and funding organizations, communicates research priorities through different channels with SEG unit. The unit follows different approaches to prioritize research topics for the center and beyond - such as communicating local research institutes, health policy makers, individual researchers, professional associations, institutional review boards, funding organizations and others. The unit advises and facilitates research institutes and agencies to register their research areas prospectively, collect primary data on priority topics of having national relevance with standard methods, and to improve data availability and accessibility for the center.

## Data Mapping Unit

The role of this unit is to map data sources with their respective data types following set research priorities of the center. The data mapping includes retrospective and prospective data types that the center requires to process. After mapping, the unit deals with the format and contents of data types and protocols of studies communicating primary owners of the data. Then collects the data with developed data templates and work with data archive, banking and sharing (DBS) unit for further processing. The unit uses data sharing policy to follow research institutes and agencies to share their data for the center.

## Data Archiving, Banking and Sharing (DBS) Unit

This unit establishes and/or strengthens databases and data warehouse for retrospective and prospective data types on identified research areas. It works with the data mapping unit to archive and bank data with standard formats. The unit follows national and institutional data sharing guidelines and it describes the use of the data at the center to generate evidence and to share the data for public and users with request. The units intended to generate evidence such as burden of



disease unit, evaluation unit, biomedical and disease control priority units are primary users of the data. The unit processes data sharing to the center and from the center with local and international collaborators according to the national data sharing policy. This unit works with national and international research institutes on data sharing rules and regulations to maintain national interest on research data driven economy development of the country. It makes sure the practice of data sharing at different levels of data sharing; Internal data sharing in the institutes, data sharing within the country, data sharing with international collaborators follows data sharing guideline of the country and international data sharing principles, ethics and privacy of participants. The unit develops mechanisms to ensure data sharing to international collaborators and research institutes to have capacity building component to EPHI, local universities and other primary data sources aiming to develop sustainable data source and capacity in the country. The unit evaluates data sharing requests with associated proposals that may include costs of data sharing (in terms of service provision to share the data and sharing the data) and facilitate the request with the Director of the center. The unit tries to avoid unnecessary delays of data sharing as much as possible. The unit develops and applies data standardization and data quality assurance measures, data acquisition and requesting forms to the center aligning with primary data sources. Activities such as data security and disaster recovery, data backups, specifying IT and infrastructures for archiving and banking are also responsibilities of this unit.

## Burden of Diseases Unit

This unit measures national and sub-national burden of diseases and tracks the progress and achievements in health in Ethiopia. The overall process of the center is critically important to provide national and sub-national burden of diseases estimates for Ethiopia. This unit follows Global Burden of Diseases (GBD) methods and approaches to provide estimates. The unit will have strong collaboration with institutions like IHME, University of Washington and others. The unit provides national and subnational burden of disease estimates using different population health metrics that include prevalence, incidence, death rates, premature mortality rates such as Years of Life Lost (YLL), Years Lived with Disabilities (YLD), Disability-Adjusted Life Years (DALYs) by cause, age, sex and years for Ethiopia. The NDMC will identify data scarce areas to answer the following concerns: which disease type requires more data as burden of diseases requires different types of data? which agency is generating what type of data? what does NDMC

need to work to obtain the right data or what the unit needs to do if the country does not have any data on specific issues? NDMC should work with national and sub-national research institutes and researchers on generating quality primary data. This unit will use demography and population database, causes of death database, non-fatal outcome and risk factors databases of the NDMC to provide estimates.

The unit also focuses to generate relevant data using surveys and surveillance systems in collaboration with local institutions and international institutes. The following are potential research priorities for the unit: conducting post-census cause of death survey and population based morbidity surveys.

### Evaluation Unit

Evaluation unit handles: managing data related to evaluation on the impact of health policies and programs in promoting health, preventing disease; evaluating the national public health status and health care delivery using trend analysis and modeling techniques; and conducting cost-effectiveness, efficacy, and effectiveness studies.

### Disease Control Priority Unit

Setting priorities is beyond understanding the burden of diseases and effectiveness of interventions. This unit uses standard methods and different perspectives to prioritize diseases for health decision.

### Biomedical Unit

This Unit processes and manages biomedical research and basic science data available at EPHI and other research institutes. The above four units undertake interlinked public health and biomedical data processing, data management and techniques to support the health policy, improve practice and knowledge in the country.

### Evidence Translation Unit

Existing Technology Transfer and Research Translation Directorate of EPHI undertakes evidence translation and knowledge management activities of this unit. The activities include developing

appropriate policy translation mechanisms and materials that includes publications, policy briefs media and web communications and evidence use tracking mechanisms. The directorate with Burden of Disease Unit will conduct dissemination workshops specific to burden of diseases; writing policy briefs, manuscripts and publications.

## Monitoring and Evaluation Unit

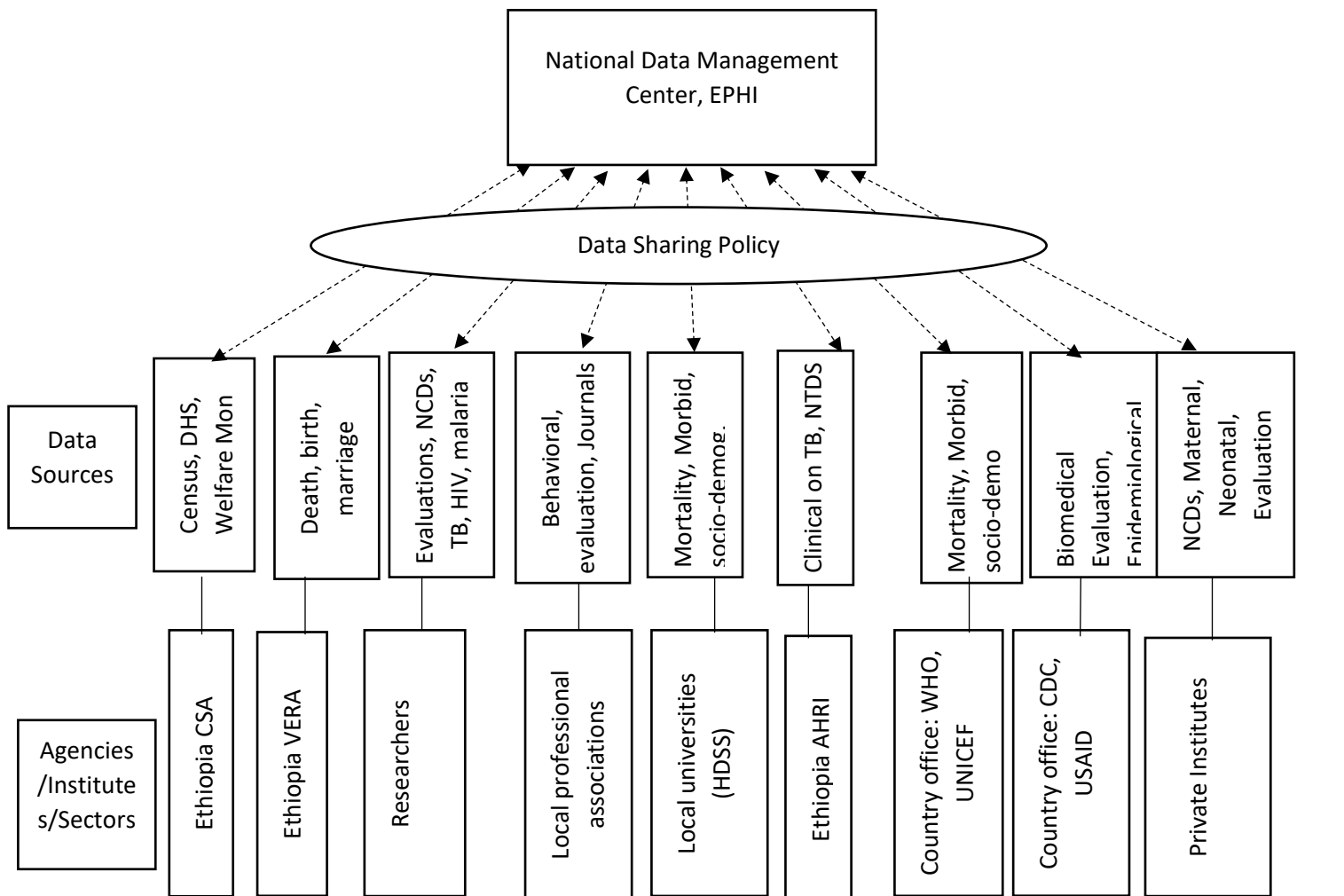
Existing Monitoring and Evaluation case team of EPHI undertake the task of this unit.

## NDMC Data Management and Processing Approaches

The NDMC collects all available data on population and demography, mortality and causes of death, morbidity and disability, health risk-factors, evaluation and socio-demographic data, biomedical and basic science data in the country. The center follows different steps to achieve its intended goals (Figure 3). The process in the center are data collection from different sources within and outside EPHI, store the data with different databases and develop data archive and data bank, process the data with standardized techniques, apply rigorous scientific methods and techniques, provide estimates and made available data for public use or make available based on request.

The data management process varies depending on the type of data available and to the priority given to generate the type of evidence; primary data management starts with data entry and cleaning while data of the different sources require systematic data searching, data extraction and standardization approaches. To provide relevant evidence, it is critically important to pool primary and non-primary data and apply rigorous scientific methods and techniques. Furthermore, NDMC conducts data and evidence gap analysis to identify public health and biomedical research areas having limited data and to invest in generating targeted data types.

Figure 3: Functional relationship of NDMC with local research institutes and international agencies to access all data inputs and provide outcomes to potential users of the center

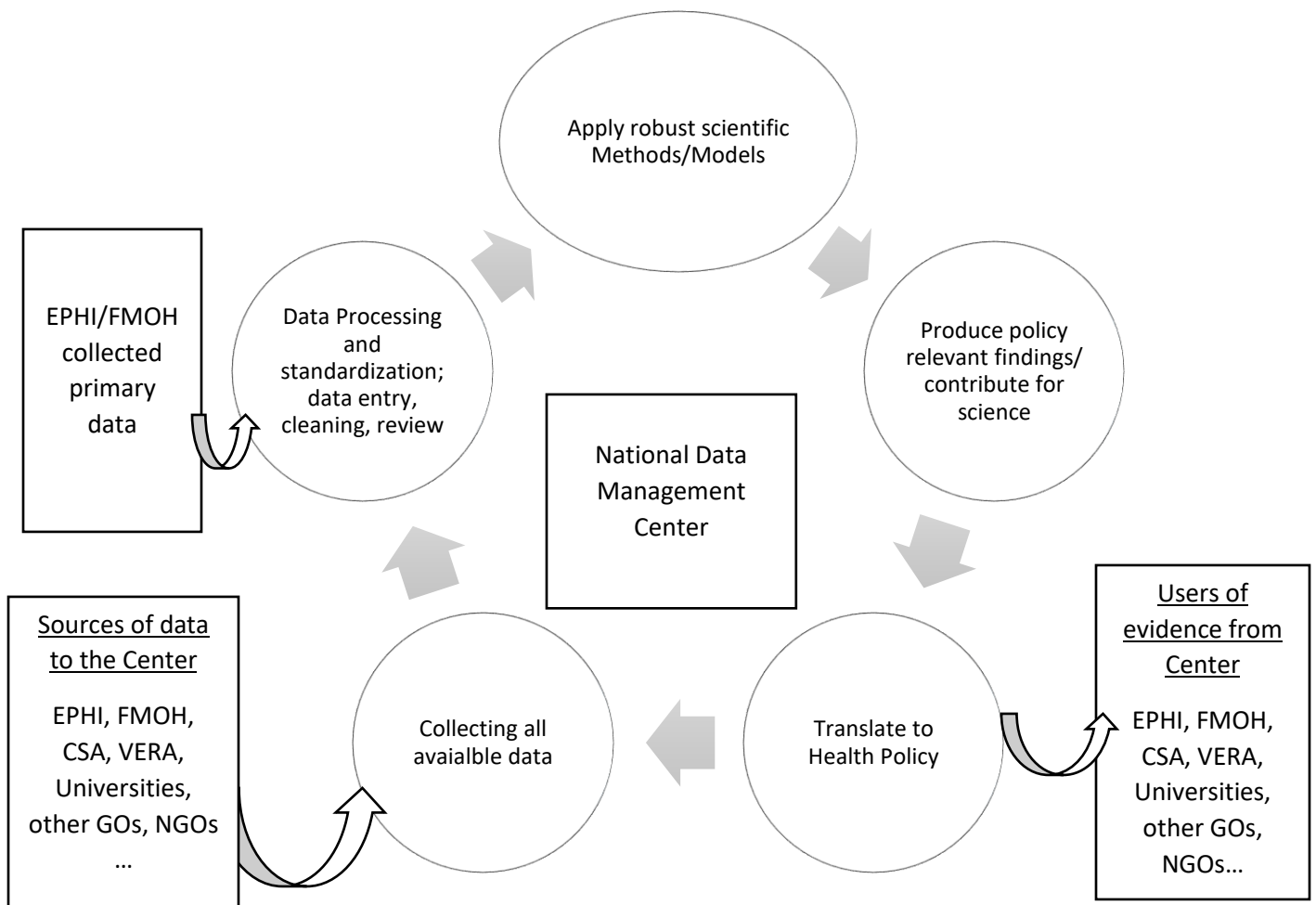


The following sectors, institutions and organizations are also major data sources for NDMC outside EPHI:

- Federal Ministry of Health for the integrated routine data and surveys,
- AHRI, CSA, VERA, National Plan Commission,
- Nine Regional and two City Administration Health Bureaus,
- Public post-graduate schools with or without HDSS sites
- Ministry of Agriculture, Ethiopia
- Ministry of Education, Ethiopia
- Metrology Agency, Ethiopia

- Private sector and private universities
- UN Agencies
- The Joint United Nations Programme on HIV/AIDS (UNAIDS),
- Local NGOs, bilateral as well as multi-lateral institutions that generates health related data.
- Universities that work in collaboration with local universities or other public services contractors.
- Data from uniformed services, refugees, public health projects

Figure 4: Data management and processing cycle of the national data management center



### Accessing available data in the country

Data sharing will be a major challenge for NDMC to function fully as data sharing culture and practice is minimal in Ethiopia. EPHI, under the leadership of FMOH, will develop national data

sharing policy for research institutes, agencies and researchers to share their research data as openly as possible to NDMC, given privacy constraints. EPHI and FMOH will insist institutions and universities to develop institutional data sharing guides. The policy streamlines IRB, technology transfer, and information technology policies and procedures accordingly. The policy encourages data sharing plans as part of funding policies and lobby for appropriate data sharing requirements by funders, and recommend that they assess a proposal's data sharing plan as part of its scientific contribution. The policy includes recognition procedures for data sharing contributions and educating trainees and current investigators on responsible data sharing and reuse practices through class work, mentorship, and professional development. The policy promotes a framework for deciding upon appropriate data sharing mechanisms and encouraging data sharing practices as part of publication policies. The policy addresses funding the costs of data sharing, support for repositories, adoption of sharing infrastructure and metrics, and research into best practices and publish experiences in data sharing to facilitate the exchange of best practices. In addition, EPHI and FMOH advocates using workshops and different media for data sharing.

## Specific NDMC Strategies

The NDMC follows the following five key strategies called CDCFU to build data management system in the country and to strengthen collaboration with national and international research institutes. In the CDCFU strategy; **C** for capacity building, **D** for data generating and sharing, **C** for collaboration, **F** for funding and **U** stands for utilization of evidence.

Strategy\_1: Build research capacity on big data management and data mining for EPHI and key collaborators (**Capacity**);

Strategy\_2: Establish specific databases within NDMC, generate data and share, and improve data availability and accessibility for local and international users (**Data**);

Strategy\_3: Establish and strengthen local and international collaborations (**Collaboration**);

Strategy\_4: Ensure local and international funding to undertake the different health and health related researches (**Funding**);

Strategy\_5: Ensure utilization of population health evidence for decision in the ministry of health and key partners (**Utilization**).

## Description of the strategies

### **Strategy\_1: Build research capacity on big data management for EPHI and key collaborators (Capacity)**

To ensure sustainability of the center, building its capacity, local universities having HDSS sites and VERA/CSA is critical. Establishing and running national database with different data types requires multi-disciplinary team with advanced training in quantitative and qualitative research methods and skill related to functions of the Units. The availability of this center greatly supports PhD training, post graduate/post-doc and short term trainings through collaborative initiatives with academic institutions. The training will be linked with the National Training Center at EPHI and may target on advanced health metrics training on burden of diseases methods and techniques, survey and surveillance methods, systematic reviews, big data management and modeling, data sharing and policy translation strategies. The capacity building will also involve visiting scholars and fellows to come from different institutions. The capacity building will be handled in collaboration with all partners and stakeholders such as Institute of Health Metrics and Evaluation, University of Washington, Bill and Melinda Gates Foundation, Center for Disease Prevention and Control (CDC) USA, London School of Hygiene and Tropical Medicine (LSHTM), WHO, UNICEF, etc.

### **Strategy\_2: Collect countrywide available data, establish databases/data archive within NDMC, generate primary data and improve data availability and accessibility (Data)**

Establishing central database and put mortality data, morbidity and disability data, health risk factors and socio-demographic data types together in a useable format through pooling or digitizing data from research institutes and agencies, universities and programs is key strategy to achieve the purpose of the center. In addition, research data and findings will be pooled to the center and further analyze for wider consumption. This approach would help to capture most of the data, as making data publicly available or publishing not common practice in the country. This is especially important to apply advanced quantitative methods to provide national and sub-national burden of diseases estimates, evaluation and disease control priority estimates. Besides, conducting data gap analysis would help to identify public health areas having limited data and to

invest in generating targeted data types. The center follows the following steps to collect all available data sources and works with national and sub-national research institutes and researchers on generating quality primary data. The steps are:

Step\_1: Conduct national data mapping and identify available data;

Step\_2: Collect all accessible data in the country;

Step\_3: Establish databases and process the data;

Step\_3: Conduct in-depth data gap analysis and collaborate to generate targeted primary data.

### **Strategy\_3: Establish and strengthen local and international collaboration (Collaboration)**

This is also another key strategy for the visibility of the center, effectiveness and impactful in Ethiopia. The center will identify local and international collaborating research institutions at national and sub-national levels and will conduct and disseminate its outputs. This may include international agencies and organizations working at national and sub-national levels, Ministry of Health, Regional Health Bureaus, local universities and research institutes at national or regional levels, public health schools and institutes and private institutes. In addition, the center will facilitate funding for primary data sources that includes universities.

### **Strategy\_4: Ensure local and international funding sources (Funding)**

To achieve the above undertakings and strategies, the center will develop collaborative grant proposals and will submit for funding agencies. In addition, the center gets annual budget from EPHI and FMOH to execute the routine activities.

### **Strategy\_5: Ensure utilization of population health evidence for decision in the ministry of health and key partners (Utilization)**

This strategy is to facilitate policy translation through estimates and to ensure the utilization of these estimates, to collect feedbacks and improve estimates and verify the relevance of the estimates for health policy in relation to HSTP and other health indicators. The NDMC will facilitate its products to be translated into health policy through the Research and Policy Translation Directorate of EPHI. Products of the center, including national and sub-national burden of diseases estimates as well as evaluation and disease control priority findings will be channeled through this directorate. To ensure data utilization, the center will apply the following three steps:



**Step\_1.** Identifying influential health programs and health system research actors to collaborate on the utilization of outputs in Ethiopia: This is helpful to facilitate evidence translation in the health programs and research actors to understand and promote the use of the estimates. These may include, but not limited to, EPHI data, FMOH, CSA, VERA, World Health Organization (WHO), UNICEF, Bill and Melinda Gates Foundation, USAID, CDC US, local professional associations, universities with and without HDSS and post-graduate schools. Overall, these actors need to understand and value the bigger picture of national burden of diseases, its strategies and uses.

**Step\_2.** Conducting dissemination workshops: This is very helpful to familiarize and clarify major activities and outputs of the NDMC. The workshop will target key stakeholders mentioned above with research institutes, agencies and associations, and researchers.

**Step\_3.** Motivating those actors to use evidence to measure their indicator of achievements and health developments, and to verify the estimates. The last step is recognizing organizations to better apply the center’s output for their decisions. This can happen through indicator data sources assessment.

## Strategy Matrices of NDMC

Strategies	Major activities
Training and research capacity building	<ol style="list-style-type: none"> <li>1. <b>Training:</b> PhD/Post-doc and postgraduate candidates and coordinate trainings</li> <li>2. <b>Staffing:</b> Identify data specialists, statisticians, demographers, IT specialists, policy translation specialist, and health researchers and hire if needed.</li> <li>1. <b>Material and equipment:</b> purchase computers, statistical software and IT materials needed for establishing and running the databases</li> </ol>
Collect countrywide available data, establish databases, generate primary data and improve data availability and accessibility	<ol style="list-style-type: none"> <li>1. <b>Collecting already available data:</b> Develop proposal and collect the data</li> <li>2. <b>Collecting primary data:</b> Develop proposal and conduct surveys/surveillance, expand HDSS sites with other universities etc.</li> <li>3. <b>Collect health and health related data from public and private institutes, NGO sectors and others:</b> this will be managed through the national data sharing policy</li> <li>4. <b>Build central database:</b> Consult experts and technicians to build central database/national data archive</li> <li>2. <b>Provide national and subnational estimates:</b> process data and apply advanced methods.</li> </ol>
Ensure utilization of available data for health decision in the country	<ol style="list-style-type: none"> <li>3. <b>Identify evidence demand:</b> identify active evidence requests from FMOH and partners, conduct evidence demand analysis with FMOH directorates and partners</li> </ol>

	<ol style="list-style-type: none"> <li>4. <b>Provide evidence:</b> identify best ways of facilitating evidence use for planning, monitoring and evaluation which may include organize workshops, publish with peer-reviewed journals and write policy briefs</li> <li>3. <b>Monitor evidence utilization and collect feedbacks:</b> monitor utilization of estimates and research results using monitoring templates</li> </ol>
Ensure local and international funding sources	<ol style="list-style-type: none"> <li>1. Develop collaborative grant proposals and secure funding</li> </ol>
Establish and strengthen local and international collaborations	<ol style="list-style-type: none"> <li>1. Advocacy and networking with local and international organizations to facilitate national and sub-national estimates uptake, for funding and technical support.</li> </ol>

### Required human resource and infrastructure

The center requires multi-disciplinary team for its scientific excellence, including, but not limited to, epidemiologists, public health professionals, clinicians, computer scientist experts, health economists, database developers, social scientists, applied mathematicians and statisticians, biomedical experts and others (depending on the data and required outputs) with different levels of training including advanced and middle level training backgrounds. The team will manage burden of diseases data, evaluation data and disease control priorities and biomedical research data so as to provide reliable estimates and results to serve for national and sub-national health decision in Ethiopia. The NDMC requires data entry clerks, data reviewers, data managers, data specialists, scholars and intellectuals to work at and with EPHI.

### Required Human Resources

#### 1. Strategic Board of Advisors

Strategic board of advisors focus on short and long term strategic directions of the center to meet both local and international expectations. Board members annually meet for 2-3 days, to evaluate the strategic plan and annual plan of the center and its performance. The EPHI Director General (DG) chairs strategic board advisors meeting. The strategic board gives strategic direction for the center considering the local and international research context and opportunities. Members of the board include FMOH and collaborating partners, local universities and universities abroad.

## *2. Scientific Advisory Committee*

This group guides the National Data Management Center scientifically and its units to achieve its intended goals and objectives. Its support mainly will be scientifically advising and technically reviewing the developments of the NDMC. It consists five to seven people composed of intellectuals and experts from Universities, Ministry of Health, Armauer Hansen Research Institute (AHRI), Central Statistics Authority, Vital Event Registration Agency, private research institutes, major research partners and others. Director for the NDMC chairs the Scientific Advisory Committee. This committee meets once a year and, attend progress reports and discuss on the annual progress of NDMC and its units and give scientific directions. The committee makes sure that NDMC and its functions are in line with national research policy directions, health program interests in the ministry and its partners, its contribution for the development of research in the country, developing collaboration and multiple funding sources. In addition, the center can establish Technical Working Groups (TWGs) composed of professionals from different expertise as required to support the units.

## *3. NDMC Director*

The director: will be responsible for the overall planning, implementation and financing of the center; will lead the teams, the units and the center to achieve its intended goals; will facilitate and involve in competitive grant schemes and will tap different funding sources; will seek institutional collaboration locally and internationally and facilitate to leverage NDMC outputs and products.

## *4. Technical Advisors*

Advisors will support and build the capacity of unit leaders and other staff members. Four technical senior advisors for each specific areas and units will be assigned: burden of diseases senior technical adviser; evaluation senior technical adviser; disease control priority senior technical adviser; and biomedical research senior technical adviser.

## *5. Unit leaders*

The team will include one health economist (1 person), epidemiologist, GIS technician, (1 person) and public health professional with strong clinical background (1 person) and a biomedical researcher (1 person). These people will be responsible to lead the Units, conduct evidence demand and supply analysis with different programs, collaborate with experts, review and interpret

estimates, develop manuscripts and policy documents, conduct data gap analysis and provide thematic research areas to institutes and agencies.

#### *6. Data base developers, network administrators, managers, analysts and data specialists*

These are highly qualified individuals: one demographer, two bio-statisticians (with advanced statistical methods and modeling, demographic techniques to produce evidence with different population health metrics), and two data base developers and network administrators. This team will ensure the quality of data, use different data standardized techniques and algorithms.

#### *7. Data entry clerks*

Data clerks team having five people will enter primary data collected by EPHI or the Ministry and clean the data and make available for analysis, extract data using standard templates from scientific literature, and standardize reviewed data on different topics. Clerks will be skilled in data coding and processing multiple data sources.

#### *8. Data search and reviewers*

This team will consist of five people and will work on inventory of all data sources in potential research institutes and agencies, data mapping and digitizing and collect available data. This team will be collecting available data and literature from EPHI, universities and other research institutes at national and sub-national levels, and will work on data acquisitions. This team will search data and literature on the web using standard searching strategies and techniques.

## Required Infrastructure

EPHI will assign rooms and offices for NDMC. Rooms with the capacity to accommodate 10 people will be used by data search and reviewers' and data clerks' teams. Rooms which can accommodate six people will be used by data managers, analysts, data specialists and unit leaders. Rooms for the office of the NDMC director and for the four senior technical advisors will also be required.

## Thematic Areas for Collaboration

The following are thematic areas of NDMC which will be conducted in collaboration with different stakeholders.

## **1. Collecting Available Data in the country**

*Objectives of collecting available data in the country:*

EPHI is planning to estimate national burden of diseases in the upcoming Global Burden of Diseases (GBD) iterations and to provide sub-national burden of diseases estimates for Ethiopia. This requires, mapping multiple data sources including data at EPHI and integrated routine data of FMOH, digitizing and collecting the data, reviewing and standardize the data. EPHI is collaborating with IHME to undertake this big data managing initiative. All the process to provide national and sub-national burden of disease will be done by Ethiopian scientists while IHME plays technical guidance. The data will be stored, archived at NDMC of EPHI; when needed the data and estimates will be publicly available for local and international users. The data collection process will be prioritized with local significance of the epidemiology of the diseases as to their significance in the health problems of the country and the policy relevance of the generated estimates.

## **2. Initiate and collaborate the establish of new Health and Demographic Surveillance Sites with local 10 universities and strengthen existing 6 HDSS sites**

*Objectives of establishing new 10 HDSS sites and strengthen existing seven sites in Ethiopia:*

Existing seven HDSS sites have contributed to the country through generating birth, death, causes of death, and pregnancy outcome data and help to measure health progress and achievements in Amhara, Oromia, SNNP and Tigray Regional states. The HDSS are university owned research centers intended to serve primarily for academic purpose. Extending their roles, HDSS sites are contributing to inform health policy through their contribution in estimating burden of diseases, disease control priority and evaluation of vaccines. However HDSS sites lack representing different populations and agro-ecology of Ethiopia. For example, there are no HDSS sites in the emerging regional states of the country such as in Gambella, B/Gumuz, Somali, and Afar and existing sites lack covering urban population.

This representation will be more important to provide sub national burden of diseases estimates for the emerging regional states of Ethiopia. NDMC is planning to strengthen the existing seven

HDSS sites and a mortality surveillance program, and to establish 10 new HDSS sites in the coming 10 years. HDSS sites will be data inputs for the NDMC and could be used to validate VERA's data. NDMC will collect, mortality, morbidity, and demographic data from the HDSS sites. This initiative will be done in collaboration with existing HDSS sites of the universities and other partners such as CDC Ethiopia Office. Strengthening existing HDSS sites will include capacity building in the respective universities.

### **3. Collaborate and conduct post-census/DHS mortality survey and national morbidity surveys**

*Objectives of conducting Post-Census or DHS mortality and national morbidity surveys:*

Ethiopia lack national representative morbidity and causes of death surveys for all causes, all age groups and both sex. Central Statistics Authority has been collecting DHS data. VERA has started collecting causes of death and other vital events data. The EPHI will collaborate with VERA and CSA to collect two rounds of national mortality and morbidity surveys for the coming 10 years. The collaboration with VERA will be assisted by capacity building for the sustainability of generating the data and for VERA's quality data contribution to NDMC. Moreover, technical trainings of NDMC will involve CSA and VERA for extended uses of their data in the NDMC, application of technology and robust techniques to collect and analyze post-census and post DHS morbidity and mortality surveys. VERA is nationally mandated to collect mortality and causes of death data and this collaborative effort will be baseline and will be conducted until VERA start to function fully.

### **4. Design EPHI fellowship program**

Generally, there is huge gap in applying advanced quantitative science in health and health related data with local universities in Ethiopia. EPHI has already built Public Health Training Center and is collaborating with local universities to establish and run NDMC and fill skill gaps. Involving local universities and faculties is important to get skilled human resource and for NDMC sustainability. On the other hand, NDMC will be used for local academic purpose and be a resource to teach students in turn to improve generating quality data in the country and facilitate the use of data for health policy in Ethiopia. EPHI will recruit and train public health fellows in Ethiopia. Fellows will work for the NDMC and the training follows the principle "learning by doing" with

few advanced biostatistics, epidemiology, data management and application of statistical software, data coding and other courses. Fellows will be either at baccalaureate or graduate levels with different disciplines including public health, biostatistics, epidemiology, health economics, demography and population study, biomedical and technology.

## **5. Train PhD and post-doctoral fellows collaborating with local and international universities**

In the coming 10 years, the center proposed to build the human resource workforce with advanced research training (40 PhD) who can serve the center on national and subnational burden of disease, health program and economic evaluation, in disease control priority and global health, in population and demography and biostatistics and biomedical research. In addition, the center proposes 15 post-doctoral fellows in relation to the above fields. The training will be in collaboration with Federal Ministry of Education that involves local universities and partners working with NDMC at EPHI.

## **6. Organizing technical workshops and advanced trainings on burden of diseases, disease control priority, evaluation and biomedical data management and estimates**

*Objectives of the short term advanced trainings:*

The people working in the NDMC require advanced training to run the center and to provide national and sub national burden of disease estimates, evaluation and disease control priorities. The center will provide short term trainings and refreshment courses to colleagues working for NDMC in collaboration with international and local research institutes and universities.

## **7. Information Technology infrastructure for the NDMC**

There are two options for IT infrastructure development

*Option 1:* In the initial phase of NDMC, EPHI has reinovated its existing IT center for NDMC to function on priority areas. EPHI, under FMOH leadership, is planning to build Tier 3 to Tier 4 IT center considered as most robust and less prone to failures to serve for NDMC and the routine data system of FMOH. Tier 4 is designed to host mission critical servers and computer systems, with fully redundant subsystems (cooling, power, network links, storage etc) and compartmentalized security zones controlled by biometric access controls methods. The center requires high capacity

computers and server, high internet network, databases and data management software, physical space, office equipment and utilities. High capacity servers and computers will be purchased to run the NDMC. The center will purchase different statistical software according to researchers' preferences. The center will have emergency backup power generators.

*Option 2:* FMOH is proposing to develop and implement a health data warehouse<sup>11</sup> that can also serve to the needs and goals of EPHI's National Data Management Center.

## Implementation Phases of NDMC

As NDMC establishment is the first in its kind for Ethiopia, the following key activities will be conducted before its implementation.

### *1. Mandate, strategy and policy document review of lead research and technology institutes in Ethiopia*

This analysis includes institutes and agencies such as EPHI/FMOH, Central Statistics Agency, Vital Events Registration Agency, AHRI, Ministry of Science and Technology (MOST), Federal Ministry of Education/Health Science Universities. This analysis is aiming to show EPHI's national mandate, national research policies to establish NDMC on health and health related data and to avoid duplication of efforts with institutes and agencies working on data.

### *2. Data landscape analysis on demand, availability and accessibility*

This will be key informant interview with health policy makers and senior researchers, and local data centers observation (EPHI, CSA, AHRI, ILRI, and Universities.....) to explore the data demand, availability and accessibility and their best practices. In addition, this is to learn about potential barriers and challenges of NDMC and to devise appropriate approaches to address the challenges and to create collaborative opportunities for the major data sources in the country. This will be very important for the sustainability and effectiveness of the NDMC in Ethiopia.

### *3. Organizing consultative workshops*

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<sup>11</sup> Federal Ministry of Health. Proposal for the development and implementation of Ethiopian health data warehouse, draft version 0.3



These workshops are to build consensus and partnership on generating data, storing and processing data to provide health measurements. First round workshop will be among EPHI and FMOH directorates to review experiences, gaps on data and evidence based health policy. This consultative meeting will consider the information revolution roadmap<sup>12</sup> of FMOH; existing research data management analysis demand in the country in line with the proposed DMC functions; national data sharing practice with EPHI experience; national data sharing policy and related regulations for wider data management exercise; funding and research collaboration related issues on top of the routine data processing. Feedbacks and comments from the first round would help to guide upcoming consultative meetings with other partners.

Second round workshop will involve lead research institutes and agencies such as CSA, VERA, AHRI, professional associations, universities, regional public health institutes and others to discuss and share direction about NDMC and potential collaboration with the institutes. Third round workshop will be held with the rest of stakeholders and funding agencies to create awareness, to advocate and mobilize resources for NDMC.

#### *4. Develop national data sharing policy:*

The TWG will work with Ministry of Health Plan and Policy Directorate and Legal office to finalize National Data Sharing Policy and other required legal and regulatory mandates.

Following the above preparation, EPHI is proposing three development phases for NDMC in Ethiopia.

#### ***First Phase (2018-2021)***

The first activity following EPHI directorates' consultative meeting will be conducting public health and biomedical data inventory available since 1980s in each EPHI directorates. The data could be available in different formats; electronically or hard copies. Recently collected data such as SPA+, SARA, NCD risk factor, Immunization coverage surveys etc. are already available with EPHI server in the IT team. However, most data types are available with the different directorates and case teams. EPHI will demonstrate NDMC using its own available data and databases before 2018 to share real experience.

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<sup>12</sup> Federal Ministry of Health. Information Revolution Roadmap. April 2016

Collaborative team will continue developing specific proposals on those thematic research areas. In this phase, NDMC will collect all available data in the country accordingly, establish databases parallel to the different units, adopt or develop data extraction template, standardize the data and will provide national and sub-national burden of disease, national and sub national evaluations and disease control priority and biomedical estimates for Ethiopia. The center will organize short term trainings and technical workshops. The center will conduct first rounds of post-census/ DHS and national morbidity surveys. The first batch Public Health Fellows will be recruited and start the training. Purchasing of required materials and staffing will be done during this phase. Five new HDSS sites will be established and strengthening of 7 existing HDSS sites will be done.

### ***Second Phase (2022-2025)***

In this phase, rounds of public health fellows will be admitted to EPHI every year as required. In addition, PhD candidates and postgraduate fellows will be admitted to EPHI collaborator local and international universities. The center will organize short term trainings on advanced courses and provide technical training workshops. All units will provide estimates and the findings will be facilitated to be translated to health policy. Five new HDS sites will be established, existing HDSS sites will be supported.

### ***Third Phase (2026-2028)***

During this phase, last rounds of public health fellows will be admitted to EPHI. The center will organize short term trainings on advanced courses and technical training workshops. All units will provide estimates and the findings will be facilitated to be translated to health policy. Strengthening of the 17 HDSS sites will be accomplished.